Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists

Presented by:
Canadian Working Group on HIV and Rehabilitation

In partnership with:
Canadian Association of Occupational Therapists (CAOT)
Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA)
Canadian Physiotherapy Association (CPA)
ACKNOWLEDGEMENTS

This course has been made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

We would like to acknowledge the Project Advisory Committee for their contribution and guidance throughout this initiative.

<table>
<thead>
<tr>
<th>Advisory Committee Member</th>
<th>Organization represented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesley Bainbridge Associate Principal</td>
<td>University of British Columbia</td>
</tr>
<tr>
<td>Dr. Debra Cameron, Occupational Therapist Assistant Professor &amp; Field work Coordinator, Department of Occupational Therapy, University of Toronto</td>
<td>Canadian Association of Occupational Therapists (CAOT)</td>
</tr>
<tr>
<td>Geoff Lawrence and Michael Bailey Educator &amp; Coordinator, CATIE Capacity Building Project</td>
<td>Canadian AIDS Treatment Information Exchange (CATIE)</td>
</tr>
<tr>
<td>Kelly O’Brien, Physiotherapist Department of Physical Therapy, University of Toronto Centre for Research on Inner City Health, St. Michael’s Hospital</td>
<td>Canadian Providers Survey Research Team, University of Toronto</td>
</tr>
<tr>
<td>Penny Parnes, Director International Centre for Disability and Rehabilitation, University of Toronto, Speech-Language Pathologist</td>
<td>International Centre for Disability and Rehabilitation, University of Toronto</td>
</tr>
<tr>
<td>Dr. Greg Robinson Family Physician</td>
<td>College of Family Physicians of Canada and Person Living with HIV</td>
</tr>
<tr>
<td>Lynne Sinclair, Director of Education, Toronto Rehabilitation Institute, Physical Therapist</td>
<td>Toronto Rehabilitation Institute</td>
</tr>
<tr>
<td>Dr. Patty Solomon, Professor, School of Rehabilitation Science, McMaster University, Physical Therapist</td>
<td>Canadian Physiotherapy Association (CPA)</td>
</tr>
<tr>
<td>Dr. Graham Smith, Family Physician</td>
<td>College of Family Physicians of Canada</td>
</tr>
<tr>
<td>Christopher Sulway, Physical Therapist Planning Department, St. Michael’s Hospital</td>
<td>CWGHR’s Education / Practice Advisory Committee</td>
</tr>
<tr>
<td>Stephen Tattle Registered Nurse</td>
<td>Canadian Association of Nurses in AIDS Care (CANAC)</td>
</tr>
<tr>
<td>Janet Wu Speech-Language Pathologist, HIV Team Professional Practice Leader, St. Michael’s Hospital, Toronto</td>
<td>Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA)</td>
</tr>
</tbody>
</table>

The project team is completed by Janet London Project Administrative Assistant, San Patten Project Evaluator, Elisse Zack CWGHR Executive Director, Natalie Gierman Assistant Project Coordinator and Gillian Bone Project Coordinator.

Charitable registration number 85699 5535 RR0001

Canadian Working Group on HIV and Rehabilitation
# TABLE OF CONTENTS

1. COURSE INFORMATION
   - Outline
   - Description, Goals and Objectives
   - Evaluation Forms
   - Pre-course Readings

2. INTRODUCTION TO HIV
   - Powerpoint Presentation Handout
   - Anti-HIV Medications - A Fact Sheet from Canadian AIDS Treatment Information Exchange
   - Dealing with Drug Side Effects - A Publication from Project Inform

3. HIV IN CONTEXT
   - Powerpoint Presentation Handout
   - BC Prevalence Study
   - Disability Issues in HIV and Other Lifelong Conditions
   - Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV
   - The Social Determinants of Health

4. LIVING WITH HIV
   - Powerpoint Presentation Handout

5. REHABILITATION ROLES
   - Powerpoint Presentation Handout
   - HIV and Rehabilitation Canadian Providers’ Survey Report and Fact Sheets
   - Policy Issues on Rehabilitation in the Context of HIV Disease
   - Experiences of Contemplating Returning to Work for People Living with HIV

6. REHABILITATION INTERVENTIONS
   - Powerpoint Presentation Handout
   - Module 7: Rehabilitation Services. A Comprehensive Guide for the Care of Persons with HIV Disease (separate document - see references)
   - Interprofessional Education for Collaborative Patient-Centred Practice: Framework and Executive Summary

7. CASE DISCUSSIONS
   - Case Scenario Worksheets

8. RESOURCES
   - HIV and Rehabilitation: A Summary of Related References and Resources
# COURSE OUTLINE

**Day 1**
- 12:30 – 13:00  Registration
- 13:00 – 14:30  Introduction to HIV
- 14:30 – 15:00  Break
- 15:00 – 16:30  HIV in Context
- 16:30 – 17:00  Summary

**Day 2:**
- 08:30 – 10:00  Living with HIV
- 10:00 – 10:15  Break
- 10:15 – 12:00  Rehabilitation Roles
- 12:00 – 13:00  Lunch
- 13:00 – 14:30  Rehabilitation Interventions
- 14:30 – 15:00  Break
- 15:00 – 16:00  Case Discussions
- 16:00 – 16:30  Wrap up and Evaluation
Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists

COURSE DESCRIPTION:
This is a one and a half day workshop for rehabilitation professionals that builds on interprofessional education initiatives, and describes recent research and best practices to explore rehabilitation in the context of HIV. People living with HIV are living longer, and may be living with impairments, activity limitations and participation restrictions due to HIV and/or its associated treatments. As a result, rehabilitation professionals have an increasingly important role to play in HIV care, treatment and support. This course will enhance and increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV. The course will use interprofessional and case-based learning principles through presentation and interactive discussion and will be facilitated by persons living with HIV and rehabilitation professionals.

COURSE GOALS:
- To increase knowledge and skills related to HIV among rehabilitation professionals
- To increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV
- To enhance interprofessional practice among rehabilitation professionals to collaboratively respond to the rehabilitation needs of people living with HIV

LEARNING OBJECTIVES
Upon completion of the curriculum, rehabilitation professionals will be able to:
1) Understand the International Classification of Functioning, Disability and Health (WHO, 2001) in the context of HIV/AIDS.
2) Understand the biology, epidemiology, transmission and progression of HIV.
3) Understand the implications of living with HIV as a lifelong, episodic condition (characterized by intermittent periods of wellness and illness).
4) Understand the impairments, activity limitations and participation restrictions that people living with HIV may experience.
5) Understand the social determinants of health and their impact on the experience of living with HIV.
6) Understand the expanded rehabilitation roles and contributions of stakeholders in the rehabilitation of persons living with HIV throughout the continuum of care.
7) Understand the importance and demonstrate the knowledge and skills associated with interprofessional, collaborative patient-centred practice.
8) Understand the issues related to sensitive practice with persons who may experience multiple vulnerabilities including living with HIV e.g. stigma, racism, homophobia.
9) Understand the emerging rehabilitation issues for people living with HIV (e.g. return to work, stroke, transplants, HIV and aging)
10) Understand the similarities and differences between HIV and other lifelong, episodic conditions and permanent disabilities (cross-disability perspective).
11) Understand ways in which rehabilitation professionals may influence policy in the context of HIV/AIDS.
12) Understand ways the issues and strategies related to rehabilitation (needs, services, programs, policies, research, etc.) in the Canadian context relate to rehabilitation issues and strategies in developing countries.

Canadian Working Group on HIV and Rehabilitation
The purpose of this self-assessment tool is to measure change in participants of the course: “Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists.”

We request that you complete this self-assessment tool before the course in order for us to take a baseline measurement of your familiarity with rehabilitation issues for people living with HIV. It should take you no longer than 10 minutes to complete.

We encourage you to complete this tool with honesty and with confidence that the results are private and confidential. Your results will be compared only against your own post-course scores and will be presented only as aggregate data.

Your participation in this measurement tool will inform the ongoing development of the curriculum and future educational activities and initiatives.
Please carefully review the following scale and use it to rate yourself in each of the following competency areas.

<table>
<thead>
<tr>
<th>Competency level</th>
<th>Score</th>
<th>Description of competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Novice/Little or None</td>
<td>1</td>
<td>Little or no previous knowledge/skill/experience of the issue being described and would require support/training to improve competence</td>
</tr>
<tr>
<td>Advanced Beginner/ Limited</td>
<td>2</td>
<td>Limited previous knowledge/skill/experience of the issue described and would require some support/training to improve competence</td>
</tr>
<tr>
<td>Competent/Somewhat</td>
<td>3</td>
<td>Reasonable fluency with the issues described and would seek occasional support/training to improve competence</td>
</tr>
<tr>
<td>Proficient/Considerable</td>
<td>4</td>
<td>Considerable knowledge/skill/experience of the issue and would need little or no additional support/training to improve competence</td>
</tr>
<tr>
<td>Expert/Extensive</td>
<td>5</td>
<td>Has vast and specialist knowledge/skill/experience of the issue described and may act as an advisor or consultant to others</td>
</tr>
</tbody>
</table>

1. How would you rate your current experience, skills or knowledge in each of these content areas?

<table>
<thead>
<tr>
<th></th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient /Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>ability to describe the rehabilitation needs specific to people living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>understanding of the role of Occupational Therapists in HIV care, treatment and support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>understanding of the role of Physiotherapists in HIV care, treatment and support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>understanding of the role of Speech-Language Pathologists and Audiologists in HIV care, treatment and support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>familiarity with the International Classification of Functioning, Disability and Health (WHO, 2001)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>understanding of how HIV/AIDS fits within the context of the International Classification of Functioning, Disability and Health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding Area</th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient / Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of the biology of HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of HIV epidemiology in Canada</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of modes and risks of HIV transmission</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the progression of HIV disease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the rehabilitation implications of episodic disabilities in general</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the similarities and differences between HIV and other lifelong, episodic conditions and permanent disabilities (cross-disability perspective).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Ability to explain the rehabilitation implications of living with HIV as a lifelong, episodic condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Ability to identify the impairments, activity limitations and participation restrictions that people living with HIV may experience</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the social determinants of health and their impact on the experience of living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Ability to identify the roles and contributions of various stakeholders in the rehabilitation of persons living with HIV, as part of the continuum of care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the importance of interprofessional, collaborative patient-centred care for people living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Feeling of adequate knowledge and skills to provide inter-professional, collaborative patient-centred care for people living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Ability to identify the multiple vulnerabilities associated with living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of sensitive practice issues with persons who may experience various vulnerabilities associated with living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Understanding of the emerging rehabilitation issues for people living with HIV (e.g. return to work, stroke, transplants, HIV and aging)</td>
<td>Novice / Little or None</td>
<td>Advanced Beginner / Limited</td>
<td>Competent Somewhat</td>
<td>Proficient /Considerable</td>
<td>Expert / Extensive</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding of policy issues (e.g. harm reduction, employment, immigration, health systems) in the context of HIV/AIDS</th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient /Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding of ways in which rehabilitation professionals may influence policy in the context of HIV/AIDS</th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient /Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding of ways in which HIV rehabilitation in the Canadian context relates to rehabilitation issues and strategies in developing countries.</th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient /Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ability to identify rehabilitation partners working in HIV across Canada</th>
<th>Novice / Little or None</th>
<th>Advanced Beginner / Limited</th>
<th>Competent Somewhat</th>
<th>Proficient /Considerable</th>
<th>Expert / Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

2. **How would you rate your overall level of personal comfort in providing rehabilitation services to people living with HIV?**
   - □ Very Low
   - □ Low
   - □ Moderate
   - □ High
   - □ Very High

3. **How would you rate your overall level of professional confidence in providing rehabilitation services to people living with HIV?**
   - □ Very Low
   - □ Low
   - □ Moderate
   - □ High
   - □ Very High

4. **Please complete the following sentence: “The one thing that I want to get out of this course is….,”**
Now that you have completed the course, we would appreciate your feedback so that we can continue to develop the course curriculum, faculty involvement and delivery for future programs and initiatives. Your honest and thoughtful insight is valuable to us.

1. Which part of the course did you like the best? Why?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

2. What could have made the course more helpful or valuable to you?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Please indicate below the extent to which you felt the goals for the course were met:

<table>
<thead>
<tr>
<th>Course Goals</th>
<th>Completely</th>
<th>Very Much</th>
<th>Somewhat</th>
<th>A Little</th>
<th>Not at All</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. To increase knowledge and skills related to HIV among rehabilitation professionals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. To increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. To increase knowledge and understanding of interprofessional learning to enhance collaborative patient centred practice</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
6. Given that this is a pilot curriculum still in development, what would you advise CWGHR to change in order to improve the course?

7. What further assistance would you need to provide rehabilitation services to people living with HIV?

<table>
<thead>
<tr>
<th>Please indicate how you feel about the following statements:</th>
<th>Please circle one</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. I have a better understanding of rehabilitation needs of people living with HIV.</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>9. The information provided was too basic for me.</td>
<td>1</td>
</tr>
<tr>
<td>10. I found the use of case studies to be an effective learning tool.</td>
<td>1</td>
</tr>
<tr>
<td>11. I found the inter-professional approach to be an effective way of discussing HIV rehabilitation issues.</td>
<td>1</td>
</tr>
<tr>
<td>12. This course was interesting.</td>
<td>1</td>
</tr>
<tr>
<td>13. I will be able to apply the content of this course to my everyday work.</td>
<td>1</td>
</tr>
<tr>
<td>14. The information provided was too advanced for me.</td>
<td>1</td>
</tr>
<tr>
<td>15. Overall, the course delivery was effective.</td>
<td>1</td>
</tr>
<tr>
<td>16. Overall, this course met my expectations.</td>
<td>1</td>
</tr>
<tr>
<td>17. I feel confident that I have the ability to provide rehabilitation services to people living with HIV.</td>
<td>1</td>
</tr>
<tr>
<td>18. I would recommend this course to my colleagues.</td>
<td>1</td>
</tr>
<tr>
<td>19. I feel that participation in this course was a valuable use of my time.</td>
<td>1</td>
</tr>
<tr>
<td>20. After this course, I will feel more comfortable working with people who are HIV-positive.</td>
<td>1</td>
</tr>
</tbody>
</table>
21. What topic areas do you feel should have been covered in more detail or greater depth?

____________________________________________________________________________________

____________________________________________________________________________________

22. What topic areas should be minimized or streamlined?

____________________________________________________________________________________

____________________________________________________________________________________

23. Please mark an “X” along the continuum, according to your opinion about the length of the course.

Too short/ brief Just right Too long/ exhaustive

____________________________________________________________________________________

24. Please mark an “X” along the continuum, according to how appropriate the balance was between rehabilitation and PHA faculty members.

I would have preferred more from Rehabilitation faculty members The balance between faculty members was just right I would have preferred more from PHA faculty members

____________________________________________________________________________________

25. Any other comments?

____________________________________________________________________________________

____________________________________________________________________________________

Thank you! ☺
HIV and Its Treatment: What You Should Know

Health Information for Patients

September 23, 2005

Fact Sheets

P.O. Box 6303, Rockville, MD 20849-6303
Telephone: 1-800-448-0440
International: 301-519-0459
Fax: 301-519-6616
TTY/TTD: 888-480-3739

Live Help: http://aidsinfo.nih.gov/LiveHelp
E-mail: ContactUs@aidsinfo.nih.gov
Web: http://aidsinfo.nih.gov
HIV and Its Treatment: What You Should Know

These fact sheets are intended for use by people recently diagnosed with HIV infection or those who are considering starting HIV treatment. The fact sheets are designed as a series but may be used as stand-alone documents. Information in these fact sheets is based on Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, developed by the Panel on Clinical Practices for the Treatment of HIV Infection, which is convened by the U.S. Department of Health and Human Services (HHS) in conjunction with the Henry J. Kaiser Family Foundation.

The Guidelines, which is a "living document," provides updates on new advances in the treatment of HIV. The current version of the document is available on the AIDSinfo Web site: http://aidsinfo.nih.gov/guidelines/.

Table of Contents

- Testing HIV Positive – Do I Have AIDS?
- Seeing an HIV Doctor
- Starting Anti-HIV Medications
- Recommended HIV Treatment Regimens
- Approved Medications to Treat HIV Infection
- Is My Treatment Regimen Working?
- HIV Treatment Regimen Failure
- Changing My HIV Treatment Regimen
- What is Treatment Adherence?
- Adhering To My HIV Treatment Regimen
- HIV and Pregnancy
- Understanding HIV Prevention
I tested HIV positive. What does this mean?

Does it mean I have AIDS?

A positive HIV test result means that you are infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS (Acquired Immune Deficiency Syndrome). Being infected with HIV does not mean that you have AIDS right now. However, if left untreated, HIV infection damages a person’s immune system and can progress to AIDS.

What is AIDS?

AIDS is the most serious stage of HIV infection. It results from the destruction of the infected person's immune system.

Your immune system is your body's defense system. Cells of your immune system fight off infection and other diseases. If your immune system does not work well, you are at risk for serious and life-threatening infections and cancers. HIV attacks and destroys the disease-fighting cells of the immune system, leaving the body with a weakened defense against infections and cancer.

Which disease-fighting cells does HIV attack?

CD4 cells are a type of white blood cell that fights infections. They are also called CD4+ T cells or CD4 T lymphocytes. A CD4 count is the number of CD4 cells in a sample of blood.

When HIV enters a person's CD4 cells, it uses the cells to make copies of itself. This process destroys the CD4 cells, and the CD4 count goes down. As you lose CD4 cells, your immune system becomes weak. A weakened immune system makes it harder for your body to fight infections and cancer.

How will I know if I have AIDS?

AIDS is not a diagnosis you can make yourself; it is diagnosed when the immune system is severely weakened. If you are infected with HIV and your CD4 count drops below 200 cells/mm³, or if you develop an AIDS-defining condition (an illness that is very unusual in someone who is not infected with HIV), you have AIDS.

What are the AIDS-defining conditions?

In December 1992, the Centers for Disease Control and Prevention (CDC) published the most current list of AIDS-defining conditions*. The AIDS-defining conditions are:

- Candidiasis
- Cervical cancer (invasive)
- Coccidioidomycosis, Cryptococcosis, Cryptosporidiosis
- Cytomegalovirus disease
- Encephalopathy (HIV-related)
- Herpes simplex (severe infection)
- Histoplasmosis
- Isosporiasis
- Kaposi's sarcoma
- Lymphoma (certain types)
- Mycobacterium avium complex
- Pneumocystis carinii/jiroveci pneumonia
- Pneumonia (recurrent)
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia (recurrent)
- Toxoplasmosis of the brain
- Tuberculosis
- Wasting syndrome

People who are not infected with HIV may also develop these diseases; this does not mean they have AIDS. To be diagnosed with AIDS, a person must be infected with HIV.

What is HIV treatment?

HIV treatment is the use of medications to keep an HIV infected person healthy. Treatment can help people at all stages of HIV disease. Although anti-HIV medications can treat HIV infection, they cannot cure HIV infection. HIV treatment is complicated and must be tailored to you and your needs.

The Fact Sheets in this series provide information about HIV treatment, including when to start medication, which medications are used, how to know if treatment is working, and what can be done if your treatment is not working.

For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1-800-448-0440 or http://aidsinfo.nih.gov.

* CDC. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. MMWR 1992;41(no. RR-17).
Seeing an HIV Doctor

I am HIV positive. What kind of doctor do I need?
Your doctor (or other healthcare provider) should be experienced in treating HIV and AIDS. You may want to see an infectious disease specialist. You will need to work closely with your doctor to make informed decisions about your treatment, so it is important to find a doctor with whom you are comfortable.

What can I expect at the doctor's office?
Your doctor will ask you questions about your health, do a physical exam, and order blood tests. This is a good time to ask your doctor questions. Write down any questions you have and take them with you to your appointment.

Women should have a pregnancy test (see HIV and Pregnancy Fact Sheet) and a gynecologic examination with Pap smear.

What questions should I ask my doctor?
You should ask your doctor about:
• Risks and benefits of HIV treatment
• Other diseases you may be at risk for
• How your lifestyle will change with HIV infection
• How you can avoid transmitting HIV to others
• How you can achieve and maintain a healthier lifestyle

What tests will my doctor order?
It is very important to have a CD4 count and a viral load test done at your first doctor's visit. The results will provide a baseline measurement for future tests.
• CD4 count – CD4 cells, also called CD4+ T cells or CD4 lymphocytes, are a type of white blood cell that fights infection. HIV destroys CD4 cells, weakening your body's immune system. A CD4 count is the number of CD4 cells in a sample of blood.
• Viral load test – A viral load test measures the amount of HIV in a sample of blood. This test shows how well your immune system is controlling the virus.

The two viral load tests commonly used for HIV are:
• HIV RNA amplification (RT-PCR) test
• Branched chain DNA (bDNA) test

Terms Used in This Fact Sheet:
Baseline: an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.
Liver function tests (LFTs): tests that measure the blood levels of liver enzymes (proteins made and used by the liver) to determine if your liver is working properly.

To ensure accurate results, viral load testing should be done at two different times, by the same laboratory, using the same type of test. The results of different types of tests may differ.

Your doctor may also order:
• Complete blood count
• Blood chemistry profile (including liver function tests)
• Tests for other sexually transmitted diseases (STDs)
• Tests for other infections, such as hepatitis, tuberculosis, or toxoplasmosis

Am I ready to begin HIV treatment?
Once you begin taking anti-HIV medications, you may need to continue taking them for the rest of your life. Deciding when or if to begin treatment depends on your health (see Starting Anti-HIV Medications Fact Sheet) and your readiness to follow a treatment regimen that may be complicated. You and your doctor should discuss your readiness to begin treatment as well as strategies to make your treatment work for you (see Adherence and Adhering to a Regimen Fact Sheets).

If my doctor and I decide to delay treatment, will I need to have my CD4 count and viral load tested again?
Yes. HIV infected people who have not started drug therapy should have a viral load test every 3 to 4 months and a CD4 count every 3 to 6 months. You and your doctor will use the test results to monitor your infection and to decide when to start treatment.

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.
Starting Anti-HIV Medications

I am HIV positive. Do I need to take anti-HIV medications?
You do not necessarily need to take anti-HIV (also called antiretroviral) medications just because you are HIV positive. You and your doctor will determine the best time to start treatment. When to take anti-HIV medications depends on your overall health, the amount of virus in your blood (viral load), and how well your immune system is working.

How will I know when to start anti-HIV medications?
You and your doctor should consider three factors in deciding when to start treatment: 1) symptoms of advanced HIV disease, 2) viral load, and 3) CD4 count.

You should start treatment if:
- you are experiencing severe symptoms of HIV infection or have been diagnosed with AIDS
- your viral load is 100,000 copies/mL or more
- your CD4 count is 200 cells/mm³ or less

You may also consider starting treatment if your CD4 count is between 200 and 350 cells/mm³; this is something you should discuss with your doctor.

If anti-HIV medications can help me stay healthy, why wait to start treatment?
Once you begin treatment, you may need to continue taking anti-HIV medications for the rest of your life. Although newer anti-HIV medications are easier to take, starting treatment usually means a significant adjustment in your lifestyle. Some anti-HIV medications need to be taken several times a day at specific times and may require a change in meals and mealtimes.

In addition to their desired effects, anti-HIV medications may have negative side effects, some of which are serious. If the virus is not suppressed completely, drug resistance can develop. Side effects and drug resistance may limit your future treatment options.

What treatment is right for me?
There are 21 anti-HIV medications approved by the U.S. Food and Drug Administration (FDA) for adults and adolescents. The U.S. Department of Health and Human Services (HHS) provides HIV treatment guidelines to doctors and patients. These guidelines recommend that you take a combination of three or more medications in a regimen called Highly Active Antiretroviral Therapy (HAART). The guidelines list "preferred" HAART regimens. However, your regimen should be tailored to your needs. Factors to consider in selecting a treatment regimen include:
- number of pills
- how often the pills must be taken
- if pills can be taken with or without food
- how the medications interact with one another
- other medications you take
- other diseases or conditions
- pregnancy

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

Terms Used in This Fact Sheet:
AIDS: Acquired Immune Deficiency Syndrome. AIDS is the most severe form of HIV infection. HIV infected patients are diagnosed with AIDS when their CD4 cell count falls below 200 cells/mm³ or if they develop an AIDS-defining illness (an illness that is very unusual in someone who is not HIV positive).
Antiretroviral: a medication that interferes with replication of retroviruses. HIV is a retrovirus.
CD4 count: CD4 cells, also called T cells or CD4+ T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.
Drug resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.
Viral load: the amount of HIV in a sample of blood.

This information is based on the U.S. Department of Health and Human Services' Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents (available at http://aidsinfo.nih.gov). Reviewed Sept. 2005
When I start treatment, what kinds of medications will I need to take?

Anti-HIV medications are used to control the reproduction of the virus and to slow the progression of HIV disease. They are also called antiretroviral medications. There are four classes of FDA-approved antiretroviral medications: NRTIs, NNRTIs, PIs, and fusion inhibitors. The Approved Anti-HIV Medications Fact Sheet lists the FDA-approved antiretroviral medications by class.

How many medications will I need to take?

The recommended treatment for HIV is a combination of three or more medications in a regimen called Highly Active Antiretroviral Therapy (HAART). How many pills you will need to take and how often you will take them depends on what medications you and your doctor choose.

Which medications should I take?

Each HAART regimen is tailored to the individual patient – there is no one “best” regimen. You and your doctor will decide which medications are right for you. For people taking HAART for the first time, the recommended regimens are:

- Sustiva + (Epivir or Emtriva) + (Retrovir or Viread)
- Kaletra + (Epivir or Emtriva) + Retrovir

Are there any other treatment regimens?

Some people may benefit from a different regimen. Recommended alternative regimens are:

- Sustiva + (Epivir or Emtriva) + (Ziagen or Videx or Zerit)
- Viramune + (Epivir or Emtriva) + (Retrovir or Zerit or Videx or Zidovudine or Viread)
- Reyataz + (Epivir or Emtriva) + (Retrovir or Zerit or Zidovudine or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Viread or Virea...
Approved Medications to Treat HIV Infection

Anti-HIV (also called antiretroviral) medications are used to control the reproduction of the virus and to slow the progression of HIV-related disease. Highly Active Antiretroviral Therapy (HAART) is the recommended treatment for HIV infection. HAART combines three or more anti-HIV medications in a daily regimen. Anti-HIV medications do not cure HIV infection, and individuals taking these medications can still transmit HIV to others. Anti-HIV medications approved by the U.S. Food and Drug Administration (FDA) fall into four classes:

<table>
<thead>
<tr>
<th>Class</th>
<th>Generic Name</th>
<th>Brand &amp; Other Names</th>
<th>Manufacturer</th>
<th>FDA Approval Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nonnucleoside Reverse Transcriptase Inhibitors (NNRTIs)</td>
<td>Delavirdine</td>
<td>Rescriptor, DLV</td>
<td>Pfizer</td>
<td>April 4, 1997</td>
</tr>
<tr>
<td></td>
<td>Efavirenz</td>
<td>Sustiva, EFV</td>
<td>Bristol-Myers Squibb</td>
<td>Sept. 17, 1998</td>
</tr>
<tr>
<td></td>
<td>Nevirapine</td>
<td>Viramune, NVP</td>
<td>Boehringer Ingelheim</td>
<td>June 21, 1996</td>
</tr>
</tbody>
</table>

NNRTIs bind to and disable reverse transcriptase, a protein that HIV needs to make more copies of itself.

| | Abacavir, Lamivudine | Epzicom | GlaxoSmithKline | Aug. 2, 2004 |
| | Abacavir, Lamivudine, Zidovudine | Trizivir | GlaxoSmithKline | Nov. 14, 2000 |
| | Emtricitabine | Emtriva, FTC, Coviracil | Gilead Sciences | July 2, 2003 |
| | Emtricitabine, Tenofovir DF | Truvada | Gilead Sciences | Aug. 2, 2004 |
| | Lamivudine | Epivir, 3TC | GlaxoSmithKline | Nov. 17, 1995 |
| | Lamivudine, Zidovudine | Combivir | GlaxoSmithKline | Sept. 27, 1997 |
| | Stavudine | Zerit, d4T | Bristol-Myers Squibb | June 24, 1994 |
| | Tenofovir DF | Viread, TDF | Gilead Sciences | Oct. 26, 2001 |
| | Zalcitabine | Hivid, ddC | Hoffmann-La Roche | June 19, 1992 |
| | Zidovudine | Retrovir, AZT, ZDV | GlaxoSmithKline | March 19, 1987 |
# Approved Medications to Treat HIV Infection

### 3. Protease Inhibitors (Pis)

*Pis disable protease, a protein that HIV needs to make more copies of itself.*

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand &amp; Other Names</th>
<th>Manufacturer</th>
<th>FDA Approval Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amprenavir</td>
<td>Agenerase, APV</td>
<td>GlaxoSmithKline, Vertex Pharmaceuticals</td>
<td>April 15, 1999</td>
</tr>
<tr>
<td>Atazanavir</td>
<td>Reyataz, ATV</td>
<td>Bristol-Myers Squibb</td>
<td>June 20, 2003</td>
</tr>
<tr>
<td>Fosamprenavir</td>
<td>Lexiva, FPV</td>
<td>GlaxoSmithKline, Vertex Pharmaceuticals</td>
<td>Oct. 20, 2003</td>
</tr>
<tr>
<td>Indinavir</td>
<td>Crixivan, IDV</td>
<td>Merck</td>
<td>March 13, 1996</td>
</tr>
<tr>
<td>Lopinavir,</td>
<td>Kaletra, LPV/r</td>
<td>Abbott Laboratories</td>
<td>Sept. 15, 2000</td>
</tr>
<tr>
<td>Ritonavir</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nelfinavir</td>
<td>Viracept, NFV</td>
<td>Agouron Pharmaceuticals</td>
<td>March 14, 1997</td>
</tr>
<tr>
<td>Ritonavir</td>
<td>Norvir, RTV</td>
<td>Abbott Laboratories</td>
<td>March 1, 1996</td>
</tr>
<tr>
<td>Saquinavir</td>
<td>Invirase, SQV</td>
<td>Hoffmann-La Roche</td>
<td>Nov. 7, 1997</td>
</tr>
<tr>
<td>Tipranavir</td>
<td>Aptivus, TPV</td>
<td>Boehringer Ingelheim</td>
<td>June 22, 2005</td>
</tr>
</tbody>
</table>

### 4. Fusion Inhibitors

*Fusion inhibitors work by blocking HIV entry into cells.*

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand &amp; Other Names</th>
<th>Manufacturer</th>
<th>FDA Approval Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enfuvirtide</td>
<td>Fuzeon, T-20</td>
<td>Hoffmann-La Roche, Trimeris</td>
<td>March 13, 2003</td>
</tr>
</tbody>
</table>
Is My Treatment Regimen Working?

How will I know if my HIV treatment regimen is working?
In general, viral load is the most important indicator of how well your regimen is working. Your viral load should decrease if your medications are effective. Other factors that can tell you and your doctor how well your regimen is working are:

- Your CD4 count. This should remain stable or go up if your drugs are working.
- Your recent health and results of physical examinations. Your treatment regimen should help keep you healthy.

How often should I have a viral load test?
Your viral load should be tested 2 to 8 weeks after you start treatment, then every 3 to 4 months throughout treatment to make sure your drugs are still working. HIV treatment should reduce your viral load to the point at which it is undetectable. An undetectable viral load does not mean that your HIV infection is gone; it simply means that the test is not sensitive enough to detect the small amount of HIV left in your blood.

If your viral load is still detectable within 4 to 6 months after starting treatment, you and your doctor should discuss how well you have adhered to your regimen (see Adherence and Adhering to a Regimen Fact Sheets). Missing medication doses is the most common reason for treatment failure and development of drug resistance. Your doctor should do a drug resistance test, which will determine if the HIV in your body has mutated into a strain that your current treatment regimen can’t control.

How fast or how much your viral load decreases depends on factors other than your treatment regimen. These factors include your baseline viral load and CD4 count, whether you have taken HIV drugs before, whether you have HIV-related medical conditions, and how closely you have followed (adhered to) your treatment. Talk with your health care provider if you are concerned about the results of your viral load tests.

How often should I have a CD4 count?
CD4 counts also indicate how well your treatment regimen is working. Your CD4 count should be tested every 3 to 6 months throughout your treatment. HIV treatment should increase your CD4 count or at least keep it from going down. Talk to your health care provider if you are concerned about your CD4 counts.

My doctor wants to change my treatment regimen. Why?
There are several reasons why you may need to change your treatment regimen. Two of the most important reasons are drug toxicity and regimen failure.

Drug toxicity means that your treatment regimen creates side effects that make it difficult for you to take the drugs. Regimen failure means that the drugs are not working well enough. See HIV Regimen Failure Fact Sheet for more information about regimen failure.

Ask your doctor to explain why you need to change your treatment. If the reason is drug toxicity, your doctor may change one or more of the drugs in your regimen. If the reason is regimen failure, your doctor should change all of your drugs to medications that you have never taken before. If you have been taking three drugs and all three drugs cannot be changed, at least two drugs should be changed. Using new drugs will reduce the risk of drug resistance. See Changing Regimens Fact Sheet for more information about changing treatment regimens.

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

This information is based on the U.S. Department of Health and Human Services’ Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents (available at http://aidsinfo.nih.gov).

Reviewed Sept. 2005
HIV Treatment Regimen Failure

What is regimen failure?
Regimen failure occurs when the anti-HIV medications you are taking do not adequately control the infection. Factors that may cause regimen failure include:

- Poor health before starting the treatment regimen
- Poor adherence to the regimen (not taking medications exactly as instructed by your doctor, including missing doses)
- Previous anti-HIV treatment and/or drug resistance
- Alcohol or drug abuse
- Medication side effects, medication toxicity, or interactions with other medications
- Medication poorly absorbed by the body
- Medical conditions or illnesses other than HIV infection

What are the three types of regimen failure?
1. Virologic failure: Regimens should lower the amount of HIV in your blood to undetectable levels. Virologic failure has occurred if HIV can still be detected in your blood 48 weeks after starting treatment, or if it is detected again after treatment had previously lowered your viral load to undetectable.

2. Immunologic failure: An effective regimen should increase the number of CD4 cells in your blood or at least prevent the number from going down. Immunologic failure has occurred if your CD4 count decreases below a baseline measurement or does not increase above the baseline count within your first year of therapy.

3. Clinical failure: Clinical failure has occurred if you experience an HIV-related infection or a decline in physical health despite at least 3 months of anti-HIV treatment.

Virologic failure is the most common kind of regimen failure. People with virologic failure who do not switch to a more effective drug regimen usually progress to immunologic failure within about 3 years. Immunologic failure may be followed by clinical failure.

Terms Used in This Fact Sheet:
Baseline: an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.
CD4 count: CD4 cells, also called T cells or CD4+ T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.
Drug resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.
Toxicity: the harm a medication can do to your body.
Viral load: the amount of HIV in a sample blood.

What happens if my regimen fails?
If your treatment regimen fails, your doctor will evaluate your treatment history, medication side effects, problems you may have had with taking the medications as directed, your physical condition, and results of drug resistance testing to determine why your regimen is failing. You and your doctor may then select a new drug regimen to better control your infection. See Changing Regimens Fact Sheet for more information about changing treatment regimens.

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.
Changing My HIV Treatment Regimen

How will my doctor and I know what medications to use next?
Before changing your treatment regimen, your doctor will try to find out why your current regimen is not working (see HIV Regimen Failure Fact Sheet for causes of regimen failure). Your doctor will evaluate your adherence to the regimen, the regimen's tolerability, and medication interactions. Whether you and your doctor decide to change your regimen and what new medications you will take will depend on why your current regimen is failing.

What is adherence?
Adherence refers to how closely you follow (adhere to) your treatment regimen. If your regimen is failing because you cannot adhere to it, you and your doctor should discuss why you are having difficulty taking your medication and what you can do to improve your adherence. Your doctor may change your regimen to reduce the number of pills you take or how often you take them. For more information about adherence, see Adherence and Adhering to a Regimen Fact Sheets.

What is tolerability?
Tolerability refers to how many and what types of negative medication side effects you experience. If the side effects are severe, you may need to change your regimen. Your doctor will ask you what side effects you have and how long you have had them. You and your doctor will decide whether to treat the side effects or to change your anti-HIV medications.

What are medication interactions?
Anti-HIV medications may interact with other medications you are taking. This may reduce the effectiveness of the medications or increase the risk of negative side effects. You and your doctor should review all of your medications, including over-the-counter medications and herbal remedies. You should also review whether your medications should be taken with food or on an empty stomach.

Terms Used in This Fact Sheet:
CD4 count: CD4 cells, also called T cells or CD4+ T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.
Drug resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.
Viral load: the amount of HIV in a sample of blood.

Changing Regimens
If your regimen is failing and you and your doctor have ruled out adherence, tolerability, and medication interactions, you should consider changing your regimen. Before changing anti-HIV medications, talk with your doctor about:
• anti-HIV medications you have taken before
• the strength of the new medications your doctor recommends
• possible side effects of the new medications
• how well you will be able to adhere to the new regimen
• the number of anti-HIV medications that you have not yet used

Your doctor will confirm that your regimen is failing with at least two viral load tests and three CD4 counts. You should also be tested for drug resistance while you are taking the failing regimen.

In general, your new treatment regimen should include three or more medications. You and your doctor will choose the medications based on your medication history, results of resistance testing, and medication side effects. If you have already taken many of the FDA-approved anti-HIV medications, your doctor may recommend a new medication under investigation. You may be eligible to participate in a clinical trial using new drugs or treatment strategies. For more information about participating in a clinical trial, ask your doctor, or visit the "Clinical Trials" section of the AIDSinfo Web site at: http://aidsinfo.nih.gov/ClinicalTrials/

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

This information is based on the U.S. Department of Health and Human Services' Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents (available at http://aidsinfo.nih.gov). Reviewed Sept. 2005
What is Treatment Adherence?

What is adherence?
Adherence refers to how closely you follow a prescribed treatment regimen. It includes your willingness to start treatment and your ability to take medications exactly as directed.

Is adherence important for HIV treatment?
Yes! Adherence is a major issue in HIV treatment for two reasons:

- Adherence affects how well anti-HIV medications decrease your viral load. When you skip a medication dose, even just once, the virus has the opportunity to reproduce more rapidly. Keeping HIV replication at a minimum is essential for preventing AIDS-related conditions and death.
- Adherence to HIV treatment helps prevent drug resistance. When you skip doses, you may develop strains of HIV that are resistant to the drugs you are taking and even to drugs you have not yet taken. This may leave you with fewer treatment options should you need to change treatment regimens in the future. Because drug-resistant strains can be transmitted to others, engaging in risky behavior can have especially serious consequences.

Although there are many different anti-HIV medications and treatment regimens, studies show that your first regimen has the best chance for long-term success. Taking your drugs correctly (adherence) increases your odds of success.

Why is adherence difficult for many people with HIV?
HIV treatment regimens can be complicated; most regimens involve taking multiple pills each day. Some anti-HIV medications must be taken on an empty stomach, while others must be taken with meals. This can be difficult for many people, especially for those who are sick or are experiencing HIV symptoms or negative drug side effects.

Other factors that can make it difficult to adhere to an HIV treatment regimen include:

- Experiencing unpleasant medication side effects (such as nausea)

Terms Used in This Fact Sheet:

- Drug resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.
- Viral load: the amount of HIV in a sample of blood.

What can I do to adhere to my treatment regimen?
There are many things you can do to better adhere to your treatment regimen. Adhering to a Regimen Fact Sheet discusses what you can do to improve your adherence both before and after you start taking anti-HIV medications.

One of the most important things you can do when starting a treatment regimen is to talk with your doctor about your lifestyle. He or she will then be able to prescribe a regimen that works best for you. Topics you should address with your doctor include:

- Your travel, sleep, and eating schedule
- Possible side effects of medication
- Other medications you are taking and their possible interaction with anti-HIV medications
- Your level of commitment to following an HIV treatment regimen

Many people adhere well to their treatment early on, but find adherence becomes more difficult over time. Talk with your health care provider about adherence during every visit. Your commitment to a treatment plan is critical; studies show that patients who take their medications correctly achieve the best results.

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

This information is based on the U.S. Department of Health and Human Services' Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents (available at http://aidsinfo.nih.gov).
Adhering To My HIV Treatment Regimen

What should I do before I begin treatment?
Before you begin an HIV treatment regimen, there are several steps you can take to help you with adherence:

- Talk with your doctor about your treatment regimen.
- Get a written copy of your treatment plan that lists each medication, when and how much to take, and if it must be taken with food or on an empty stomach.
- Understand how important adherence is (see Adherence Fact Sheet).
- Be honest about personal issues that may affect your adherence. Adherence may be harder for people dealing with substance abuse or alcoholism, unstable housing, mental illness, or other life challenges.
- Consider a "dry run." Practice your treatment regimen using vitamins, jelly beans, or mints. This will help you determine ahead of time which doses might be difficult to take correctly.
- Develop a plan that works for you.

Many people find it helpful to identify the activities they normally do at the times they will be taking their medication. People who arrange their medication schedule around their daily routines adhere to their treatment plans better than those who do not.

How can I maintain adherence after I start treatment?

- Take your medication at the same time each day.
- Put a week's worth of medication in a pill box at the beginning of each week.
- Use timers, alarm clocks, or pagers to remind you when to take your medication.
- Keep your medication in the place where you will take it. You may want to keep backup supplies of your medication at your workplace or in your briefcase or purse.

What should I do if I have problems adhering to my treatment regimen?

It is important that you tell your doctor right away about any problems you are having with your treatment plan. If you are experiencing unpleasant side effects, your dose may need to be adjusted or you may need a change in your regimen (see Changing Regimens Fact Sheet for more information about changing your treatment regimen). Missed doses may be a sign that your treatment plan is too complicated or unrealistic for you to follow. Talk with your doctor about other treatment options. Your doctor needs to stay informed to help you get the most out of your treatment regimen and to provide workable treatment options.

For more information:
Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

Term Used in This Fact Sheet:
Adherence: how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

- Keep a medication diary. Write the names of your drugs in your daily planner, then check off each dose as you take it.
- Plan ahead for weekends, holidays, and changes in routine.
- Develop a support network of family members, friends, or coworkers who can remind you to take your medication. Some people also find it helpful to join a support group for people living with HIV infection.
- Monitor your medication supply. Contact your doctor or clinic if your supply will not last until your next visit.
HIV and Pregnancy

I am HIV positive and pregnant. Should I take anti-HIV medications?

You should take anti-HIV medications if:

• you are experiencing severe symptoms of HIV or have been diagnosed with AIDS
• your CD4 count is 200 cells/mm³ or less
• your viral load is greater than 1,000 copies/mL

You should also take anti-HIV medications to prevent your baby from becoming infected with HIV. Specific treatment to prevent mother-to-child transmission of HIV is discussed below.

What medications should I take if I am pregnant or think I might become pregnant?

If you are pregnant or may become pregnant, you should consider the risks and benefits of HIV treatment to both you and your child. Some medications (such as Sustiva) should be avoided because they may cause birth defects if taken early in pregnancy. The effects of other anti-HIV medications are not yet known. It is important for you to talk with your doctor before and during your pregnancy so that together you can decide on the best treatment for you and your baby.

To reduce the risk of passing HIV to your baby, your treatment regimen should include a three-part ZDV (also known as zidovudine, AZT, or Retrovir) regimen.

I am already on an HIV treatment regimen. Do I need to change my medications?

If you are already taking anti-HIV medications, talk with your doctor about the potential risks and benefits to your baby if you decide to continue your treatment regimen during your pregnancy. You and your doctor may decide to change your medications or change your medication dose. Make sure that your regimen includes the appropriate dose of ZDV.

In general, efavirenz (Sustiva), stavudine (Zerit), hydroxyurea, and the oral liquid form of amprenavir (Agenerase) should not be used during pregnancy.

What is the three-part ZDV regimen?

1. HIV infected pregnant women should take ZDV starting at 14 to 34 weeks of pregnancy. You can take either 100 mg five times a day, 200 mg three times a day, or 300 mg twice a day.
2. During labor and delivery, you should receive ZDV intravenously (through an IV in the vein).
3. Your baby should take ZDV (in liquid form) every 6 hours for 6 weeks after he or she is born.

Will my baby be born HIV infected?

No one can tell you for sure if your baby will be born HIV infected. The three-part ZDV regimen has been shown to reduce the risk of passing HIV to your baby by almost 70%.

Additional anti-HIV medications can treat your infection and may provide extra protection for your baby. However, the possible problems with using multiple medications during pregnancy are not well understood.

Other actions to help you protect your baby include getting regular prenatal care and adhering to your HIV drug treatment plan (see Adherence and Adhering to a Regimen Fact Sheet).

AIDSinfo has developed a series of five fact sheets that discuss HIV and pregnancy in more detail. These fact sheets are available at www.aidsinfo.nih.gov/other/factsheet.asp.

For more information:

Contact your doctor or an AIDSinfo Health Information Specialist at 1–800–448–0440 or http://aidsinfo.nih.gov.

Terms Used in This Fact Sheet:

CD4 count: CD4 cells, also called T cells or CD4+ T cells, are white blood cells that fight infection. HIV destroys CD4 cells, making it harder for your body to fight infections. A CD4 count is the number of CD4 cells in a sample of blood.

Mother-to-child transmission: also called perinatal transmission. HIV may be passed from an HIV infected mother to her baby during pregnancy or delivery. HIV may also be passed from mother to child through breast milk.

Viral load: the amount of HIV in a sample of blood.

Understanding HIV Prevention

I am HIV positive and don't want to infect others. What should I do?
Understanding how HIV is transmitted is an important step in prevention. Talk with your health care provider about how HIV is transmitted and what you can do to prevent infecting others. Each time you visit your health care provider, discuss your high-risk behaviors, such as unprotected sex and needle sharing.

You may feel reluctant to talk with your health care provider about your high-risk behaviors. It can be difficult to change behaviors, even when you want to. However, it is important to be honest with your provider about risky activities. You and your provider can then discuss ways to minimize the risk of infecting others.

If you are a woman, you and your doctor should discuss ways to prevent pregnancy. If you want to become pregnant, you and your doctor can talk about what you should do to prevent transmitting HIV to your baby (see HIV and Pregnancy Fact Sheet).

How can I prevent infecting someone else?
Successful HIV treatment can lower your viral load, which may reduce the risk of HIV transmission. But there are other factors that influence sexual transmission of HIV, such as:
- presence of other sexually transmitted diseases (STDs)
- genital irritation
- menstruation
- lack of circumcision in men
- taking birth control pills
- hormone imbalances
- vitamin and mineral deficiencies

Always use prevention strategies, such as condoms and safer sex practices. If you inject drugs, don't share your works with anyone else. Talk with your health care provider if you have trouble sticking to these prevention strategies. You and your provider can then find ways to make your high-risk behaviors safer.

Should I tell my partners that I am HIV infected?
Yes. It is very important that you tell your sexual partners and people with whom you have shared injected drugs that they may have been exposed to HIV and should be tested. You and your health care provider can discuss the best way to notify your partners. Some health departments and HIV clinics have anonymous partner notification systems—your partners are told that they have been exposed, but are not told who reported their names or when the reported exposure occurred.

It is important to use HIV prevention strategies even if your partner is also HIV infected. Your partner may have a different strain of the virus that could act differently in your body or be resistant to different anti-HIV medications.

I am taking anti-HIV medications and my viral load is undetectable. Am I cured?
Can I infect others?
An undetectable viral load does not mean that you are cured. It means that the amount of HIV virus in your blood is so low that the viral load tests cannot detect it. You are still infected with HIV and can infect others. You should continue to use prevention strategies and should see your health care provider regularly.

For more information:
The Centers for Disease Control and Prevention (CDC) National Prevention Information Network (NPIN) provides information about prevention of HIV infection, other sexually transmitted diseases, and tuberculosis.

If you have questions about ways to prevent transmitting HIV, contact your doctor or a CDC NPIN Information Specialist at 1–800–458–5231 or http://edenpin.org.

This information is based on the U.S. Department of Health and Human Services' Incorporating HIV Prevention into the Medical Care of Persons Living with HIV (available at http://aidsinfo.nih.gov).
PRE-COURSE READING - CASE SCENARIOS

Scenario 1:

Gradually over the last twelve days Sonia, a 28 year old female, has noticed decreased energy levels and for the last four days she has had a persistent cough, fever and shortness of breath. She goes 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, she has no significant previous medical history except for a tonsillectomy at the age of seven. Until 6 months ago Sonia worked as a social services worker helping people get supportive housing, she is currently unemployed. She lives alone and has become too weak to care for herself. She reports use of marijuana and occasional injection drugs, mainly heroine, over the last year.

On physical examination Sonia has a fever of 39 degrees, is 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.

Scenario 2:

James has been HIV positive for 6 years; it has been a year and a half since his last hospitalization related to medication toxicity. He is now on a stable anti-retroviral medication regimen. He has been on long-term disability for 5 years and is considering returning to work. Although James is looking forward to going back he has several concerns about his ability to keep up with the demands of work. He previously worked as a respiratory therapist in a community hospital. His energy levels still fluctuates, he can often have a full day with no need to rest, but 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.

As a result of the HIV and anti-retroviral therapy James has peripheral neuropathy leaving him with a mild decrease in sensation in both feet and hands. At times he finds that he stumbles while walking and has difficulty with some manual dexterity tasks. In addition the physical challenges that he faces, he has fears about work place phobias and how he will be accepted. At his last work place he experienced work place harassment and it was common to hear colleagues make comments under their breath in the staff room.
Scenario 3:

Louis is an 83 year old male living alone in the community. 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 was diagnosed with bipolar disorder at the age of 55, and HIV infection approximately 2 years ago.

Louis lives in a 1 bedroom apartment, in the downtown area. As a community therapist, during your home visit, you noticed that his home is cluttered, disorganized and has not been recently cleaned. Louis has difficulty with ambulation and uses the furniture around his home to provide support for walking. Louis tells you he has a companion that 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.

Louis is currently not on any medication and you are the first health care provider to visit him at home.

Scenario 4:

Natasha is a 16 year old living with cerebral palsy and HIV. She currently lives with her mother in a 2 bedroom apartment. 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 re-started highly active antiretroviral therapy (HAART), on a new combination of medications, and finds the side effects make her feel weak and nauseous. 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 it she has cancer. Natasha expresses that she does not want to be stigmatized or discriminated against, especially considering her family’s religious background.

The paediatric rehabilitation team is assessing Natasha’s needs to commence planning for transition to adult health and social care services.
Introduction to HIV
Rehabilitation in the Context of HIV

Presented by
Canadian Working Group on HIV and Rehabilitation

Course Agenda Day 1

• Overview
• Introduction to HIV
• HIV in Context
• Summary
Course Agenda Day 2

• Living with HIV
• Rehabilitation Roles
• Rehabilitation Interventions
• Case Discussion
• Wrap up and Evaluation

Course Goals

• To increase knowledge and skills related to HIV among rehabilitation professionals
• To increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV
• To enhance interprofessional practice among rehabilitation professionals to collaboratively respond to the rehabilitation needs of people living with HIV

Introduction to HIV
Session Outline

- Introduction to CWGHR
- Incidence and Prevalence
- Transmission and Pathophysiology
- Systemic Involvement
- Related Illnesses

What is CWGHR?

Canadian Working Group on HIV and Rehabilitation

- National, multi-sector working group
- Addresses rehabilitation issues in the context of HIV
- Centred on the needs of people living with HIV

Goals of CWGHR

- Rehabilitation programs and resources for people living with HIV
- Innovation and excellence in the field of disabilities episodic and cyclic in nature
- Generate awareness of and access to rehabilitation services
- Address the needs and concerns of families, caregivers, communities and people living with HIV-related disabilities
Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building Through Development of New Knowledge, Curriculum Resources and Partnerships

Purpose

To increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS in Canada

Project Objectives

1. To develop new and enhance existing knowledge-based relationships
2. To increase awareness of existing and new curriculum resources, educational initiatives, programs & tools
3. To increase knowledge & skills related to HIV among rehab professionals
Section A: Interprofessional HIV Curriculum Specific to Rehabilitation Professionals

Section B: HIV Curriculum Specific to Rehabilitation Professionals (no IPE)

Section C: Interprofessional HIV Curriculum for Health Care Professionals (may or may not include rehab professionals)

Section D: HIV Curriculum for Health Care Professionals (may or may not include rehab professionals)

Other Health Care Professionals

Key Informants
- People Living with HIV
- Rehabilitation professionals
- Curriculum experts
- Academics
- Placement coordinators
- Policy makers
- IPE networks

Themes
- Curriculum Content
  - HIV 101
  - Rehabilitation related impairments, activity limitations and participation restrictions and strategies to address them
  - Issues related to sensitive practice
- Curriculum Delivery
  - Engaging people living with HIV as educators
  - Providing usable information in a practical form
  - Problem based
  - Interprofessional
Project Deliverables

• Interprofessional Curriculum
• Compendium of Resources
• Project Final Report, Evaluation and Fact Sheets
• Broad Dissemination

Future Opportunities

• Distance learning module
• Integrate into rehabilitation professional curriculum
• Rehabilitation and HIV module for other health providers
• Rehab & HIV self/community advocacy tools
• Mentorship program
• Best Practice Guideline development
• Rehabilitation and HIV special interest groups
• Future areas for Research/Education/Practice/Policy...

What do you already know about HIV and AIDS?
Statistics in Canada

> 56,000 people living with HIV in Canada

20% rise in positive HIV tests over last 5 years
Increase in Women 15-29 years of age
Increase in Aboriginal persons

30% (17,000) are not aware of their HIV infection

www.phac-aspc.gc.ca/hast-vsmt/
Universal Precautions

• glove if you may come in contact with body fluids
• mask, goggle and gown if you may be splashed by body fluids
• no different than working with any other client population
• using unnecessary precautions sends the wrong message

Basic Pathophysiology

• HIV is a retrovirus
• Attracted to cells bearing CD-4 receptor (or T-cells)… eventually may lead to deterioration of immune system
• Enzymes facilitate reproductive cycle of HIV
  • Reverse transcriptase
  • Integrase
  • Protease
Surrogate Markers

- **CD-4 count**
  - Otherwise known as T-cell count
  - Measured in cells/ml
  - HIV’s target cells
  - Represents integrity of the immune system

- **Viral Load**
  - Measures amount of virus in the circulating blood
  - Measured in copies of virus/ml
  - Indicates level of virus circulation activity
  - Undetectable ≠ no virus

Stages of HIV Infection

- **Primary HIV infection**
  - flu-like symptoms
  - 2-4 wks after infection
  - decrease in CD4 count

- **Seroconversion**
  - body starts to respond to infection by making antibodies to the virus
  - approx 3 months post infection
CDC Classification System for HIV Infection

A. Asymptomatic infection
   • persistent generalized lymphadenopathy (PGL)
   • may last years

B. Symptomatic infection
   • whole body symptoms
   • decrease CD4 (200-400 cells/mm³)

C. Advanced Disease – AIDS

What is AIDS?

• Acquired Immune Deficiency Syndrome
  • not a disease...a category
  • case reporting / surveillance

• CDC 1993 classification
  • CD-4 count < 200 cells/mm³
  • 26 clinical conditions
    • opportunistic infections
    • neoplasms
    • miscellaneous

AIDS-Defining Illnesses

• Bacterial Infections
  • TB
  • MAC Bacterial pneumonias
• Fungal Infections
  • Thrush
  • Cryptococcosis
• Protozoan Infections
  • Toxoplasmosis
  • PCP
  • microsporidiosis
• Viral Infections
  • CMV (cytomegalovirus)
  • herpes zoster (shingles)
  • herpes simplex
• Other
  • cervical cancer
  • Kaposi’s sarcoma
  • Lymphoma
  • wasting syndrome
  • AIDS dementia complex
**Evolution of HIV/AIDS**

- 1996 - Advances in medical management
- People are experiencing improvements in health and staying healthy longer
- Unpredictable cycles of wellness and illness
- Increased chronicity mirrored by increased prevalence of impairments, activity limitations and participation restrictions

**Antiretroviral Medication**

Not a cure
Interfere with the life cycle of the virus
Assist to decrease VL and increase CD4
Combination therapy HAART
(Highly Active Antiretroviral Therapy)
Often fraught with unwanted adverse effects

- a) nucleoside reverse transcriptase inhibitors
- b) non-nucleoside reverse transcriptase inhibitors
- c) protease inhibitors
- d) Fusion inhibitors

**Risks and Benefits of Therapy**

**Benefits**
- ↓VL and delay progression
- preserve immune function
- ↓ risk of resistance with viral suppression
- possible ↓ risk of transmission

**Risks**
- drug related ↓QOL (side effects, toxicity)
- drug resistance
- limit future treatment options
Indications for Drug Initiation

• Treat
  • Symptomatic
  • Asymptomatic CD4 < 200

• Offer
  • Asymptomatic
    – CD4 between 200 and 350
    – CD4 > 350, VL >55,000
  • Readiness ($, side effects, adherence)

Systemic Impacts of HIV

Multi System Involvement
• Musculoskeletal
• Metabolic and endocrine
• Cardiopulmonary
• Neurological

Musculoskeletal System
• Polymyositis
• Arthritis
• Myofascial involvement
• Secondary complications

Metabolic and Endocrine System
• Lipodystrophy
Cardiopulmonary System

Pulmonary manifestations are a major cause of morbidity and mortality in HIV

- Pneumocystis carinii pneumonia
- Tuberculosis
- Cytomegalovirus
- Histoplasmosis
- Cardiac conditions

Neurological System

- Toxoplasmosis
- progressive multifocal leukoencephalopathy (PML)
- AIDS dementia complex (ADC)
- Cryptococcosis
- primary CNS lymphoma
- vacuolar myelopathy
- inflammatory demyelinating polyneuropathy
- distal sensory polyneuropathy

HIV Related Malignancies

- Kaposi’s sarcoma (KS)
- Non-Hodgkin's lymphoma
- Cervical, anorectal and lung cancer
What About Rehabilitation?

- People are living longer lives with HIV
- Increasing prevalence of impairments, activity limitations and participation restrictions
- Multisystemic disease affecting neurological, cardiopulmonary and musculoskeletal systems
- Unpredictable cycles of wellness and illness
Anti-HIV Medications (Anti-retroviral Therapy)

Anti-HIV medications are an important part of your treatment against HIV infection. They are medications that slow down the growth of the HIV virus. Because HIV is a special type of virus called “retrovirus,” the medications are usually called “anti-retrovirals.”

What kinds of anti-HIV medications are available?
There are different types (or classes) of anti-HIV medications. Each type of anti-HIV medication works by blocking a different protein that the HIV virus need in its reproduction.

Currently there are two major classes of anti-HIV medications available on the market:

- medications that block the protein “reverse transcriptase,” known as reverse transcriptase inhibitors or RT inhibitors (RTIs).
- medications that block the protein “protease,” known as protease inhibitors (PIs).

The RT Inhibitors (nukes and non-nukes)
The RT inhibitors, or RTIs, are divided into 3 groups based on differences in their chemical structures: nucleoside RT inhibitors (also called “nukes” or NRTIs), non-nucleoside RT inhibitors (also called “non-nukes” or NNRTIs), and nucleotide RT inhibitors (also called NtRTIs).

Medications from the class of nukes or NRTIs include:
- AZT (also called zidovudine or Retrovir)
- ddI (also called didanosine or Videx or Videx EC)
- ddC (also called zalcitabine or Hivid)
- d4T (also called stavudine or Zerit or Zerit XR)
- 3TC (also called lamivudine or Epivir)
- Abacavir (also called ABC or Ziagen)
- Combivir (a combination medication of AZT + 3TC)
- Trizivir (a combination medication of AZT, 3TC + abacavir)

Medications from the non-nuke or NNRTI class include:
- nevirapine (also called Viramune)
- delavirdine (also called Rescriptor)
- efavirenz (also called Sustiva)
Anti-HIV Medications (Anti-retroviral Therapy)

The approved medication from the **NtRTI** class is:
- tenofovir (also called Viread)

Medications from the class of **protease inhibitors** include:
- saquinavir (also called Invirase and Fortovase)
- indinavir (also called Crixivan)
- ritonavir (also called Norvir)
- nelfinavir (also called Viracept)
- amprenavir (also called Agenerase)
- Kaletra (lopinavir + ritonavir)

**When should I start taking anti-HIV medications?**

Starting anti-HIV medications is a big decision. You have to be ready before you start these medications because usually they need to be taken on a regular schedule every day for them to work. This may involve making some changes in your daily routine and lifestyle.

It is important to find a doctor who is knowledgeable about HIV treatments and is sensitive to your situation and culture when working with you in making treatment decisions.

In general, anti-HIV medications are recommended if:
- Your CD4+ cell count (measure of your immune system) is less than 350.
- Your viral load (measure of amount of HIV virus in your blood) is greater than 55,000.
- You have had any symptoms of HIV disease.

**Which medications should I be taking?**

The current standard of HIV treatment includes the use of a combination of at least 3 different anti-HIV medications from different classes.

There are 2 major reasons for using a combination of anti-HIV medications from different classes together:
- Using different classes of medications enables you to block different proteins that the HIV virus needs at different steps of its reproduction, therefore combination therapy will be more effective than medication from only one class.
- The HIV virus can change itself with every reproduction and may become resistant to certain anti-HIV medications, which means that those medications won't be effective at fighting your virus anymore. When different medications are used together, it is much harder for the virus to change itself to be able to resist all the medications together.

When choosing which medications to be used in your combination, your doctor should work with you to consider a combination that:
- includes different types of anti-HIV medications (that attack the HIV virus at different stages of its reproduction).
- maximizes your ability to take the medications regularly.
- minimizes side effects.
- leaves options open for future changes.

Ask your doctor or pharmacist for detailed information about each of the medications being
recommended for you to take and talk with them about any concerns you have before you start taking these medications.

How do I know if the medications are working?
If your anti-HIV medications are working (that is, if they are effective in controlling the HIV virus), you should expect:

- a decrease in your viral load (ideally to “undetectable” level).
- an increase in your T-cell count.
- fewer infections and symptoms related to HIV.
- better general health.

By going to your doctor regularly to have checkups and blood tests to check your viral load and T-cells, you will get a better idea if the medications are working for you.

When do I need to change medications?
You may need to change the anti-HIV medications in your combination if:

- the medications are not working (this is called “treatment failure”).
- the medications give you very bad side effects.

If you need to change medications because your combination is not working, that is, it’s no longer effective in controlling the virus, your doctor would usually suggest changing at least 2 of the 3 medications in your combination, or maybe all of them. If you have taken many different HIV medications before, your doctor may need do a special test, called “resistance testing,” before changing your medications. This test lets you and your doctor know which drugs will not work against HIV in your body.

If you are having very bad side effects from your medications, your doctor may suggest decreasing the dose of the medication that is causing the problem or replacing it with another medication. In this case you do not need to change all the medications in your combination because they are still working.

As we learn more about the effects of anti-HIV medications and as newer medications become available, the treatment guidelines may change. Please make sure you work with your doctor and pharmacist to get the most up-to-date information and decide on a medication combination that will work best to meet your specific needs.
Antihiv Medications (anti-retroviral Therapy)
DEALING WITH DRUG SIDE EFFECTS

suggestions for coping with the side effects from taking medications

Dealing with drug side effects can be a challenge for anyone. Every anti-HIV drug has its own possible side effects. This is also true of drugs that prevent and treat infections. These effects can vary from one person to the next. Some people experience few or no side effects at all, while some have ones that are mild and manageable. For others, they may be quite severe. This publication provides a discussion on coping with side effects and tips for managing them. On pages 4–6, charts provide information about the side effects seen in studies and the percentage of people who had them.

The key to coping with your side effects

The key to coping with side effects is knowing what to watch out for and having a plan in place to respond if problems occur. If a drug you are taking or are planning to take has a side effect that may be life-threatening, it’s important to know what early symptoms of that effect are and to monitor for them. It is also possible to prevent or reduce the seriousness of some side effects by taking certain preventive therapies a few days before or at the same time as starting a new regimen.

Before starting any therapy, talk to your doctor about the risk of side effects from various drugs. This information usually comes from studies conducted on the drug. Ask how often side effects were reported.

Are women different?

Women may experience a different type or frequency in side effects compared to men, including therapies not related to HIV. Why this is so is not well understood. It may be due to differences in the way a woman’s body breaks down or stores drugs. Generally speaking, women have smaller body weight/sizes than men. It may be that, for their weight, some women take too high a dose of drug. This could also be an issue for men with small frames. Women’s hormones may also affect drugs. Or it may be due to other unknown differences. Still, current information about side effects remains useful in guiding the ways women manage them.
What to look for, what to do?

Many people experience an adjustment period when starting a new therapy. This period usually lasts about four to six weeks as your body adapts to the new drug. During this time, you may experience headache, nausea, muscle pain in your arms and occasional dizziness. These kinds of side effects typically lessen or disappear as your body adjusts.

Learn to recognize, monitor and manage side effects should they arise. Often, simple solutions exist to lessen many side effects. In other cases, a particular side effect may be an important signal that requires immediate medical attention.

Once you notice any unusual reactions after starting or changing a drug, report the side effects to your doctor. If possible, talk to others who have used the same drug. They may be able to offer solutions.

Caring for your whole self

Some conditions believed to be side effects may actually be due to anxiety, depression or stress. Caring for your whole self—including your emotions, thoughts and general health, as well as specific anti-HIV strategies—can help minimize negative feelings and their effects.

There are some things you can do that may make the adjustment period easier. If possible, take some time off work or lighten your schedule to allow yourself to adjust to the change. If things get hard, see if someone can help out around the house or with children or other obligations.

Take time to re-prioritize your health needs, and make sure you get plenty of sleep and rest. Eat well and keep foods on hand that help combat common side effects like nausea and diarrhea (see pages 3 & 8). Try to get a little exercise during the day—even if just taking a walk.

Most importantly, reach out for support—be it your family, friends or support group. If you can, let them know what’s going on. Sometimes just talking helps, but they may also have ideas to help ease side effects that your doctor might not mention.

A word about switching

Sometimes people facing serious side effects will switch drugs simply to improve their quality of life, even though the drugs were controlling HIV well. This is one way to deal with the side effects linked to that drug.

Switching a drug solely because of side effects may also save that drug as a future treatment option. In fact, side effects that you have with a drug at one time may not occur again if or when you try that drug again.

However, it is dangerous to simply stop taking one drug in your regimen, reduce its dose without talking to your doctor or pharmacist, or decide only to take it periodically. This can do more harm than good as it leads to drug resistance, making that drug—and perhaps others—less useful for you now or in the future.

Getting a handle on side effects

Side effects often occur after starting a new anti-HIV drug but lessen or disappear after a few weeks. Other times they persist as long as that drug or combination is used.

Many symptoms related to drug side effects are also conditions that people face when they have other health conditions. This may include infections, hormonal imbalances, pregnancy, depression or HIV itself.

Whenever you have symptoms, it’s important to talk to your doctor to diagnose the cause. But regardless of how severe or persistent the side effects are, you can try some things to manage them. The tips on the following pages are for medication side effects.

Fatigue

It’s not unusual to feel tired, especially when life is hectic. A sense of tiredness that doesn’t go away with rest is a problem. If ignored, fatigue can worsen.

Symptoms of fatigue can be physical—like it’s difficult to get out of bed or walk up stairs. They can also be psychological—like having a hard time concentrating. Fatigue is also a symptom of another drug side effect—anemia.

Getting a handle on fatigue begins with acknowledging it. If you’re feeling fatigued, ask yourself: how long have you been tired? Are there activities that are difficult today that weren’t a problem a few months ago? Are you having trouble concentrating? Are you having trouble sleeping or sleeping more than normal? The more information you can give your doctor about your physical, psychological and daily habits, the more likely the two of you will be able to decide the proper treatment for your fatigue.
Rash
Rash seems to occur slightly more often among women taking certain anti-HIV drugs than men, though it does occur in men as well. Nevirapine (Viramune) and nelfinavir (Viracept) appear to be the main culprits, but more research on rash among women taking other anti-HIV drugs is needed. Of note is the fact that it is not just that rash seems to occur more often in women, but women appear more prone to severe rash. It’s important to check your skin for discoloration and changes in its surface, especially after starting a new medicine.

TIPS FOR RASH
- Keep medications like Benadryl on hand in case you develop a rash. It will soothe and comfort the skin.
- Try using unscented, non-soap cleansers or oatmeal soaps.
- Avoid extra hot showers or baths. They irritate the skin.
- Protect your rash from sun exposure as the ultraviolet (UV) rays of the sun may exacerbate a rash.

Peripheral Neuropathy
Peripheral neuropathy is caused by damage to nerves. When these nerves are damaged, it can cause a sensation of burning, stinging, stiffness, tickling or numbness in the feet, toes or hands. These sensations can be mild or severe enough to prevent someone from being able to walk. Peripheral neuropathy can be caused by HIV itself or as a side effect of certain anti-HIV drugs or drugs to treat opportunistic infections. Treatment of peripheral neuropathy usually involves stopping or decreasing the offending drug. This usually results in clearing up the symptoms. However, there is no drug that can reverse nerve damage. Talk to your doctor if you have signs of peripheral neuropathy. If neuropathy is severe, it’s a good idea to consult a doctor that specializes in pain management.

TIPS FOR PERIPHERAL NEUROPATHY
- Wear loose-fitting shoes, roomy cotton socks, and padded slippers around the house. Good air circulation around the feet helps.
- Keep feet uncovered in bed. Bedding that presses down on your toes can add to the problem.
- Walk around, but not too much. Walking helps blood circulate in the feet (a good thing), but too much walking or standing can make the problem worse.
- Soak feet in ice water to reduce foot pain.
- Massage your feet. This reduces foot pain temporarily.
- Try ibuprofen to reduce pain and swelling.
- Use L-acetyl carnitine (available at health food stores or through prescription) to prevent the peripheral neuropathy related to ddI, d4T and/or hydroxyurea.

Diarrhea
Aside from being annoying, the biggest concern is that diarrhea can cause dehydration. So the first course of action is to replenish lost liquids by drinking plenty of fluids, like Gatorade, ginger ale, chicken or beef broth, herb tea or just plain water. Chronic diarrhea may lead to weight loss. Foods that provide nutrients, calories, and absorb liquid (like the BRAT diet—bananas, rice, applesauce and toast) are good ways to deal with diarrhea.

Anti-diarrhea medications like Lomotil, Kapectate, Imodium, or Pepto-Bismol can help, as can bulking laxatives like Metamucil. Nutritional supplements, such as L-Glutamine, Provir or Shaman Botanicals-Normal Stool Formula (SB-NSF) may also help, but can be expensive.

TIPS FOR DIARRHEA
- Eat foods high in soluble fiber, which slows diarrhea by absorbing liquid. In addition to the BRAT diet, these foods include oatmeal, cream of wheat, grits and soft bread (not whole grain).
- Try psyllium husk fiber bars (another source of soluble fiber). A recent study showed that two bars eaten one hour before bedtime with a large glass of water can really help diarrhea. They can be found at health food stores.
- Avoid foods high in insoluble fiber, like the skins of vegetables and fruits. These foods can make diarrhea worse.
- Try to avoid milk products and greasy, high-fiber or very sweet foods. They tend to aggravate diarrhea.
- Try calcium supplements (500mg twice a day).
Side effects chart of drugs used to treat HIV

This chart may not adequately reflect the percentages of side effects seen in women due to the limited number of women in many studies of these drugs.

### HOW TO USE IT

The left hand column (vertical) lists all the side effects reported for the combined list of drugs. The top row (horizontal) lists drugs most commonly used in HIV disease. The columns underneath each drug heading lists the rough percentage of people reporting each side effect for each drug.

<table>
<thead>
<tr>
<th>DRUG SIDE EFFECTS</th>
<th>Protease Inhibitors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal pain</td>
<td>Amprenavir</td>
</tr>
<tr>
<td>Altered taste</td>
<td>○</td>
</tr>
<tr>
<td>Anorexia (reduced appetite)</td>
<td>○</td>
</tr>
<tr>
<td>Arthralgia (joint pain)</td>
<td></td>
</tr>
<tr>
<td>Chills</td>
<td>○</td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td>○</td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td>Fevers</td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td></td>
</tr>
<tr>
<td>Insomnia (sleep problems)</td>
<td></td>
</tr>
<tr>
<td>Malaise</td>
<td></td>
</tr>
<tr>
<td>Menstrual Irregularities</td>
<td></td>
</tr>
<tr>
<td>Myalgia (muscle pain)</td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>■</td>
</tr>
<tr>
<td>Nephrolithiasis (kidney stones)</td>
<td>●</td>
</tr>
<tr>
<td>Neurological Symptoms</td>
<td></td>
</tr>
<tr>
<td>Neuropathy (pain/tingling in arms/legs/hands/feet)</td>
<td>○</td>
</tr>
<tr>
<td>Pancreatitis (inflammation of pancreas)</td>
<td></td>
</tr>
<tr>
<td>Paresthesia (numbness, prickling, tingling)</td>
<td>○</td>
</tr>
<tr>
<td>Rash</td>
<td></td>
</tr>
<tr>
<td>Seizures</td>
<td></td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
</tr>
</tbody>
</table>

### DRUG SIDE EFFECTS ON LAB VALUES

<table>
<thead>
<tr>
<th>DRUG SIDE EFFECTS ON LAB VALUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anemia (low red blood/hemoglobin count)</td>
</tr>
<tr>
<td>Leukopenia (low white blood cell count)</td>
</tr>
<tr>
<td>Neutropenia (low neutrophil count)</td>
</tr>
<tr>
<td>Thrombocytopenia (low platelet count)</td>
</tr>
<tr>
<td>Elevated Alkaline Phosphatase (liver)</td>
</tr>
<tr>
<td>Elevated Amylase (pancreas)</td>
</tr>
<tr>
<td>Elevated Bilirubin (liver)</td>
</tr>
<tr>
<td>Elevated Cholesterol</td>
</tr>
<tr>
<td>Elevated Creatinine (kidney)</td>
</tr>
<tr>
<td>Elevated Glucose (blood sugar)</td>
</tr>
<tr>
<td>Elevated Liver Functions</td>
</tr>
<tr>
<td>Elevated Triglycerides (cholesterol)</td>
</tr>
</tbody>
</table>

### EXPLANATION OF BULLETS

- ■ Reported in >15% of people in clinical studies.
- ○ Reported in 5–15% of people in clinical studies.
- ◊ Reported in <5% of people in clinical studies.
- c Side effect reported only in children, or more commonly in children.
- ‡ Potentially fatal side effect.
### Other Side Effect Warnings

**ALL anti-HIV drugs**

Changes in body fat distribution, called lipodystrophy, has been associated both with HIV infection and anti-HIV therapy. A warning about lipodystrophy is now included in the label information for all anti-HIV drugs.

**ALL nucleoside analogs (NRTIs)**

A build-up of lactic acid in the body (lactic acidosis) and severe liver enlargement (hepatomegaly) with fatty liver (steatosis), including fatal cases, have been reported with using NRTIs alone or in combination. Fatal lactic acidosis has been reported in pregnant women who took d4T (stavudine, Zerit) and ddi (didanosine, Videx) with other anti-HIV drugs. The combination of d4T and ddI should be used with caution during pregnancy.

**AZT**

AZT (zidovudine, Retrovir) has been associated with low neutrophil counts (neutropenia) and severe reductions in red blood cells (anemia), particularly in patients with advanced HIV disease. Prolonged use of AZT has been associated with muscle weakness (myopathy).

**Abacavir**

Fatal hypersensitivity reactions have occurred in up to 8.5% of people taking abacavir (Ziagen). People with fever, skin rash, fatigue, nausea, vomiting, diarrhea, abdominal pain, and/or respiratory symptoms are advised to call their doctor immediately and stop using abacavir if directed, as soon as a hypersensitivity reaction is suspected. Once abacavir treatment is stopped, it should be permanently discontinued as a more severe reaction may recur within hours if it is restarted and may include life-threatening symptoms and death.

**d4T/ddI**

Fatal and non-fatal inflammation in the pancreas (pancreatitis) has occurred with the combination of d4T and ddI. Neither d4T nor ddI should be used in people with suspected or confirmed pancreatitis.

**Enfuvirtide**

Nearly 100% of people using enfuvirtide (T-20, Fuzeon) will have injection site reactions including redness, inflammation, pain and hardening of the skin.
Side effects chart of drugs used to treat common OIs

This chart may not adequately reflect the percentages of side effects seen in women due to the limited number of women in many studies of these drugs.

<table>
<thead>
<tr>
<th>DRUG SIDE EFFECTS</th>
<th>MAC/MAI</th>
<th>PCP</th>
<th>CMV</th>
<th>FUN-GAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal pain</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Altered taste</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Anorexia (reduced appetite)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Arthralgia (joint pain)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Chills</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Constipation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Depression</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Dizziness</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fatigue</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fevers</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Headache</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Insomnia (sleep problems)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Malaise</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Menstrual Irregularities</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Myalgia (muscle pain)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Nausea</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Nephrolithiasis (kidney stones)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Neurological Symptoms</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Neuropathy (pain/tingling in arms/legs/hands/feet)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Pancreatitis (inflammation of pancreas)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Paresthesia (numbness, pricking, tingling)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Rash</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Seizures</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Vomiting</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DRUG EFFECTS ON LAB VALUES</th>
<th>MAC/MAI</th>
<th>PCP</th>
<th>CMV</th>
<th>FUN-GAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anemia (low red blood/hemoglobin count)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Leukopenia (low white blood cell count)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Neutropenia (low neutrophil count)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Thrombocytopenia (low platelet count)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Alkaline Phosphatase (liver)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Amylase (pancreas)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Bilirubin (liver)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Cholesterol</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Creatinine (kidney)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Glucose (blood sugar)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Liver Functions</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Elevated Triglycerides (cholesterol)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

**EXPLANATION OF BULLETS**

- ■ Reported in >15% of people in clinical studies.
- ○ Reported in 5–15% of people in clinical studies.
- ◊ Reported in <5% of people in clinical studies.
- □ Side effect has not been reported.
- c Side effect reported only in children, or more commonly in children.
- ‡ Potentially fatal side effect.
Anemia

Anemia is low red blood cells. Those are the cells that deliver oxygen to different parts of your body. When your body is short on oxygen, you feel fatigued. Long-term or severe anemia can cause damage to your body. Most people with HIV have anemia at some point. HIV can cause it. So do many drugs used to treat HIV, like AZT (Retrovir).

For women, problems with periods can also be a cause or symptom of anemia.

To check for anemia, have blood work done at least every three months, even if you're not using anti-HIV drugs. A change in diet or nutritional supplements can lower the risk of developing anemia. Using medication to correct moderate anemia (Procrit, Epogen) can also help. In some cases, stopping or changing the drugs that are causing anemia may be necessary. Treating severe anemia requires a blood transfusion.

- Know your red blood cell (hemoglobin) count! Get it checked regularly.
- Fish, meat, and poultry are high in iron and vitamin B-12, both of which may lower risk of anemia.
- Spinach, asparagus, dark leafy greens, and lima beans are high in folic acid, another nutrient that may lower risk of anemia.

Dry Mouth

Dry mouth can result from taking certain medicines. It is an uncomfortable condition, making chewing, swallowing and talking difficult. Dry mouth can affect your sense of taste and can promote mouth problems, like tooth decay and oral yeast infections (thrush). Treating dry mouth can be as simple as drinking plenty of liquids during or between meals. Avoid sugary or sticky foods or caffeinated drinks as they can make your mouth even drier. Chewing sugarless gum can stimulate saliva. If these things don't work, your doctor can prescribe a synthetic saliva or other medicine, like pilocarpine.

- Rinse your mouth throughout the day with salted warm water.
- Try slippery elm or licorice tea (available in health food stores)—they lubricate the mouth and taste great!
- Suck on sugarless candies, lozenges or crushed ice to cool the mouth and give it moisture.
- Ask your doctor to prescribe products or mouth rinses to treat dry mouth.

Headache

The most common cause of headache is tension, something most people have at some point! Different kinds of medicines can also cause them. Headaches are mostly just a pain and can be eased by over-the-counter medicines like aspirin, acetaminophen, ibuprofen, or naproxen sodium. They can also be helped, and prevented, by reducing stress.

- For on-the-spot headache relief: try resting in a quiet, dark room with your eyes closed; place cold washcloths over your eyes; massage the base of your skull with your thumbs and massage both temples gently; take hot baths.
- To prevent headaches from recurring: try to anticipate when pain will strike. Avoid or limit foods known to trigger headaches, especially caffeine (from coffee, tea, soft drinks or some medications), chocolate, red wine, citrus fruit (if more than 1/2 cup a day), food additives (like monosodium glutamate, or MSG), nuts, onions, hard cheese and vinegar.

Hair Loss

Most people experience hair loss as they get older. This is normal and affects some people more than others, especially if baldness runs in the family. Hair loss can be disturbing nonetheless and can damage one's self-confidence.

Sudden or abnormal hair loss can result from taking certain drugs (like some used to treat HIV, cancer, circulatory disorders, ulcers or arthritis).

- To protect your hair from further damage and loss: avoid or decrease damaging hair care practices or use them infrequently. These include dyeing, perming, straightening, braiding, corn-rowing, using hair dryers, etc.
- Don’t be fooled by fraudulent claims for products that promise to cure baldness. They do not exist! The only remedy that comes close is the medication Rogaine, available over-the-counter. It has shown promising results for some (but not many) cases of baldness.
- Stress can make hair loss worse, so taking steps to reduce stress and anxiety often help.
**Nausea and Vomiting**
Feelings of nausea and the urge to vomit vary greatly among people. The two symptoms often occur together. Certain medications used to treat HIV or related conditions can cause nausea. (See the Drug Side Effects Chart on pages 4–6 to identify drugs that may commonly cause nausea.)

Persistent vomiting can lead to serious medical problems, like dehydration, chemical imbalances and even tearing of the esophagus (throat). Call your doctor if you vomit repeatedly throughout the day or if nausea or vomiting is persistent and/or interferes with your ability to take your medication.

- **The BRAT Diet** (Bananas, Rice, Applesauce, and Toast) helps with nausea and diarrhea.
- Leave dry crackers by your bed. Before getting out of bed in the morning, eat a few and sit in bed for a few minutes. This can help reduce nausea.
- Try some peppermint, chamomile or ginger tea—they can calm the stomach.
- Sip cold carbonated drinks like ginger-ale, 7-Up or Sprite. They can help avoid nausea.
- Avoid hot, spicy, strong-smelling and greasy foods.
- If vomiting occurs, replenish fluids with broth, carbonated beverages, juice, Jell-O or popsicles.
- Talk to your doctor about the benefits/risks of anti-nausea medications (such as Compazine, Marinol, Ativan, Zofran and Phenergan).

**Weight Loss**
Weight loss can be a serious problem in HIV disease. It can result from some of the side effects discussed in this section—like vomiting, nausea, dry mouth, anemia or fatigue.

Unfortunately, even though the signs of weight loss can be obvious, it is not always seen as a problem. In fact, many positive women who lose weight due to HIV-related problems are praised and told they “look good”.

If you’re losing weight and it’s not because you altered your diet or exercise patterns for that purpose, it’s **never** a good thing. Talking to a doctor to identify its cause is critical to treating unwanted weight loss.

- Monitor your weight. If you are losing weight, work with your doctor to determine the cause. Is it stress-related? Is it accompanying nausea or vomiting? Has it occurred after starting a new medicine? What other things are going on?
- Try high protein shake mixes, like Med-Rx or Metabol. Look for products high in protein and low in sugar. These are available at most health food and vitamin stores.
- Ask about discounts at health food and vitamin stores. They sometimes provide people with life-threatening diseases special savings on nutritional products.

**Period Problems**
Period problems are common in all women, but particularly in women with weakened immune systems. These problems include irregular, heavier, lighter and/or painful periods or the end of menstrual bleeding altogether. Problems with periods can be a side effect of some medications. Most recently, excessive menstrual bleeding has been seen when using ritonavir (Norvir).

More research is needed to determine which anti-HIV drugs have an effect on menstruation. Meanwhile, it’s a good idea to track your periods, noting changes if they occur, particularly around the time of beginning a new anti-HIV drug.

- Consider what else is happening in your life. Have you lost weight? Are you stressed out? These factors might give you clues as to why you’re having period problems. Addressing them might help in more ways than one!
- For menstrual cramps, hold a hot water bottle or a heating pad over your lower stomach or back. Or take a hot bath. This reduces stress, too!
- Do mild exercise, like walking or stretching. Exercise may increase blood flow and decrease period pain.
- Oral contraceptives (the Pill) are sometimes used to regulate abnormal periods. Some anti-HIV drugs interact with the Pill. A list of drug interactions can be found in Project Inform’s publication, GYN Conditions in Women Living with HIV/AIDS.
HIV in Context

Session Outline

• Conceptualizing HIV using the ICF Framework
• Prevalence of Disability in HIV/AIDS
• Episodic Disability
• Social Determinants of Health

What About Rehabilitation?

• People are living longer lives with HIV
• Increasing prevalence of impairments, activity limitations and participation restrictions
• Multisystemic disease affecting neurological, cardiorespiratory and musculoskeletal systems
• Unpredictable cycles of wellness and illness
Common Framework

International Classification of Functioning, Disability and Health (ICF)

**Impairment** - Any problem in body function or structure

**Activity Limitation** - Any difficulty an individual may have in carrying out a task or action

**Participation Restriction** - Any problems an individual may experience in involvement in life situations

---

International Classification of Functioning, Disability and Health - ICF (WHO 2001)

Health Condition
(disorder/disease)

Body function and structure
(Impairment)

Activities
(Limitation)

Participation
(Restriction)

Environmental Factors

Personal Factors

---

Examples of Disability

**Impairments:**
- pain, weakness, cognitive impairment, decreased endurance

**Activity Limitations:**
- difficulty walking, difficulty carrying out daily self care activities such as bathing

**Participation Restrictions:**
- difficulty engaging in work, employment or education, difficulty engaging in recreation or leisure activities
Prevalence of Disability Among Persons Living with HIV – The Need

“BC Prevalence Study”


http://www.hqlo.com/content/2/1/46
Results

Impairments
- Diarrhea, Reduced libido, Weakness, Poor concentration, Headache, Chronic fatigue, Stiff joints, Decreased endurance, Altered sensation, Shortness of breath, Wasting, Pain

Activity Limitations
- Vigorous-moderate activity, Sexual activities, Household chores, Laundry, Banking, Shopping, Public transportation

Participation restrictions
- Sexual roles, Student and Employee roles, Community involvement, Financial roles, Discrimination

Summary

“BC Prevalence Study”
- Demonstrated remarkably high prevalence of disablement among persons living with HIV in British Columbia
  - At least 80% experienced at least one impairment, activity limitation or participation restriction in the past month.
  - High prevalence of mental health issues – Could this be linked to uncertainty?
- Demonstrated need for rehabilitation among persons living with HIV
How does this Disability change over time?

Episodic Nature of Disability

Many of the types of disablement (impairments, activity limitations and participation restrictions) may be similar and/or unique across different illness… however the way in which the disablement is experienced may be similar… episodic in nature…

Episodic Disability Framework

So What Comes Next?

The Episodic Disability Movement

CWGHR’s Cross Disability Project: Investigating Episodic Disability

Cross Disability Project - Phase I: Looking Beyond the Silos

Objectives:

- To explore similar “disability” and “rehabilitation” issues between people living with HIV-related disability and other episodic and unpredictable illnesses
- To initiate dialogue between different groups and explore future partnerships between organizations for future policy work

Results - Emerging Themes Indicating Common Issues among Episodic Illnesses:

- Need for definitions of rehabilitation and disability
- Care, treatment and support
- Workplace issues
- Income Security and Support
- Legislation and Policy
- Stigma and Prejudice
- Education

Looking Beyond the Silos

Conceptual Model of Cross Disability Issues

- Permanent Disability:
  - Lifelong and relatively consistent
  - Issues include legislation, employment equity, income security, long term care and support, independent living
- Episodic Disability:
  - Issues include unpredictability, working, insurance, vocational rehabilitation
- HIV and Rehabilitation:
  - Share concerns with both permanent and episodic disability groups

However gaps still existed in our knowledge and understanding of the day to day lived experiences of persons living with HIV in relation to the unpredictable and episodic nature of illness... Phase II
Cross Disability Project - Phase II: Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV

To examine the experiences of people living with HIV in regard to the uncertain, unpredictable, episodic and fluctuating nature of this disabling condition and the roller-coaster like trajectory of that reality


Themes From Focus Groups

• Reflections on Diagnosis
• Learning to Live
  • Riding the roller-coaster of everyday life
  • Re-establishing a public face
  • Redefining self
• Rebuilding Relationships
  • Family, significant others, friends, health care professionals
• Finding a Way to Feel Productive
  • Work
  • The conundrum: all or nothing at all

Learning to Live

“It’s hard to go from expecting to die and then all of a sudden realizing, well, maybe that’s not going to be the case…it’s a hard transition to make…to do that turnaround was like you’d been reborn…and it was really scary”
Episodic Unpredictable Nature of HIV

“I’m not able to do everything like a normal person does…some days I’m fine, I can do a lot, but there’s other days I just curl up in bed and stay there for the whole day”.

Finding a Balance

“right now I’m really busy (working)…and so I’m not doing the things that were really good for me, like yoga three times a week and going to the gym three times a week and all those kinds of things…it was like oh I can be busy and I can keep these things up… but I would immediately sacrifice my own self care in order to be there and be busy because that really boosts the self-esteem… it just seems like I have to pick one or the other…I can’t seem to find a balance of both…”

Rebuilding Relationships

“You don’t want to show too much of your symptoms because you’re trying to maintain other people’s health. And even though you have a need to talk about it, you can’t because of how other people are going to deal with it.”
Finding a Way to Feel Productive

“…you’re sick inside but yet you got to be on the outside looking like you’re well and physical and capable of doing it and meanwhile it’s very stressful…”

Shadow of Uncertainty

“the last time I went back to work…it just caused a total collapse of my cocktail…I mean I want to go back to work in some ways but in other ways it’s like what happens if that happens all over again”
Conclusions

- Adjustments in identity, relationships, and physical and psychological well-being to manage multi-layered uncertainty
- Definition of episodic nature of HIV
  - Acute episodes of illness
  - Shadows that accompany experiences of everyday living
  - Continued vigilance of attending to signals, anticipated and actual, that relate to health status

What are the Dimensions of Disability Experienced by People Living with HIV/AIDS?

How Does this Impact their Overall Health?

Dimensions of “Episodic Disability”

Symptoms / Impairments
Medications - “Trade-off”

- So there are all those side effects that you have to deal with. But then you know, you get to a point where you think you can, side effects is nothing, you can deal with that. The point is that if it assists your health, the medication it’s a better option than not taking medication.” FG-2

Uncertainty - Worrying about the Future

- “It haunts you… It haunts you in that you’re not sure how long you are going to live, in that you’re never sure when you’re going to be sick,… you don’t know how people are going to treat you if they find out, it haunts you in your place of work, in your abilities, and how it will affect your abilities in the future, or even in the present…” INT-012

- “that’s the thing that really kind of bothers me, is the fear of not knowing what’s going to happen next… I know eventually something’s going to happen. I know for sure it’s going to happen, but I don’t know what it is, and I don’t know when it’s going to happen. And it can paralyze me at times…” INT-001

Uncertainty - Worrying about the Future
Emotions – Self-Esteem

Influenced by body composition and ability to work

- “The back of my neck is humped and my enlarged stomach. That has affected me a lot. When I’m wearing anything without a collar, I have to be very aware of it… So if someone is sitting behind me, I’m thinking it’s going to affect me…” FG-4

- “there are times where I feel because I’m not working,… I’m a person that’s been working all my life… So now that I haven’t been, I don’t feel of use. I feel that it’s taken away a lot of my, not respect for myself… but just that financial responsibility has been taken away from me…” FG-4
Uncertainty - Worrying about the Future

Emotions – Shame / Embarrassment

Influenced by body composition, issues surrounding diagnosis

• “I get a little bit of shame. I sometimes feel gross, I feel diseased. I don’t want people to touch me anyway cause I feel gross. The biggest thing… the medication that I’m on causes body changes, and fat and stuff. The changes have been so mortifying, and it’s really personal, but I don’t want to get into bed with anybody now cause it’s just like my body is so abnormal and theirs isn’t… I’m mortified about it.” INT-010

Uncertainty - Worrying about the Future

Emotions - Loneliness / Isolation / “Different”

Feeling “different”, isolated or marginalized

• “I just don’t feel like a normal person. It’s a really big thing for me, I know a lot of people want to be non-conformist and on the outside and all of that. Me, I want to fit in, I want to be like everybody. And being on the outside and sort of marginalized, with that disease, with that tag, or whatever, it bothers me. It makes me feel like I’m on the outside, and I hate that feeling. I like to feel included, and one of everybody else, you know.” INT-010

• “the moment you test HIV positive you feel like someone different, you feel like a different person…” INT-011

Challenges of Social Inclusion

Parental Roles

Influenced by fatigue, and unpredictable episodic nature of HIV

• “simple stuff like if they want to go to the mall, and I’ll promise them for days, we’re going to go, but I don’t have the energy or anything… I don’t want to have to be promising my kids all the time, ‘Okay, we’re going to go to Wonderland this weekend,’ then we can’t go because I’m not feeling good.” INT-009
Challenges of Social Inclusion

Work & School

Considerations of returning to work influenced by finances, ODSP limitations, potential to increase social interaction, unpredictable nature of HIV

• “I am considering getting a job…something that I can do and stay within my pension and ODSP so they’re not unhappy with me, and cut money even more…. I know I can’t do 9 to 5. I can’t do 5 days a week. I just know it… So, something part-time. And I’m doing this for a number of reasons: money of course, but I’m also looking at myself… I spent a lot of years…being a hermit…not meeting anybody, and really not happy. So now it’s to the point that I want to be happy…” INT-003

Challenges of Social Inclusion

Personal Relationships

Difficulty initiating and maintaining personal relationships, including intimacy. [Includes relationships with family, friends, partners]

• “I haven’t been dating in a long time because of this. Meeting people and then explaining to them…. Oh, I have HIV and blah blah blah”. And then I discover awfully, I was so disillusioned I find out that they knew nothing. And then they would be all freaked out, and they were worried, if they, like cuddling with me or something, they were worried if they caught it, and they’d make this big deal and it would create this friction in our relationship. So I felt like I was just constantly having to educate people, and I was starting to resent that.” INT-010

Challenges of Social Inclusion

Travel and Other Social Limitations

Limiting travel, joining the army, advocacy, and influencing life decisions such as purchasing a home or having children

• “I’d like to travel a lot as I get older, but I was told that there are certain places that I can’t go to… Joining the army would be cool…and I thought about joining the Reserves, but you can’t.” INT-013

What are the Factors that Influence Disability Experienced by People Living with HIV/AIDS?

Influential Factors that Can Alter Episodes of Disability
(from the perspective of the person living with HIV)

- Level of Support
- Social Interaction with Others
- Maintaining Sense of Control over Life
- Effects of Aging
- Stigma

Sensitive Practice

- Stigma and Discrimination
- Gender
- New Immigrants
- Sexual Orientation
- Addictions and Mental Health
- Aboriginal Health
- Sex Work
- Multiple Vulnerabilities
Social Determinants of Health

- Income inequality
- Social inclusion and exclusion
- Employment and job security
- Working conditions
- Contribution of the social economy
- Early childhood care
- Education
- Food security
- Housing

Summary – Take Home Messages

- High prevalence of disablement among people living with HIV/AIDS
- Disability is multi-dimensional and episodic in nature – fluctuates on daily basis or over entire course living with HIV
- Specific sensitive practice issues in the HIV context
Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia


Melanie Rusch (mrusch@interchange.ubc.ca)
Stephanie Nixon (stephanie.nixon@utoronto.ca)
Arn Schilder (arn@cfenet.ubc.ca)
Paula Braitstein (paulab@interchange.ubc.ca)
Keith Chan (keith@cfenet.ubc.ca)
Robert S Hogg (bobhog@cfenet.ubc.ca)

ISSN 1477-7525

Article type Research
Submission date 11 Jun 2004
Acceptance date 6 Sep 2004
Publication date 6 Sep 2004
Article URL http://www.hqlo.com/content/2/1/46

This peer-reviewed article was published immediately upon acceptance. It can be downloaded, printed and distributed freely for any purposes (see copyright notice below).

Articles in Health and Quality of Life Outcomes are listed in PubMed and archived at PubMed Central.

For information about publishing your research in Health and Quality of Life Outcomes or any BioMed Central journal, go to

http://www.hqlo.com/info/instructions/

For information about other BioMed Central publications go to

http://www.biomedcentral.com/

© 2004 Rusch et al., licensee BioMed Central Ltd.
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.
Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia

Melanie Rusch*1,2, Stephanie Nixon3, Arn Schilder1,4, Paula Braitstein1,2,4, Keith Chan1, Robert S Hogg1,2

Address: 1Department of Population Health, British Columbia Centre for Excellence in HIV/AIDS, St. Paul’s Hospital, Vancouver, Canada; 2Department of Health Care and Epidemiology, University of British Columbia, Vancouver, Canada; 3Department of Physical Therapy, University of Toronto, Toronto, Canada; 4British Columbia Persons with AIDS (BCPWA) Society, Vancouver, Canada

Email: Melanie Rusch* - mrusch@interchange.ubc.ca, Stephanie Nixon - stephanie.nixon@utoronto.ca, Arn Schilder - arn@cfenet.ubc.ca, Paula Braitstein - paulab@interchange.ubc.ca, Keith Chan - keith@cfenet.ubc.ca, Robert S Hogg - bobhog@cfenet.ubc.ca

*Corresponding author
Abstract

**Background:** To measure the prevalence of and associations among impairments, activity limitations and participation restrictions in persons living with HIV in British Columbia to inform support and care programs, policy and research.

**Methods:** A cross-sectional population-based sample of persons living with HIV in British Columbia was obtained through an anonymous survey sent to members of the British Columbia Persons With AIDS Society. The survey addressed the experience of physical and mental impairments, and the experience and level of activity limitations and participation restrictions. Associations were measured in three ways: 1) impact of types of impairment on social restriction; 2) impact of specific limitations on social restriction; and 3) independent association of overall impairments and limitations on restriction levels. Logistic regression was used to measure associations with social restriction, while ordinal logistic regression was used to measure associations with a three-category measure of restriction level.

**Results:** The survey was returned by 762 (50.5%) of the BCPWA participants. Over ninety percent of the population experienced one or more impairments, with one-third reporting over ten. Prevalence of activity limitations and participation restrictions was 80.4% and 93.2%, respectively. The presence of social restrictions was most closely associated with mental function impairments (OR: 7.0 for impairment vs. no impairment; 95% CI: 4.7 – 10.4). All limitations were associated with social restriction. Among those with ≤ 200 CD4 cells/mm3, odds of being at a higher restriction level were lower among those on antiretrovirals (OR: 0.3 for antiretrovirals vs. no antiretrovirals; 95% CI: 0.1-0.9), while odds of higher restriction were increased with higher limitation (OR: 3.6 for limitation score of 1-5 vs. no limitation, 95%CI: 0.9-14.2; OR: 24.7 for limitation score >5 vs. no limitation,
95% CI: 4.9-125.0). Among those with >200 CD4 cells/mm³, the odds of higher restriction were increased with higher limitation (OR: 2.7 for limitation score of 1-5 vs. no limitation, 95% CI: 1.4-5.1; OR: 8.6 for limitation score >5 vs. no limitation, 95% CI: 3.9-18.8), as well as by additional number of impairments (OR: 1.2 for every additional impairment; 95% CI: 1.1-1.3).

**Conclusions:** This population-based sample of people living with HIV has been experiencing extremely high rates of impairments, activity limitations and participation restrictions. Furthermore, the complex inter-relationships identified amongst the levels reveal lessons for programming, policy and research in terms of the factors that contribute most to a higher quality of life.

**Keywords:** disablement, impairments, activity limitations, participation restrictions, disability, HIV/AIDS
Background

For most people who are able to access and tolerate highly active antiretroviral therapy (HAART), HIV/AIDS has become a chronic condition characterized by cycles of illness and wellness. People live longer lives, but with physical, psychological and social challenges that affect quality of life [1-3]. Evidence of this phenomenon may be found in qualitative studies describing the ways in which improved health has also brought about different and unforeseen social, psychological and physical challenges for many people who had previously been facing end-stage disease.

For instance, Brashers et al (1999) identified four categories of “uncertainties” resulting from the experience of “revival” brought about by HAART, including (a) renegotiating feelings of hope and future orientation in the face of questionable durability of immune restoration; (b) fear about social roles and identities, in the transition from a person who is dying to a person living with a chronic illness; (c) concerns with interpersonal relations, including the potential of stigmatizing reactions from employers and co-workers; and, (d) reconsidering the quality of their lives, captured in this quote from one participant, ‘The good news is you’re going to live, the bad news is you’re not going to enjoy the rest of your life’ [1].

Sowell et al. (1998) used in-depth interviews to explore the psychological changes and care delivery issues experienced by HIV-positive men who were facing end-stage disease but had experienced dramatic physical improvements [4]. Key findings included themes around
protease inhibitors as a reprieve from death, shifting perspectives on roles and relationships, and a renewed need for advocacy related to care, treatment and support. Others have examined particular aspects of living with HIV in the post-HAART era, such as challenges related to income and employment [5]. Along with qualitative literature, the HIV communities themselves have responded with a wave of community-based studies, publications and programming to address challenges related to living with the ups and downs of life on combination therapies [6-9].

Quantitative studies exploring the life- and health-related consequences of living with HIV are limited. An exception is the HIV Cost and Services Utilization Survey in the United States, which described physical and social role restrictions in a nationally representative sample [10]; however, no similar work exists in Canada. The American study was undertaken during the early years of HAART, and so the majority of participants were not yet on protease inhibitors. As such, there is a gap in the literature in terms of studies that systematically quantify the prevalence of life- and health-related challenges associated with living with HIV since the advent of HAART.

The International Classification of Functioning, Disability and Health (WHO, 2001) offers a useful framework for studying disablement and health-related consequences of disease based on the following three concepts: impairments, activity limitations and participation restrictions [11]. Impairments are understood to be problems with physiological functioning or anatomical (e.g., organs, limbs) structure of the body. Activity limitations are defined as difficulties in executing a task or action. Finally, participation restrictions are problems
relating to involvement in life situations. This classification system and its precursor, the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980), have been used to frame a plethora of studies on a diverse array of diseases and conditions [12-15]. Furthermore, this framework has been used to conceptualize HIV [16], and informs the policy, research and advocacy work of organizations such as the Canadian Working Group on HIV and Rehabilitation [17].

This article addresses this gap in the literature by reporting on the results of a quantitative investigation into the prevalence of and associations among impairments, activity limitations and participation restrictions experienced by people living with HIV in British Columbia.

Methods

Data sources

Individuals living with HIV were involved in all stages of this project, from identification of the research question to data collection and analysis. A lead partner was the British Columbia Persons With AIDS Society (BCPWA), an organization of more than 3,600 HIV positive individuals living in British Columbia, which was created to provide support, information and advocacy for its members.

From May to September of 2002, the BCPWA in conjunction with the British Columbia Centre for Excellence in HIV/AIDS conducted a survey of HIV positive individuals living in British Columbia. The anonymous self-administered questionnaire was mailed to the 1508 HIV positive individuals registered with the BCPWA who had consented to receive mailings.
Definition of disability

A section of the survey on diagnosed conditions asked participants to indicate if a doctor had ever in their lifetime diagnosed them with any conditions from a list of thirteen, including depression, schizophrenia, bipolar disorder and post-traumatic stress disorder, as well as a space to indicate any diagnoses that was not present in the list.

Participants identified their experiences during the past month using check-lists of impairments, activity limitations and participation restrictions that included space to identify unlisted items.

Participants were asked: “Within the last month have you experienced any of the following…” after which they were able to check off symptoms from a list of twenty-two, including a space for unlisted items. The list of impairments was categorized into mental, internal system, sensory and neuromusculoskeletal groups based on the International Classification of Functioning, Disability and Health [12]. Mental impairments included reduced libido, poor concentration, poor appetite, chronic fatigue, decreased endurance, decreased memory, impaired cognition and aphasia. Internal impairments included diarrhea, gastric reflux, shortness of breath, constipation, wasting, weakness, vomiting and incontinence. Sensory impairments included headaches, altered sensations, nausea, mouth pain and decreased vision. Neuromusculoskeletal impairments included altered muscle tone, stiff joints, seizures, hemiparesis and paraparesis. This section was followed by a question which asked participants how much HIV-related pain they had experienced in the past.
month, with categorical options including none, a little bit, mild or infrequent, moderate, severe or persistent and don’t know. Participants were also asked to pinpoint the location(s) of their HIV related pain.

Activity limitations were addressed by asking the participants “[h]ow well can you manage these typical daily activities?” with an indication to circle the response which best describes their experience in the past month. A fifteen-item list including ability to walk one block, eat, shower, and dress followed. For each item, participants indicated whether they were (a) completely able, (b) somewhat limited or (c) unable to perform the activity. Overall prevalence of activity limitations was calculated by including anyone indicating (b) or (c) for any one of the fifteen items.

In the same way, participants were asked “[h]as your health limited your usual [role/participation]” in any of a number of categorical activities and functions. Participants were indicated to choose the response that came closest to the way they had been feeling during the past month. A ten-item list was used to assess levels of restriction in social, student, and cultural roles. Participants indicated whether they were (a) not limited, (b) somewhat limited or (c) very limited with respect to their ability to function in these roles. Overall prevalence of participation restrictions was calculated by including anyone indicating (b) or (c) for any one of the ten items.
Statistical analysis

Rates of impairments, activity limitations and participation restrictions among the participants were compared across three categories of CD4 cell counts (≤200 cells/mm³, 201 to 500 cells/mm³ and >500 cells/mm³) using a chi-squared test for categorical variables and the Kruskal-Wallis test for continuous variables. Bonferroni corrections for multiple comparisons were done for each item and those which remained significant are indicated in bold.

To test the hypothesis that social role restrictions would be more strongly associated with mental function impairments and personal care and mobility limitations, a series of logistic regression models were tested with each category of impairment and limitation. A dichotomous outcome was used, collapsing “somewhat” and “very much” social role restriction into any social restriction. Likewise, specific activity limitations were dichotomized into “no limitations” vs. “some effort” required or “unable” to accomplish the activity. Associations of social restriction with impairment categories and specific activity limitations were examined univariately and in adjusted models accounting for age, sex, income, depression, pain, risk category (men who have sex with men, injecting drug users, heterosexual contact, combination) and number of symptoms for activity limitation models.

A scoring system was then used to develop categories of activity limitation and participation restriction. If a participant indicated an activity limitation item at the highest level (“unable” to accomplish) or a participatory role restriction at the highest level (“very much” restricted), two points were received, while participants indicating an activity limitation item at moderate
level (requiring “effort” to accomplish) or a participation restriction item at a moderate level (“somewhat” restricted), one point was received. Overall scores for participation restriction and activity limitation were therefore dependent on both the severity and total number of challenges in activities or participatory roles.

The participation restriction score, with an overall maximum of 20, was then categorized into three levels: 0 to 5 points, 6 to 10 points and >10 points, based on the population distribution of the score. Likewise, the activity limitation score, with an overall maximum of 28, was also categorized based on distribution as follows: 0, 1 to 5 points, and >5 points. The higher the score, the greater the disablement.

An overall model examined the associations of increasing participation restriction level with number of impairments and activity limitation scores, testing the hypothesis that impairments may account for some of the associations seen between activity limitations and participation restrictions, but that both of the former would have independent associations with the latter. Ordinal logistic regression was implemented, using the three-level participation restriction outcome and testing number of symptoms, categorical limited activity score, pain and mental diagnoses as explanatory variables. All models were stratified on CD4 levels, with separate models built for individuals with counts below 200 cells/mm3, and adjusted for age, gender, employment, years since diagnosis and risk category.

Results

Population characteristics
Of the 762 people living with HIV who completed the survey, 614 provided information about their CD4 levels and were included in this analysis. The population answering the BCPWA survey was comprised mainly of white (88.7%), sexual-minority males (76.6%) between the ages of 30 to 49 (63.9%). The 148 respondents who were not included in the analysis because they did not provide CD4 information were in a lower income bracket (42.5% vs 19.9%; p-value <0.001), were more likely to be current IDUs (11.3% vs 4.3%; p-value <0.001) and more likely to be First Nations/Inuit/Metis (17.6% vs. 6.5%; p-value <0.001).

A comparison of all BCPWA members who received the survey and the subset who responded found a similar distribution of age and a similar proportion identifying as Aboriginal (7.1% vs. 8.7%). The proportion of females was higher among the total BCPWA population than among the subset of respondents (13.5% vs.10.2%; p=0.001).

**Prevalence of impairments, activity limitations and participation restrictions**

Table 1 describes levels of diagnoses, impairments, activity limitations and participation restrictions among participants. Mental health diagnoses were reported by 62.9% (N=479) of the participants. The most prevalent diagnosis was depression with an overall prevalence of 58.1%. Among those listing one or more diagnoses, 92.5% experienced depression as one of their diagnoses. While the overall number of participants with depression appeared lower among those with CD4 ≤200 cells/ml, the percent of those listing depression out of those with any diagnosis remained close to 92.5% across all strata.
The presence of multiple impairments among the participants was also high, with a median of 7 (3,12) impairments and approximately one third of the participants experiencing more than ten impairments. At least one impairment was reported by 91.5% (N=697). There was a significant difference in the distribution of impairments across CD4 categories, which remained after Bonferroni correction (CD4 ≤200 cells/ml vs CD4 >500 cells/ml, p-value=0.002; CD4 ≤200 cells/ml vs CD4 between 200 and 500 cells/ml, p-value=0.017). Mental impairment was reported by 78.2% (N=596), sensory impairment by 71.9% (N=548), neuromuscular impairment by 49.5% (N=377), and internal impairment by 81.0% (N=617) of the participants.

Pain was reported by over half of the participants, and by over three quarters of the participants with CD4 ≤200 cells/ml. Approximately one-third reported little or mild pain and 37.1% reported moderate or severe pain. For participants with lower CD4 counts, more people reported moderate and severe pain (50.4% vs. 38.7% vs. 34.9%; p-value 0.08), although comparisons of each CD4 category to the others showed no significant differences.

Activity limitations were reported by 80.6% (N=607) of the participants. The median number of activity limitations reported by an individual was 3 (1, 7). Six hundred and ninety-nine individuals (93.2%) reported some level of participation restriction. The median number of participatory roles in which individuals felt somewhat or highly restricted was 7 (3, 9). Although distributions of activity limitations and participation restrictions were significantly different, adjustment for multiple comparisons across the CD4 categories resulted in no significant difference in prevalence.
Figures 1-3 summarize the prevalence of impairments, activity limitations and participation restrictions, respectively. The most prevalent impairments experienced by participants included diarrhea (57.1%), reduced libido (55.8%), general weakness (48.2%), poor concentration (47.0%), headaches (46.9%) and chronic fatigue (46.6%). Vigorous and moderate activities, sexual activities and household chores were the most frequently reported limitations. The level of participation restrictions was high for all CD4 categories, with sexual roles, student/employee roles and financial roles being the most prevalent.

**Univariate associations of impairments and activity limitations on social role restrictions**

Table 2 describes the univariate odds ratios for presence of social role restriction (yes vs. no) based on impairment categories and type of activity limitation. All impairments and activity limitations were significantly associated with social role restriction. Social role restriction was most strongly associated with limitations in using the toilet, (OR: 18.5 for toilet difficulties vs. no toilet difficulties; 95%CI: 4.5 – 76.3), followed by banking, (OR: 11.3 for banking difficulties vs. no banking difficulties; 95%CI: 5.4 – 23.5). Social role restriction had the weakest association with getting out of bed, (OR: 3.6 for difficulties getting out of bed vs. no difficulties; 95%CI: 2.3 – 5.6). With respect to impairment categories, social role restriction was most strongly associated with mental impairments (OR 7.0 for mental impairments vs. no mental impairments; 95% CI 4.7-10.4) although the other three impairment categories had odds ratios higher than four.
Adjusted odds ratios stratified by CD4 counts remained significant for getting groceries, doing laundry, household chores, and mental functioning, regardless of CD4 levels, although the estimates were higher for participants with counts under 200 cells/mm3. For those with CD4 counts above 200 cells/mm3, difficulties with eating, public transportation, moderate or vigorous activities, sexual activities, neuromuscular functioning and sensory functioning also remained significantly associated with social restrictions. Adjusted odds ratios for using the toilet and getting dressed were unable to be estimated as these were co-linear with the outcome. Stratified, unadjusted estimates of 9-fold and 37-fold increases in social restriction were seen with limitations in toileting.

Stratification by CD4 levels indicated a general effect modification across activity limitations and impairment categories, with greater, although more unstable, associations with social restrictions being found among participants with <200 cells/mm3.

**Multivariate associations of impairments and activity limitations with participation restriction levels**

Table 3 describes the ordinal logistic regression model examining associations with a three-category measure of participation restriction level, stratified by CD4 cell counts. Among those with CD4 counts under 200 cells/mm3, being in a higher category of participation restriction was strongly associated with having activity limitation scores above ten, and was marginally inversely associated with being on antiretrovirals. Increasing number of impairments did not show any significant association.
Among participants with CD4 counts above 200 cells/mm³, being in a higher category of participation restriction was associated with increasing levels of limited activity [(OR: 2.7 for limited activity scores of 4-10 vs. scores < 4; 95%CI: 1.4 – 5.1) and (OR: 8.6 for limited activity scores >10 vs. scores < 4; 95%CI: 3.9 – 18.8)]. A higher participation restriction category was also significantly associated with increasing number of impairments, with a 19% increase in the odds with additional impairment. Increased participation restriction level was only marginally significantly associated with moderate or severe pain; however, point estimates for the pain categories suggested a dose response relationship, as did the inclusion of pain as a continuous variable (p-value 0.066).
Discussion

This study has demonstrated that a population-based sample of people living with HIV in British Columbia have been experiencing strikingly high levels of depression, body impairments, activity limitations and participation restrictions. The latter two categories were higher among this population than a national survey of HIV positive persons in the United States[10]. However, the American study was conducted prior to HAART availability, underscoring the importance of examining quality of life issues faced in the post-HAART era. In a study examining similar concepts of activity limitation among cancer patients, the percent experiencing any difficulties ranged from 18.0 to 70.0%, depending on the type of cancer, but was only 30.0% overall [18]. Another study of cancer survivors found a similar prevalence to that seen in the present study (80.0%) when including all ambulatory difficulties, not just activities of daily living [19]. The elevated levels of limitation among the BCPWA population were also emphasized in a comparison with the general population and with those identifying as suffering from a chronic illness, where the least difference showed a five-fold increase [20].

The level of depression among this population was extremely high. Nearly 60.0% of the participants reported ever having been diagnosed with depression by a doctor. Levels of depression among HIV positive persons reported in the literature range from 5.0% to 40.0%, although among HIV positive women, 60.0% prevalence has been reported [21, 22]. Depression is generally found to be higher, regardless of HIV status, among women and men who have sex with men [21]. Studies conducted among MSM have found prevalence of major depression to range from 23.0 to 37.0%, while Aboriginal populations in general, and
Aboriginal MSM in particular, have been shown to have higher depression scores [23, 24, 25]. Likewise, depression among IDU populations has been seen to be as high as 47.0% [24]. Some study scales may capture current depression but may miss the experience of people with recurrent episodes who feel well at the time of testing. The high level of depression recorded in this study may be the result of a large percentage of men who have sex with men in the sample as well as the survey’s ability to capture more cumulative measures of depression. The high prevalence may be due in part to the self-report of the diagnosis as well, which may result in recall bias and increased reporting of non-diagnosed depression. Regardless, this common experience of depression demands consideration by researchers, policy-makers and care providers concerned with the quality of life of people living with HIV.

The prevalence of impairments was also high, with diarrhea at the top of the list, followed by problems with fatigue and endurance. Furthermore, challenges with daily activities and social roles were extremely common, at greater than 80.0 and 90.0%, respectively. The high proportion of individuals experiencing impairments, activity limitations and participation restrictions sheds light on the spectrum of challenges related to living with HIV. Even among those with relatively high CD4 counts, the impact of HIV on disability and health is not trivial.

Of note, the differences experienced between people according to categories of CD4 levels were less and less apparent going from impairments (problems at the level of organ or body part) to activity limitations to participation restrictions (problems with social roles). This
draws attention to the variety of influences affecting a person’s ability to perform daily tasks and participate in regular societal roles above and beyond his/her clinical measures of disease status.

All types of activity limitation were associated with the experiencing of social role restrictions. After accounting for impairments, depression and pain levels, there remained significant associations between household upkeep, including laundry and groceries, and social role participation. Although it was hypothesized that personal care issues would have stronger associations, this was not the case. This may be because the severity of personal care limitations (dressing, eating, showering) is such that among those experiencing these limitations, the presence of pain or numerous impairments overshadows any independent association between the limitation and social restriction.

Household chores, getting groceries and doing laundry as well as moderate and vigorous activities had significant associations with social role restrictions and had the highest prevalence in this population. Therefore, interventions that target these types of limitations may provide the most benefit at a population level. Whether or not these interventions would have any impact on an individual's feelings of participatory restriction remains to be seen; however, coordinating these types of simple interventions might offer contact with people in need of social support.

Mental impairments were the most prevalent of the four impairment categories and were found to have a significant association with participation restrictions. These results mirror a
study describing disability among a national sample of people living with HIV in the United States which reported a correlation between general fatigue and increased limitations in both physical and role functions [10]. Other reports have also found relationships among neuropsychological performance, depression, stress levels and perceived disability [26]. It is suggested that increased social support networks can result in improved mental health, which may indicate that the association between the presence of mental impairment and the ability to interact in social and community roles is not unidirectional.

The adjusted models (Table 3) indicate that both impairments and activity limitations remain associated with participation restrictions independent of one another for people with high CD4 counts. The use of antiretrovirals among those with low CD4 counts is associated with lower participation restriction levels. Since this cannot be accounted for through a lessening of impairments or limitations among those on antiretrovirals, it is more likely a reflection of the type of support and interaction with the health care system among those who are able to access antiretrovirals.

**Limitations of the study**

Limitations of the study include the somewhat homogeneous nature of the participants, which affects the generalizability of these findings to other populations. The participants were mainly white, sexual-minority males with moderate yearly incomes and stable housing. The under-representation of people who are homeless, injection drug users, female and Aboriginals becomes apparent when comparing the low proportions seen amongst the
BCPWA membership to the higher proportions seen in incident cases reported by the British Columbia Centre for Disease Control [27].

The survey was sent to BCPWA members consenting to receive mail. Individuals who did not consent were more likely to reside in the Greater Vancouver region, suggesting a greater geographical representation from outside of this urban area. Non-consenting BCPWA members were also more likely to be female (15.8% vs 11.9%) and more likely to be First Nations, Inuit or Metis (27.1% vs 8.4%). Furthermore, because the survey was anonymous and self-reported, there are issues with missing data and incomplete records. For example, almost 20.0% of the sample, again representing a high proportion of women and First Nations, were excluded because of missing CD4 information. While the exclusion of this population may have affected the power and generalizability of the study, one may argue that challenges reported in this study may be an underestimation of the restrictions in this population due to compounding social inequity issues.

Lastly, there are limitations in the nature of self-reported diagnoses. Participants may have trouble recalling the presence or absence of impairments, limitations or restrictions over the past month. Although there was no direct incentive, participants may be biased towards increased reporting of problems as they may feel that this would be beneficial for program funding and support.

Despite these limitations, this survey represents a large provincial sample and is one of few attempts to collect information from a population-based sample on this scale. Furthermore, this is one of the first studies to systematically quantify levels of disablement among persons living with HIV.
Conclusions

This study revealed a strikingly high prevalence of impairments, activity limitations and participation restrictions among a population-based sample of people living with HIV in British Columbia. The complicated interplay among these categories requires further study, but it is clear that interventions designed to help overcome activity limitations and social support programs are required, especially those addressing mental impairments and depression. While impairments and limitations are not always reversible, innovative programs that help people living with HIV address these challenges may help to decrease the subsequent high rates of participatory restrictions experienced. Antiretroviral treatments have enabled the prolongation of the lives of people who are HIV-infected; now we need to give due attention to optimizing the quality of these extended lives.

Acknowledgments

This work was supported by the Canadian Working Group on HIV and Rehabilitation (CWGHR), by the Michael Smith Foundation for Health Research through a Senior Scholar Award to Dr. Robert Hogg, a Doctoral Scholar Award to Paula Braitstein and a Training award to Melanie Rusch, as well as by the Canadian Institutes for Health Research through a Fellowship to Stephanie Nixon.

Special thanks to Ruth Marzetti and Ryan Kyle from the BCPWA society. The authors are indebted to all the members of the British Columbia PWA society who participated in this survey.
Authors’ Contributions

MR and KC carried out the statistical analyses; SN and AS participated in the design of the study and the development of the study instrument; PB participated in the conceptualization of the study and the interpretation of the results; RH participated in the conceptualization and design of the study. All authors read and approved the final manuscript.
References


17. Canadian Working Group on HIV and Rehabilitation. [www.hivandrehab.ca]


Figure legends

**Figure 1:** Prevalence of specific impairments for participants with CD4 counts ≤ 200 cells/mm³ (speckled bars), 201 to 500 cells/mm³ (downward diagonally-striped bars) and > 500 cells/mm³ (horizontally-striped bars). Significant p-value from chi-square test across CD4 categories.

**Figure 2:** Prevalence of specific activity limitations for participants with CD4 counts ≤ 200 cells/mm³ (speckled bars), 201 to 500 cells/mm³ (downward diagonally-striped bars) and > 500 cells/mm³ (horizontally-striped bars). Significant p-value from chi-square test across CD4 categories.

**Figure 3:** Prevalence of specific participation restrictions for participants with CD4 counts ≤ 200 cells/mm³ (speckled bars), 201 to 500 cells/mm³ (downward diagonally-striped bars) and > 500 cells/mm³ (horizontally-striped bars). Significant p-value from chi-square test across CD4 categories.
Table 1: Prevalence of diagnosed conditions, impairments and pain, activity limitations and participation restrictions experienced by BCPWA participants by CD4 cell counts

<table>
<thead>
<tr>
<th></th>
<th>CD4&lt;200</th>
<th>CD4 201 to 500</th>
<th>CD4&gt;500</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosed conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>64 (52.0)</td>
<td>183 (59.2)</td>
<td>110 (61.5)</td>
<td>0.238</td>
</tr>
<tr>
<td>General Anxiety</td>
<td>11 (8.9)</td>
<td>34 (11.0)</td>
<td>14 (7.8)</td>
<td>0.488</td>
</tr>
<tr>
<td>Post traumatic Stress</td>
<td>6 (4.9)</td>
<td>18 (5.8)</td>
<td>13 (7.3)</td>
<td>0.677</td>
</tr>
<tr>
<td>Panic Disorder</td>
<td>8 (6.5)</td>
<td>35 (11.4)</td>
<td>12 (6.7)</td>
<td>0.124</td>
</tr>
<tr>
<td><strong>Median number of impairments (IQR)</strong></td>
<td>9 (5, 13)</td>
<td>7 (2.5, 12)</td>
<td>7 (3, 12)</td>
<td>0.006</td>
</tr>
<tr>
<td><strong>% With any impairment</strong></td>
<td>120 (97.6)</td>
<td>285 (92.5)</td>
<td>161 (89.9)</td>
<td>0.041</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>25 (20.7)</td>
<td>82 (29.4)</td>
<td>48 (28.4)</td>
<td>0.079</td>
</tr>
<tr>
<td>Little/mild</td>
<td>35 (28.9)</td>
<td>89 (31.9)</td>
<td>62 (36.7)</td>
<td></td>
</tr>
<tr>
<td>Moderate/severe</td>
<td>61 (50.4)</td>
<td>108 (38.7)</td>
<td>59 (34.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Median number of activity limitations (IQR)</strong></td>
<td>3 (1, 7)</td>
<td>3 (1, 7)</td>
<td>2 (1, 5)</td>
<td>0.015</td>
</tr>
<tr>
<td><strong>% With any Activity Limitation</strong></td>
<td>108 (87.8)</td>
<td>236 (77.4)</td>
<td>137 (76.5)</td>
<td>0.031</td>
</tr>
<tr>
<td><strong>Median number of Participation Restrictions (IQR)</strong></td>
<td>7 (4, 9)</td>
<td>7 (3, 9)</td>
<td>7 (3, 9)</td>
<td>0.251</td>
</tr>
<tr>
<td><strong>% With any Participation Restrictions</strong></td>
<td>121 (98.4)</td>
<td>278 (91.5)</td>
<td>161 (89.9)</td>
<td>0.017</td>
</tr>
</tbody>
</table>

**Bold** print indicates comparison that remained significant at the p=0.016 level after Bonferroni correction for multiple comparisons.
Table 2: Univariate and adjusted odds ratios for social role restriction given each activity limitation and prevalence of these limitations in this population

<table>
<thead>
<tr>
<th>Activity</th>
<th>Prevalence (%)</th>
<th>Odds Ratio</th>
<th>Adjusted Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(95% CI)</td>
<td>(95% CI)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>≤ 200 cells/ml</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>8.9 (54)</td>
<td>4.03</td>
<td>7.90** (0.45 - 137)</td>
</tr>
<tr>
<td>Getting out of bed</td>
<td>20.8 (125)</td>
<td>3.63</td>
<td>1.15 (0.31 - 4.14)</td>
</tr>
<tr>
<td>Laundry</td>
<td>28.1 (171)</td>
<td>7.53</td>
<td>8.41 (1.32 - 54)</td>
</tr>
<tr>
<td>Eating</td>
<td>20.1 (122)</td>
<td>4.66</td>
<td>0.87 (0.26 - 2.94)</td>
</tr>
<tr>
<td>Driving</td>
<td>21.5 (121)</td>
<td>3.51</td>
<td>1.59 (0.45 - 5.49)</td>
</tr>
<tr>
<td>Groceries</td>
<td>32.6 (198)</td>
<td>8.43</td>
<td>3.97 (1.21 - 13)</td>
</tr>
<tr>
<td>Public Transportation</td>
<td>25.2 (148)</td>
<td>6.75</td>
<td>4.36 (0.91 - 21)</td>
</tr>
<tr>
<td>Household chores</td>
<td>39.6 (241)</td>
<td>6.89</td>
<td>5.12 (1.62 - 16.2)</td>
</tr>
<tr>
<td>Using the toilet</td>
<td>6.3 (38)</td>
<td>18.47</td>
<td>9.14** (0.52 - 159)</td>
</tr>
<tr>
<td>Showering</td>
<td>10.2 (62)</td>
<td>6.62</td>
<td>3.38 (0.41 - 28)</td>
</tr>
<tr>
<td>Household chores</td>
<td>39.6 (241)</td>
<td>6.89</td>
<td>5.12 (1.62 - 16.2)</td>
</tr>
<tr>
<td>Bank</td>
<td>16.4 (99)</td>
<td>11.27</td>
<td>3.78 (0.33 - 42)</td>
</tr>
<tr>
<td>Walking one block</td>
<td>13.2 (80)</td>
<td>5.33</td>
<td>3.33 (0.54 - 20)</td>
</tr>
</tbody>
</table>
Table 2: continued

<table>
<thead>
<tr>
<th>Activity</th>
<th>Prevalence (%)</th>
<th>Odds Ratio (95% CI)</th>
<th>Adjusted Odds Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>&lt;200 cells/ml</td>
<td>&gt;200 cells/ml</td>
</tr>
<tr>
<td>Moderate activity</td>
<td>42.4 (258)</td>
<td>5.87 (4.11 – 8.37)</td>
<td>2.10 (0.76 - 5.77)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.10 (1.62 - 5.93)</td>
<td></td>
</tr>
<tr>
<td>Sexual activity</td>
<td>46.6 (283)</td>
<td>5.33 (3.81 – 7.47)</td>
<td>2.56 (1.00 - 6.57)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.06 (1.16 - 3.68)</td>
<td></td>
</tr>
<tr>
<td>Vigorous activity</td>
<td>71.9 (437)</td>
<td>5.09 (3.61 – 7.19)</td>
<td>2.69 (0.97 - 7.48)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.60 (1.37 - 4.96)</td>
<td></td>
</tr>
<tr>
<td><strong>Impairment Category</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental functioning</td>
<td>78.7 (481)</td>
<td>7.02 (4.73 – 10.4)</td>
<td>18.71 (2.31 – 151)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.32 (2.20 – 8.51)</td>
<td></td>
</tr>
<tr>
<td>Neuro-musculoskeletal</td>
<td>49.3 (301)</td>
<td>4.12 (2.98 – 5.69)</td>
<td>1.77 (0.67 – 4.68)</td>
</tr>
<tr>
<td>functioning</td>
<td></td>
<td>1.76 (1.03 – 3.00)</td>
<td></td>
</tr>
<tr>
<td>Sensory functioning</td>
<td>72.3 (442)</td>
<td>4.12 (2.94 – 5.78)</td>
<td>0.85 (0.27 – 2.65)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.17 (1.20 – 3.93)</td>
<td></td>
</tr>
<tr>
<td>Internal functioning</td>
<td>81.4 (500)</td>
<td>4.15 (2.82 – 6.12)</td>
<td>2.48 (0.69 – 8.91)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.84 (0.96 – 3.51)</td>
<td></td>
</tr>
</tbody>
</table>

*Adjusted for age, gender, income, number of impairments (for activity limitation models), pain, risk category and doctor-diagnosed depression

**Small sample size; analysis stratified on CD4 but not adjusted due to zero cells.
Table 3: Ordinal logistic regression estimating the probability of being in a higher category of the three level participation restriction score based on levels of impairment, limited activity scores and pain.

<table>
<thead>
<tr>
<th>CD4 ≤ 200</th>
<th>OR*</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Limited Activity score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>0.91 – 14.2</td>
</tr>
<tr>
<td>1-5</td>
<td>3.58</td>
<td>0.91 – 14.2</td>
</tr>
<tr>
<td>&gt;5</td>
<td>24.7</td>
<td>4.85 – 125</td>
</tr>
<tr>
<td><strong>Number of impairments</strong></td>
<td>1.01</td>
<td>0.94 – 1.12</td>
</tr>
<tr>
<td><strong>Antiretroviral use</strong></td>
<td>0.28</td>
<td>0.08 – 0.93</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CD4 &gt; 200</th>
<th>OR*</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Limited Activity score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>1.40 – 5.12</td>
</tr>
<tr>
<td>1-5</td>
<td>2.67</td>
<td>1.40 – 5.12</td>
</tr>
<tr>
<td>&gt;5</td>
<td>8.56</td>
<td>3.90 – 18.8</td>
</tr>
<tr>
<td><strong>Number of impairments</strong></td>
<td>1.19</td>
<td>1.12 – 1.25</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>1</td>
<td>0.71 – 2.44</td>
</tr>
<tr>
<td><strong>Antiretroviral use</strong></td>
<td>1.39</td>
<td>0.83 - 2.35</td>
</tr>
</tbody>
</table>

*adjusted for age, gender, employment, education, years since diagnosis and risk category
HIV Associated Disability among People Living with HIV in British Columbia

Results from the 2002 Survey Conducted by the BC Persons With AIDS Society in Collaboration with the BC Centre for Excellence in HIV/AIDS
HIV Associated Disability among People Living with HIV in British Columbia

A population-based survey conducted jointly by the BC Persons With AIDS Society and the BC Centre for Excellence in HIV/AIDS

People living with HIV in British Columbia (BC) have been able to freely access antiretroviral therapy for the treatment of HIV infection via the provincial HIV/AIDS Drug Treatment Program since 1992. The introduction of highly active antiretroviral therapy (HAART) in the mid-1990’s marked a turning point in the HIV/AIDS epidemic. Before HAART, people with HIV infection faced serious illnesses with immense effects on their quality and length of life. Many people have had their lives and health extended by HAART; however, it is important to remember that while these drugs are toxic to HIV, they are also toxic to people. As a result, those taking HAART often find it causes unwanted and sometimes-disfiguring side effects. As HAART increases the life expectancy of people living with HIV, quality of life issues become more and more important. Although many people are keeping their HIV infection under control, they may still find it difficult to function and take part in everyday life activities.

Functioning and disability

Day-to-day functioning encompasses functioning at three levels: body parts and organs function individually; the body functions as a person, carrying out daily activities and tasks; and people function within their homes, their environment and society.

Things can go wrong at any one of these levels. As such, individuals may experience physical or psychological symptoms, may have a reduced ability to perform every-day-tasks, and may become less able to participate in life situations. Often, HIV related symptoms or side effects of HAART can lead to decreased functioning at other levels. However, how a person functions on a day-to-day basis and how they are able to cope with life in social situations may also be influenced by other physical and psychological problems. Accurately identifying the contributing factors on an individual basis is essential to improving the lives of people with HIV.
The BC Persons With AIDS (BCPWA) Society

The BCPWA has over 3500 HIV positive members and is Western Canada’s largest organization of people living with HIV. Their mission is to empower persons living with HIV/AIDS through mutual support and collective action. Membership is free and open to anyone living with HIV/AIDS in BC. It includes benefits such as a free subscription to "Living Positive", a magazine dedicated to treatment, news, and advocacy; use of community facilities; access to individual advocacy services; and a complementary health fund. The society also organizes retreats, operates a range of support groups, offers links to AIDS service organizations all over the province, engages the community in events such as the annual AIDS Walk Vancouver, provides prison outreach, and participates in scientific research as described here.

Surveying HIV-related disability in BC

In 2002, the BCPWA and BC Centre for Excellence in HIV/AIDS jointly mailed out surveys to 1508 HIV-positive BCPWA members, of which 762 were completed and returned. The survey asked questions about physical and psychological health (symptoms or impairments), the experience and level of functioning as a person (activity limitations) and the ability to participate in life situations (participation restrictions). Survey participants were mainly white men who have sex with men, with moderate yearly incomes and stable housing. The survey was anonymous.

Survey participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>Proportion of survey participants</th>
<th>Proportion of general population of BC*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>90%</td>
<td>47%</td>
</tr>
<tr>
<td>Female</td>
<td>10%</td>
<td>53%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>85%</td>
<td>83%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>20%</td>
<td>52%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>80%</td>
<td>48%</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $10,000</td>
<td>24%</td>
<td>5%</td>
</tr>
<tr>
<td>$10,000--$50,000</td>
<td>60%</td>
<td>52%</td>
</tr>
<tr>
<td>More than $50,000</td>
<td>16%</td>
<td>43%</td>
</tr>
</tbody>
</table>

*National Population Health Survey
Physical and psychological health

Survey participants were asked specific questions about certain diagnosed conditions, as well as about a wide range of symptoms in order to assess their physical and psychological health. Symptoms were divided into five categories as follows:

- **Internal impairments** including diarrhea, gastric reflux, shortness of breath, constipation, wasting, weakness, vomiting, and incontinence.

- **Mental impairments** including reduced libido, poor concentration, poor appetite, chronic fatigue, decreased endurance, decreased memory, reduced reasoning, and difficulties with language.

- **Sensory impairments** including headaches, altered sensations, nausea, mouth pain, and decreased vision.

- **Nerve and muscle impairments** including altered muscle tone, stiff joints, seizures, weakness or paralysis of one side of the body, weakness of both legs.

- **Pain** ranked according to a five-point scale (none, little, mild, moderate or severe).

The survey revealed that people living with HIV in BC are especially vulnerable to depression, with approximately two out of every three individuals (58%) reporting their doctor diagnosed them with this condition. In addition:

- Nine out of ten individuals reported experiencing **one or more** symptoms.

- Half of those surveyed reported experiencing **seven or more** symptoms.

- One in three of those surveyed reported experiencing **more than ten** symptoms.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Proportion of participants reporting symptoms</th>
<th>Most commonly reported symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal</td>
<td>81%</td>
<td>Diarrhea (57%)</td>
</tr>
<tr>
<td>Mental</td>
<td>78%</td>
<td>Reduced libido (56%)</td>
</tr>
<tr>
<td>Sensory</td>
<td>72%</td>
<td>General weakness (48%)</td>
</tr>
<tr>
<td>Nerve and muscle</td>
<td>50%</td>
<td>Headache (47%)</td>
</tr>
<tr>
<td>Pain</td>
<td>80%</td>
<td>Moderate or severe pain (40%)</td>
</tr>
</tbody>
</table>
**Functioning as a person**

Survey participants were asked to indicate whether they were (a) completely able, (b) somewhat limited or (c) unable to perform a variety of tasks such as walk, eat, get dressed, shower, etc., in order to assess how well people living with HIV cope with day-to-day activities. Individuals who answered with b) or c) were counted as having an *activity limitation*.

- Eight out of ten individuals reported *one or more* activity limitations.
- Half of those surveyed reported experiencing limitations in *three or more* types of activity.

**Prevalence of activity limitations reported by people living with HIV in BC**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Proportion of survey participants reporting somewhat or very limited ability to perform the specified activity</th>
<th>Proportion of survey participants reporting somewhat or very limited ability to perform the specified activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undertake vigorous activity</td>
<td>72%</td>
<td>Get out of bed</td>
</tr>
<tr>
<td>Undertake sexual activity</td>
<td>47%</td>
<td>Eat</td>
</tr>
<tr>
<td>Undertake moderate activity</td>
<td>42%</td>
<td>Bank</td>
</tr>
<tr>
<td>Perform household chores</td>
<td>40%</td>
<td>Walk one block</td>
</tr>
<tr>
<td>Shop</td>
<td>33%</td>
<td>Shower</td>
</tr>
<tr>
<td>Do the laundry</td>
<td>28%</td>
<td>Get dressed</td>
</tr>
<tr>
<td>Use public transport</td>
<td>25%</td>
<td>Use the toilet</td>
</tr>
<tr>
<td>Drive</td>
<td>22%</td>
<td></td>
</tr>
</tbody>
</table>
**Functioning in life situations**

Survey participants were asked to indicate whether they were (a) not limited, (b) somewhat limited, or (c) very limited in their ability to function in various roles including social roles, student roles, and cultural roles, in order to assess how well people living with HIV cope with life situations. Individuals who answered with b) or c) were counted as having a *participation restriction*.

- Nine out of 10 of individuals reported *one or more* participation restrictions.
- Half of those surveyed indicated they felt somewhat or highly restricted in *seven or more* of the selected roles.

**Prevalence of social restrictions reported by people living with HIV in BC**

<table>
<thead>
<tr>
<th>Role</th>
<th>Proportion of survey participants reporting somewhat or very limited ability to function in the specified roles</th>
<th>Proportion of survey participants reporting somewhat or very limited ability to function in the specified roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual role</td>
<td>67%</td>
<td>Social role</td>
</tr>
<tr>
<td>Hobby, sports and leisure roles</td>
<td>68%</td>
<td>Experience discrimination</td>
</tr>
<tr>
<td>Student or employee role</td>
<td>58%</td>
<td>Volunteer role</td>
</tr>
<tr>
<td>Experience financial independence</td>
<td>59%</td>
<td>Household role</td>
</tr>
<tr>
<td>Community or family role</td>
<td>61%</td>
<td>Cultural or religious role</td>
</tr>
</tbody>
</table>
Impact of symptoms and activity restrictions on social participation

The survey shows that many people living with HIV experience high levels of depression, multiple symptoms, reduced ability to perform every-day tasks and reduced social participation.

Survey participants who reported reduced mental functioning (including reduced libido, poor concentration, poor appetite, chronic fatigue, decreased endurance, decreased memory, reduced reasoning, and difficulties with language) were least likely to be able to participate socially. Experiencing restrictions in life roles can have compounding negative effects on mental state, the ability to cope on a day-to-day basis, and physical abilities. With almost two-thirds of those surveyed having reported a diagnosis of depression, it is likely that these individuals are particularly vulnerable to HIV-associated disability.

Large numbers of those surveyed told us they have diarrhea, headaches, feel tired, have a reduced libido and difficulty concentrating. All types of activity limitations were associated with a reduced ability to cope in social situations. Perhaps not surprisingly, being unable to use the toilet was most detrimental to social participation. Given that people living with HIV commonly reported having diarrhea, it is likely that they may feel unable to leave home for fear of having an episode while out.

In the survey, a person’s ability to perform household chores, get groceries, do the laundry, as well as undertake moderate and vigorous activities such as carrying the groceries, running, or lifting heavy objects was related to their ability to participate socially. If they were experiencing difficulty with performing these day-to-day activities, they were also less able to participate in life situations. An inability to carry out household chores was strongly linked with other functional limitations and it may be that this acts as a marker of a level of disability that coincides with an individual’s ability to function in their normal roles. Alternatively being unable to complete simple household chores may be psychologically detrimental to a person’s preparedness and ability to remain involved in their normal day-to-day life and social environment.

The survey highlights the need for interventions designed to help overcome activity limitations and social support programs that deal with psychological health problems and depression. While symptoms and activity limitations are not “curable”, innovative programs that help people living with HIV to adapt to their illness and keep them engaged in life are likely to have a significant impact on wellbeing. Antiretroviral therapies have lengthened the lives of people living with HIV. Now it is time to provide for quality of life.
The Social Determinants of Health: An Overview of the Implications for Policy and the Role of the Health Sector

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

Introduction

In late 2002, 400 social and health policy experts, community representatives, and health researchers met at York University at a conference entitled “Social Determinants of Health Across the Life-Span”. The purpose of the conference was to consider the state of key social determinants of health (SDOH) across Canada, explore the implications for the health of Canadians, and discuss policy directions to strengthen these social determinants of health.

Following the conference, Health Canada contracted with Peggy Edwards to prepare:

- summaries of a series of research papers and presentations on nine SDOH (see Appendix A)
- an overview paper that ties all of the issues together under a population health approach.

This overview is based on the papers and presentations from the conference, including an overview presentation by Dennis Raphael. All of the papers are rich in content and ideas, but not totally inclusive. In some cases, the authors and presenters chose to focus on a particular aspect of the issue. No attempt was made to move beyond the data base and population groups covered in the original papers and presentations. For example, some presenters included data related to Aboriginal peoples or new immigrants; others did not.

There are additional social determinants of health (such as peace, social support and family violence) that are not covered by the summaries. There are also other basic determinants of health (such as genetic endowment and the physical environment) that interact with the SDOH to provide the broad picture of why some people are healthy and others are not. Some discussion of the role of the health care system as a SDOH is included in this overview; however, there is no summary of this, because a full, referenced paper was not available. It should be remembered, however, that universal access to medical care is an important aspect of the SDOH. Without this, Canadians who become ill or injured would be forced to spend a large share of their income on treatment, leaving little money for other SDOH, such as housing and food.

This overview summarizes and interprets the conference papers as they relate to the implications for policy and the role of the health sector in terms of nine SDOH and the interactions among them:

- income inequality
- social inclusion and exclusion
- employment and job security
- working conditions
- contribution of the social economy
- early childhood care
- education
- food security
- housing.

The reader can find more in-depth information on each of these topics by reading the individual summaries and/or accessing the original papers and presentations. Please see Appendix B for some definitions of the above terms as used in the conference papers.
Current Situation

A wealth of evidence from Canada and other countries supports the notion that the socioeconomic circumstances of individuals and groups are equally or more important to health status than medical care and personal health behaviours, such as smoking and eating patterns (Evans et al., 1994; Frank, 1995; Federal/Provincial/Territorial Advisory Committee on Population Health, 1999). The weight of the evidence suggests that the SDOH have a direct impact on the health of individuals and populations, are the best predictors of individual and population health, structure lifestyle choices, and interact with each other to produce health (Raphael, 2003). In terms of the health of populations, it is well known that disparities—the size of the gap or inequality in social and economic status between groups within a given population—greatly affect the health status of the whole. The larger the gap, the lower the health status of the overall population (Wilkinson, 1996; Wilkinson and Marmot, 1998).

Canada has been a world leader in research related to the SDOH. Yet, according to the Canadian Population Health Initiative of the Canadian Institute for Health Information: “Canada has fallen behind countries such as the United Kingdom and Sweden and even some jurisdictions in the United States in applying the population health knowledge base that has been largely developed in Canada” (CPHI, 2003).

All of the conference papers describe a discouraging picture of increased disparities in the SDOH across Canada over the last 15 to 20 years. Many factors have contributed to the growing gap, including some government policies, with some exceptions—most notably in Quebec where some recent policies (such as universal $5 a day child care and increases in social housing) have been enacted to improve the SDOH.

Income Inequality

- Between 1997 and 2000, Canadians enjoyed increases in personal incomes as a result of higher levels of employment (particularly among full-time workers) and wage growth. However, the poverty rate among all Canadians—with the notable exception of seniors—is still higher than it was in pre-recession 1989. The failure to reduce poverty levels to at least 1989 levels points to the trend of growing income inequality in Canada. The poverty gap—the gap between the poverty line and the average income of poor families or persons below the line—increased over the last decade, even as the economy boomed. (Scott, 2002).

- Incomes have become more polarized. Taxes and transfers have helped to offset this growing inequity; however, the pattern of increasing disparity is still evident when looking at after-tax income. For example, the income share of the bottom 20% of families in 2000 from earnings and investments was 2.8%, compared to 45.1% among top quintile families—that is, 16.1 to 1. After transfers and taxes, the income share of the bottom quintile was 7.3%, compared to 38.8%—a ratio of 5.3 to 1 (Scott, 2002).

Job Security and Working Conditions

- Globalization, slow growth in the ‘70s and recessions in the early ‘80s and ‘90s resulted in workforce rationalization, layoffs and the emergence of new styles of work, including increases in temporary, part-time, casual, contract and self-employment. Today, only one-half of all working Canadians has a single, full-time job that has lasted six months or more; only one in two is eligible for employment insurance due to changes in the requirements and these new styles of work (Tremblay, 2002). Less than half of non-unionized workers have access to employer-sponsored benefits and pensions (Jackson, 2002). Thus, half of working Canadians are experiencing income and job insecurity. These “precarious workers”, who are often young parents, cannot afford to go the dentist, nor to take their children there. Frequent short-term unemployment is high, with limited access to income support from employment insurance.
• Increased pressure for competitiveness in a global market and changes in the nature of work has led to high levels of workplace stress and related health problems linked to long working hours, job insecurity, physical injuries such as repetitive strain, decreases in worker participation and control, and problems related to work-family balance (Jackson, 2002; Polanyi, 2002).

Housing and Food Security
• In the 1990s, the federal government and most provinces stopped providing social housing. At the same time, some provinces reduced social assistance rates (by as much as 22% in one province). This has led to a housing crisis among renters and the growing ghettoization of residential neighbourhoods in large cities. Low-income individuals and families—especially Aboriginal, new immigrant and sole parent families—have been hit particularly hard. In November 2001, the federal and provincial governments made a unanimous agreement to build significantly more social housing units. One year later, the National Housing and Homelessness Network reported that outside of Quebec (which has committed itself to funding 2900 new units this year) no province has made a serious commitment to building new affordable housing (NHHN, 2002). In addition, several provinces had still not signed the bilateral agreement (Bryant, 2002). Meanwhile homeowner wealth increased from 29 times that of renters in 1984, to 70 times in 1999 (Statistics Canada, 1999). When rents take 30 to 50% or more of one’s income, there is little money left for food, recreation, transportation and the other necessities of life.
• The 1998/99 National Population Health Survey revealed food insecurity among 10.1% of Canadian households, representing 3 million people, including 678,000 children. The odds of reporting food insecurity increased with declining income and reliance on social assistance. Prevalence was greatest among lone mothers with children (Che and Chen, 2001). In the 1994 National Longitudinal Survey on Children and Youth (NLSCY), families headed by single-mothers were eight times more likely to report that their children were hungry, compared to other families. Children from families receiving welfare were 13 times more likely to experience hunger than non-welfare families (McIntyre, Walsh and Connor, 2001).

Education and Care in Early Life
• Although 65 to 85% of mothers are in the labour force, there are only regulated child care spaces for about 12% of Canadian children. Despite the growing evidence of the positive effect of high quality early childhood education and care (ECEC) on child development and future health, total spending on ECEC has dropped in recent years in every province except Quebec (Friendly, 2002).
• Since its inception in the late 19th century, universal public schooling in Canada has prepared the young for the responsibilities of adult citizenship. Today, public schools in Canada are under stress due to budget cutbacks, labour conflicts, and increased needs for special education, and language and cultural diversity. Failure to respond to these challenges puts public schooling at risk. This, in turn, endangers the health of Canadians and the well-being of the social structure (Ungerleider and Burns, 2002).
• Disadvantaged children and youth do not perform as well in school as advantaged young people. For Aboriginal people, rates of high school graduation and attendance at post-secondary schools are well below the rest of Canada. Children in low-income families are more likely to exhibit developmental delays and delinquent behaviours. Relative level of disadvantage is also important. Societies with larger gradients in socioeconomic status are more likely to encounter developmental problems in disadvantaged children (Keating, 2002).

Social Exclusion
• There is evidence of growing social exclusion in Canadian society, particularly for Aboriginal people, racialized groups and immigrants from countries other than Europe. For example, Aboriginal people and racialized groups are more than twice as likely to live in poverty and three times as likely than the average Canadian to be unemployed, despite the high credentials of many immigrants. Previous trends that saw immigrants forge ahead after a few years in Canada have reversed. Studies show that visible minority immigrants (who are now the majority of new Canadians) are at high risk for persistent poverty. Members of minority groups often encounter institutionalized racism in the health care and justice systems. The incarceration rate of Black males has increased over 200% in the last 10 to 15 years. These findings are mirrored in reports from several provinces on the experiences of Aboriginal people with the justice system (Galabuzi, 2002).
• Social exclusion is exacerbated by gender, age, ability, sexual orientation, race ethnicity and religion. For example, women from racialized groups make up almost all of the workers in the garment industry that employs contingent workers in Canada’s low paying and often unsafe “sweat shops” (de Wolff, 2000).

Most people in difficult living situations face more than one disadvantage. Shaw and colleagues argue in The Widening Gap: Health Inequalities and Policy in Britain that “Health inequalities are produced by the clustering of disadvantage — in opportunity, material circumstance, and behaviours related to health across people’s lives.” (Shaw et al, 1999).

Taking Action on the Social Determinants of Health

The situation described above exists within a broader context, including:

• the decline of the social welfare state, which supported progressive tax structures, and social and employment programs to protect workers, families and people who needed assistance
• the rise of transnational corporations that pressure nations and businesses into reducing costs and maximizing profits at the expense of the worker
• the decline of institutional and government structures that mitigated against social exclusion and conflicts between business and labour
• the recessions of the early ’80s and ’90s, which led to the systematic cutting of budgets and rapid policy changes in the health, social and education sectors, in order to reduce deficits
• the growth of market-driven political ideologies that see the individual as responsible for his or her place in the market economy and little or no room for governments to provide social protection for individuals and groups that require assistance.

Yet, within these global shifts, countries such as Finland and Sweden have systematically incorporated equality-oriented action on the SDOH into their national and regional policy agendas, while simultaneously enjoying economic growth (Raphael, 2003). Within Canada, there are jurisdictions at the provincial and local level that provide examples of successful policy and program changes that improve the SDOH and the economy and labour market at the same time (Vaillancourt et al, 2002). An analysis of the various actions suggested in the conference papers suggests that Canadian policy-makers might consider adopting six key strategies to improve the SDOH and the resulting health status of the population. Improved health will inevitably lead to improvements in productivity and reductions in the cost of treatment for illness and injuries.

Six Key Strategies to Enhance the Social Determinants of Health

1. Adopt a framework for social inclusion to guide the implementation of policies and practices that reduce inequities related to income, race, gender, ethnicity, geographic location, age, ability and sexual orientation.
2. Promote full employment, job security and healthy working conditions for all Canadians. Make employment insurance available to workers in precarious jobs that need it most.
3. Protect universal access to a high quality health system that recognizes and addresses mental,
social and spiritual health, and includes strong, adequately funded infrastructures for health promotion, disease prevention and health protection.

4. Protect and maintain Canada’s high quality public education system, expand programs in early childhood education and care, and increase opportunities for meaningful experiences in lifelong learning and employment training.

5. Uphold and ensure the right of all Canadians to adequate housing and food.

6. Reduce income disparities by ensuring minimum wages and levels of social assistance that allow all Canadians to access the basic necessities for healthy living in Canada, and by enacting tax transfers and social, health, labour and education policies that help create a level playing field for individuals and families that require support at various times in their lives.

The next section deals with the role of the health sector in addressing these six broad strategies.

**The Role of the Health Sector**

Despite clear evidence that the SDOH affect health and illness, the health sector has been reluctant to champion policies that improve social conditions because areas of social and economic policy largely fall outside of the health department’s jurisdiction. There has been a reluctance to “step on toes” and to explore ways of collaborating across sectors. Yet the health sector has at least three key roles to play in addressing disparities in the social determinants and the strategies outlined above:

1. **Leader.** In some cases, the health sector has a direct leadership role to play in addressing the health and long-term care needs of certain population groups, and as a large employer of many workers,

2. **Influencer.** In many cases, the health sector can act as an influential catalyst, advocate, mediator and collaborator in finding win-win situations that convince other sectors to develop public policies and assign public resources to improving the SDOH.

3. **Communicator and knowledge broker.** In all cases and at all levels, the health sector can communicate with the public and with decision-makers about the impact of policies in labour, finance, housing and other sectors on the health, well-being and productivity of Canada’s citizens. The sector can also serve as a knowledge broker in building and sharing our understanding about the value of and mechanisms for reducing disparities in the SDOH, and subsequently in health status.
References


Appendix A

List of Papers, Authors and Presenters

Income Equality

Paper and main speaker
Katherine Scott
Senior Policy Analyst, Canadian Council on Social Development

Respondent
Richard Lessard
Director of Public Health, Régie régionale de la santé et des Services sociaux de Montréal-Centre

Employment Security

Paper and main speaker
Diane-Gabrielle Tremblay
Professor and Research Director, Télé-universite and Canada Research Chair in Social and Organizational Challenges of the Knowledge Economy

Respondent
Andrew King
National Health, Safety and Environment Coordinator, United Steelworkers of America

Employment and Working Conditions

Paper and main speaker
Andrew Jackson
Senior Economist, Canadian labour Congress, Ottawa

Respondent
Michael Polanyi, Assistant Professor, Saskatchewan Population health Research and Evaluation Unit, and Faculty of Kinesiology and Health Studies, University of Regina

Contribution of the Social Economy

Paper and main speaker
Yves Vaillancourt
Directeur, Laboratoire de recherche sur les politiques et les pratiques sociaux, and Professor, School of Social Work at the Université du Québec in Montreal

Respondent
Pat Armstrong
Chair in Health Services and Nursing Research, Canadian Health Services Research Foundation and Canadian Institutes of Health Research, and professor, Department of Sociology, York University.
Early Life

*Paper and main speaker*
Martha Friendly
Coordinator and Director, Childcare Resource and Research Unit, Centre for Urban and Community Studies, University of Toronto.

*Respondent*
Gina Browne, Professor, Nursing and Clinical Epidemiology and Biostatistics, and Director, System-Linked Research Unit, McMaster University.

Education

*Paper and main speaker*
Charles Ungerleider
Professor, Sociology of Education, University of British Columbia and former Deputy Minister of Education for the Province of British Columbia.

*Respondent*
Daniel Keating
Atkinson Professor of Early Child Development and Education, Department of Human Development and Applied Psychology at the Ontario Institute for Studies in Education, University of Toronto.

Food Security

*Paper and main speaker*
Lynn McIntyre
Professor, Faculty of Health Professions, Dalhousie University.

*Respondent*
Valerie Tarasuk
Associate Professor in the Department of Nutritional Sciences, Faculty of Medicine, University of Toronto.

Housing

*Paper and main speaker*
Toba Bryant
Post-doctoral fellow, Centre for Health Studies, York University.

*Respondent*
Sharon Chisholm, Executive Director, Canadian Housing Renewal Association, Ottawa.

*Panelist*
Cathy Crowe, Street Nurse, Toronto
Social Exclusion

*Paper and main speaker*
Grace-Edward Galabuzi
Researcher, Centre for Social Justice and Doctoral Candidate, Department of Political Science, York University

*Respondent*
Ronald Labonte, Director, Saskatchewan Population Health and Evaluation Research Unit and Professor, Community Health and Epidemiology, University of Saskatchewan, Professor, Kinesiology and Health Studies, University of Regina.

SDOH: Research and Policy

*Paper and main speaker*
Dennis Raphael
Associate Professor, School of Health Policy and Management, York University, Toronto.
Appendix B: Relevant Definitions Used in the Papers and Summaries

Housing
Canada Mortgage and Housing Corporation (CMHC) uses the term ‘core need’ to track the number of households unable to access adequate rental accommodation in their community. The term measures affordability, suitability of accommodation and adequacy (Layton, 2000).

Early Childhood Education and Care
Early childhood education and care” (ECEC) describes an integrated, multifunctional approach to policies and services that is inclusive of all children and parents, regardless of employment or socioeconomic status. In Canada, this definition encompasses child care centres and other regulated care services — such as family child care in private homes — whose primary focus is to allow mothers to participate in the paid labour force. It also includes kindergartens, nursery schools and preschools, whose primary purpose is early childhood education (Friendly, 2002).

Employment Security and Insecurity
Employment or job insecurity is largely subjective—something an individual feels, given his or her personal job situation, perception of risk and the overall economic situation. The validity and relevance of traditional objective measures of employment security is sometimes questionable in today’s knowledge economy and changed labour market. For example, the unemployment rate no longer offers a correct measurement of the true supply of labour or insecurity because it fails to take into account the new diversity of employment status (casual, temporary, reduced-time, part-time, etc.) and other factors such as caregiving (Tremblay, 2002).

Food Insecurity
In developed societies, food insecurity is defined as “the inability to acquire or consume an adequate diet quality or sufficient quantity of food in socially acceptable ways, or the uncertainty that one will be able to do so” (Davis and Tarasuk, 1994). Food insecurity includes problems in obtaining nutritionally adequate and safe foods due to a lack of money to purchase them, or the limited availability of these foods in geographically isolated communities (Campbell, 1991).

Social Economy
In Quebec, the term “social economy” is widely used and refers to a vast array of groups, mostly non-profit organizations including advocacy groups, voluntary organizations and other community-based organizations, including cooperatives. The term is not widely used in English Canada but is most close to the term “voluntary and community sector” (which includes organizations dealing with both voluntary and paid work) The mission of these organizations is to provide empowering services to members and community and not profit-oriented (Vaillancourt, Aubrey, Tremblay and Kearney, 2002).

Social Exclusion
Social exclusion describes the structures and dynamic processes of inequality among groups in society. In the Canadian context, social exclusion refers to the inability of certain groups or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political and cultural resources. These inequalities arise out of oppression related to race, class, gender, disability, sexual orientation, immigrant status and religion.
Working Conditions

Jackson (2002) has identified the following working conditions have been identified as central to whether a job is healthy or not:

- job and employment security
- physical conditions at work
- work pace, control and stress
- working time (number of hours)
- opportunities for self-expression and individual development at work
- participation and relationships at work

work-life balance.
Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions

Report prepared by: Peggy Proctor
May 2002

Project undertaken by: Canadian Working Group on HIV and Rehabilitation (CWGHR)

With financial support from: Office for Disability Issues, Human Resources Development Canada (HRDC)
TABLE OF CONTENTS

EXECUTIVE SUMMARY

INTRODUCTION ................................. 1

PROJECT DESCRIPTION .......................... 2
  Terminology .................................. 2
  Objectives .................................. 3
  Method ..................................... 3
  Participants ................................ 3

PHASE I: KEY INFORMANT INTERVIEWS ..................... 4

PHASE II: ONE-DAY CROSS-DISABILITY FORUM ........... 5
  Suggested Actions ......................... 9
  Evaluation of Forum by Participants ........ 10

EMERGING THEMES ................................ 10

PROJECT ANALYSIS ............................... 12

PHASE III: MEETING WITH DR. CAROLYN BENNETT ........ 14

LOOKING BEYOND THE SILO ................................ 15

APPENDICES

APPENDIX A: CWGHR Environmental Scan Findings (2001)

APPENDIX B: List of Key Informants / Interview Discussion Template

APPENDIX C: “Success Story” Examples

APPENDIX D: List of Invited Participants
Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions

EXECUTIVE SUMMARY

DESIRED OUTCOMES: The CWGHR Cross Disability Project was designed to bring people together to define some common ‘disability’ and ‘rehabilitation’ issues among people living with lifelong episodic conditions. The intent was to initiate dialogue among various Canadian disability groups and to explore the concept of future cross disability partnerships between organizations. Discussion with federal policy makers regarding the unique concerns of people living with episodic illness was also articulated as a desired outcome.

PROCESS: The research question emerged from an environmental scan involving a literature review and key informant interviews to determine emerging issues/gaps in knowledge of rehabilitation in the context of HIV. A multi-sectoral advisory team including people living with HIV, government, health care and academia guided the research. The timeframe for the project was November 1, 2001 – March 30, 2002, and was composed of three major components. Phase one involved interviews with non-HIV groups dealing with lifelong episodic illness/disability to identify areas of mutual concern. Phase two involved a national consultation with several key organizations to explore shared program/policy issues and potential collaboration. Phase three involved a face-to-face meeting with the Chair of the Sub-committee on the Status of Persons with Disabilities (Government of Canada) regarding cross disability concerns.

GUEST LIST: The following organizations participated in the project: Canadian AIDS Society / Canadian Physiotherapy Association / Multiple Sclerosis Society of Canada / Canadian Breast Cancer Foundation / Canadian Psychiatric Association / Canadian Mental Health Association / Canadian Association of Occupational Therapists / Canadian Diabetes Association / College of Family Physicians of Canada / Canadian Psychological Association / Canadian Centre on Disability Studies / Reach Nova Scotia Association / CWGHR.

EMERGING THEMES: There were a number of themes identified by participants in the key informant interviews and in the one-day forum including: the need develop new definitions pertaining to ‘disability’ and ‘rehabilitation’; concerns regarding provision of care, treatment and support for individuals living with episodic illness; workplace accommodation and employment; income security and support; legislation and policy; stigma and prejudice; and need for education at many levels regarding episodic illness. These themes were shared in a follow-up meeting with Dr. Carolyn Bennett, MP, Chair of the Sub-committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities.

FUTURE DIRECTIONS: Many organizations expressed their commitment to continue collaboration on cross disability issues, and project participants generated several ideas for possible next steps.

May 31, 2002
The Canadian Working Group on HIV and Rehabilitation (CWGHR) gratefully acknowledges the following people and organizations for their support of, and contributions to, this project:

- Office for Disability Issues, Human Resources Development Canada, for their generous financial support
- Peggy Proctor, Cross Disability Project Coordinator, for her energy, expertise, time and commitment to the project
- Nancy Lawand, Tom McAulay, Stephanie Nixon, and Elisse Zack, members of the Cross Disability Project Advisory Committee, for their time and leadership in overseeing development of the project
- Dr. Carolyn Bennett, Member of Parliament, Government of Canada, for her willingness to meet and work with CWGHR on issues pertaining to lifelong episodic disability
- All the individuals and organizations mentioned in this report, who contributed to the project by sharing their time, energy and expertise in both the key informant interviews and the one-day cross disability forum
- Peter Crighton, for his administrative support throughout

Thank You
The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sectoral and multi-disciplinary working group. CWGHR was formed in 1998 with a mission to enhance the quality of life for Canadians living with HIV disease by facilitating the development of rehabilitation programs and resources, promoting innovation and excellence in the field and by generating awareness of, and access to, rehabilitation services. The mandate of CWGHR includes two roles: a development and advisory role, and a project and research funding role.

CWGHR members include: people living with HIV disease; community based HIV organizations; national professional organizations working with HIV and rehabilitation; relevant divisions of government; and private sector organizations and businesses.

INTRODUCTION

Health care providers, institutions, and organizations often separate different disease groups into distinct “silos” (e.g., Multiple Sclerosis Society, Cancer Society, Arthritis Society, Canadian AIDS Society, etc.) and these groups tend to operate autonomously, despite overlapping experience and many shared concerns.

As HIV disease has evolved into a more chronic and medically manageable condition, CWGHR has had a growing sense that collaboration with other disability groups would be both informative and beneficial. It was felt that other “consumer” and “provider” groups with experience in episodic illness might make effective partners in the effort to affect change.

CWGHR conceived of a cross disability project that would engage various disability groups and service providers in a discussion of commonalities between their “silos” and allow groups to explore possible collaborative work. There was also the intent to meet with policy makers to share collective concerns pertaining to episodic illness, as part of the project.
PROJECT DESCRIPTION

As part of a larger CWGHR project funded by the Office for Disability Issues (ODI) through Human Resources Development Canada (HRDC), a parcel of funding was devoted to “targeted research.” The focus for this research was determined by an environmental scan of current and emerging issues in rehabilitation in the context of HIV disease, completed by CWGHR in October 2001 (see Appendix A: Environmental Scan Findings).

The proposal for a specific Cross Disability Project was approved by CWGHR in October 2001.

The timeframe for the project was established as November 1, 2001 – March 31, 2002.

The purpose of the Cross Disability Project was to explore issues of similarity between people living with HIV related disability and people living with other chronic, episodic and unpredictable illness and/or disability.

A Cross Disability Project Advisory committee was formed to oversee and guide the research and was comprised of the following members:
- Stephanie Nixon; CWGHR Co-Chair
- Nancy Lawand; Director, CPP Program Direction (HRDC) and CWGHR member
- Tom McAulay; British Columbia Persons with AIDS Society, CWGHR member, and person living with HIV disease
- Elisse Zack; Executive Director, CWGHR

A project consultant, Peggy Proctor, was retained to coordinate the project under the direction of the Project Advisory Committee.

Terminology

The Advisory Group began the project using the descriptors “chronic, episodic and cyclical” to describe the illness or disease specific groups being invited to participate in the project.

During the course of the project, direction by participants led to a change in the use of the descriptors “chronic, episodic and cyclical” to “lifelong and episodic” illness.

There was a feeling that the word “cyclical” was misleading (and should be omitted) because it implied some sort of predictability or rhythm to the disease.
In fact, living with an episodic illness is an extremely UNPREDICTABLE experience, which participants felt should be reflected in the terminology.

**Objectives**
The CWGHR Cross Disability Project was designed to bring people together to define common ‘disability’ and ‘rehabilitation’ issues among people living with episodic conditions. There was a strong desire to initiate dialogue among various Canadian disability groups, and to explore the concept of future cross disability partnerships between organizations. Discussion with federal policy makers regarding the unique concerns of people living with episodic illness was also articulated as a desired outcome.

**Method**
The research question emerged from the environmental scan undertaken by CWGHR (see Appendix A) that identified emerging issues/gaps in knowledge of rehabilitation in the context of HIV. The project was organized into three phases:

- **Phase One** involved key informant interviews with primarily non-HIV groups dealing with lifelong episodic illness/disability to identify areas of mutual concern. These non-HIV groups were selected by brainstorming and discussion among Advisory Group members to identify a cross-section of “consumer” and “provider” groups that may be dealing with similar issues in terms of episodic and unpredictable illness.
- **Phase Two** involved a national one-day forum with invited key organizations to explore shared program/policy issues and potential collaborations.
- **Phase Three** involved a meeting with the Chair of the Sub-committee on the Status of Persons with Disabilities (Government of Canada) regarding cross disability concerns.

**Participants**
Ten (10) key informants were interviewed in Phase One including representatives from: The Canadian Psychological Association; Canadian Association of Occupational Therapists; Multiple Sclerosis Society; Reach Nova Scotia; Canadian AIDS Society; Canadian Mental Health Association; Canadian Psychiatric Association; College of Family Physicians of Canada; Canadian Breast Cancer Foundation; and the Canadian Centre on Disability Studies.

Thirteen (13) invited participants attended the one-day forum including representatives from: The Canadian Psychological Association; Canadian Association of Occupational Therapists; Multiple Sclerosis Society; Reach Nova Scotia; Canadian AIDS Society; Canadian Mental Health Association; Canadian Psychiatric Association; College of Family Physicians of Canada; Canadian Breast Cancer Foundation; Canadian Centre on Disability Studies; Canadian Physiotherapy Association; Canadian Diabetes Association; and CWGHR.
Many other invited organizations sent their regrets, and asked to receive copies of the final project report. A full list of invited participants (with contact information) is included in Appendix D.

PHASE I: KEY INFORMANT INTERVIEWS

Key informant interviews were conducted by telephone with representatives of various national organizations. A table containing the names of individuals interviewed and a copy of the interview discussion template can be found in Appendix B. Informants were asked to explain the terms ‘disability’ and ‘rehabilitation’ in the context of people living with various episodic conditions and to identify key issues/concerns/gaps or barriers in regards to same. Informants were also asked to share “success stories” in terms of projects, partnerships or initiatives on behalf of their organizations. A list of “success story” examples can be found in Appendix C.

Major themes emerging from the key informant interviews included:

I a) **Definitions:** Many groups do not use the words ‘disability’ or ‘rehabilitation’ in their lexicon. For example, a woman with breast cancer would likely not consider herself as having a “disability”; likewise a person struggling with mental illness may not view appropriate care and services as “rehabilitation”. The word “disability” tends to imply permanent physical disability to most people, while the word “rehabilitation” tends to imply a one-time intensive treatment and recovery that is time-limited (for example, cardiac rehabilitation following a heart attack or physical rehabilitation following a spinal cord injury).

All informants stressed the need for new definitions pertaining to lifelong, episodic illness. For example, many conventional medical and insurance policy definitions do not “fit” the unique reality of living with episodic illness. Criteria for access to services, programs and support are often worded and interpreted with “permanent” disability as the standard.

I b) **Access to Care:** All key informants raised critical issues relating to recognition of the unique needs of people living with lifelong episodic illness and the need to meet those needs with appropriate service and care. The need for national standards of care was emphasized, and the disparity across Canada in regards to programs and services was often mentioned. The issue of drugs and drug costs due to new and emerging drug therapies was also raised as a common concern.

I c) **Workplace Issues:** Common themes pertaining to the right to meaningful employment and the need for flexible workplace policies and duty to
accommodate were consistently articulated. For example, a worker may be well for six months, then unwell for a period of time, then return to work, then need surgery and a regime of treatment, then feel well again, etc. The unpredictable health status of the worker poses a unique set of challenges for both employer and employee.

I d) **Income Security:** There appears to be a shared frustration with public and private insurance programs/policies that make it very difficult for people to qualify for benefits while entering and re-entering the workforce. Policies are rigid and unresponsive to the unique and ever changing circumstances of people living with episodic illness. People voiced the need for income protection that will carry them through periods of being well/unwell, working/not working, and part-time work. Most disability insurance policies and benefits do not make allowances for variable work patterns.

I e) **Need for “Barrier Free” Legislation:** Many informants raised a concern regarding lack of policy development in ensuring barrier free access to Canadians. The ‘Americans with Disabilities Act’ was mentioned as an effective piece of legislation that Canada should consider as a model. This is an example of policy that mandates the removal of barriers for people living with disabilities.

I f) **Stigma and Prejudice:** There was a sense that people living with mental illness often face debilitating stigma and prejudice that are similar to persons living with HIV disease. Stigma and prejudice are huge barriers that limit human potential. Many people with episodic illness attempt to “hide” their condition due to the stigma involved in disclosing it, and struggle to maintain their “healthy person” image at all costs, despite the up and down nature of their health status.

**PHASE II: ONE-DAY CROSS DISABILITY FORUM**

The one-day forum was held Monday, February 11, 2002, in Toronto. Of those invited, there were twelve participants in attendance, along with three CWGHR members, the executive director of CWGHR, and the project consultant. The participant list with contact information can be found in Appendix D.

The one-day forum provided an opportunity to discuss issues related to ‘disability’ and ‘rehabilitation’ for people living with lifelong, episodic and unpredictable conditions. An interactive approach was used to facilitate dialogue and idea sharing.
The morning session involved asking participants to identify the barriers (boulders) and facilitators (canoes) in the Canadian environment (the river) affecting the ability of people living with episodic illness to reach their potential. The group identified a wide assortment of issues, many of which were “big picture” issues relating to health and social service policy and delivery.

The early afternoon session was designed to have participants respond to the following question:

“What are specific issues that are UNIQUE to living with a lifelong episodic condition?”

The themes which emerged over the course of the day included: the need for common definitions; concerns regarding care, services and support; workplace accommodation and employment issues; income support and insurance issues; and, policy implications.

II a) **Definitions of ‘Disability’:** Current definitions tend to be based on “continuous disability” versus “episodic disability” and often have an inherent bias toward “physical disability.” Definitions used in legislation and policy are sometimes written and/or interpreted differently by various government departments. Terms and definitions used by medical and rehabilitation providers are sometimes different from definitions used by insurance providers or government benefit programs.

A ‘Federal Definitions Project’ is soon to be initiated across several federal government departments, and it was suggested that some cross disability advocacy on behalf of those living with episodic illness would be timely and appropriate, in terms of providing input.

II b) **Care, Treatment, and Support Services:** The health care system and service providers are often not well equipped to handle the unique and complex needs of people living with lifelong episodic illness. There is a need for integrated interdisciplinary care and services delivered in a community context. A concern was voiced regarding disparate access to care and services in various geographical regions across Canada, and between rural and urban settings.

Individuals living with episodic and unpredictable illness face a unique set of challenges in regards to their everyday life. The analogy of a “roller-coaster” was used – that is, one never knows what is coming around the next bend. The personal identity and body image of the person is often shifting (well vs. unwell) and this is very hard on self-esteem and concept
of self. Life goals are difficult (or impossible) to set, and a sense of failure often ensues. Depression was mentioned as common to the experience of living with lifelong episodic illness.

Although the importance of “support systems” is well recognized in the management of chronic illness, this also poses difficulties in the context of episodic disability, where the need for more or less support is often unknown, unpredictable and ever changing. In the words of one participant, “It’s the difference between knowing you’re on a roller coaster and cannot see what’s around the corner vs. not seeing that next week you’re going to be on a different roller coaster altogether.”

“The day-to-day management is tough – with no predictability. Each day can be a totally different experience. It is very difficult to make any plans.”

Kris McDonald
person living with MS
Multiple Sclerosis Society

Furthermore, basic determinants of health such as nutrition, poverty and homelessness must be considered -- these issues were raised repeatedly, especially by those participants representing mental health related organizations around the table.

II c) Workplace Accommodation / Employment Issues: Flexibility is very important in regards to workplace environment and accommodation. Policies to support part-time work and flextime for workers with health issues are seen as critical. There is a need for employer associations, insurance industry representatives, governments, unions, and disability organizations to come together and explore/encourage means of accommodation for the unique health needs of workers living with episodic illness.

“Our society is now working around the clock -- 24/7/365 -- 24 hours/day, 7 days/week, 365 days/year – it’s hard to work or go to school without committing to it everyday.”

Tom McAulay
person living with HIV
II d) Income Support and Security: The long-term economic forecast for many people living with lifelong episodic illness is bleak. The phrase ‘income security’ implies a reliable and predictable source of income. While income support and security is a concern among all people with disabilities, the unpredictable nature of episodic illness poses unique challenges in terms maintaining a steady income. If your main source of income is a disability pension (tied directly to your health status) and your health status is changing frequently due to the nature of your condition, then income security is tenuous, at best. Disability benefits may be “cut off” during periods of improved health status, and then be difficult to reinstate later, when your health status takes a turn for the worse. There is an acknowledged need for integrated health and social policy and service provision relating to income support.

A number of issues pertaining to long-term disability insurance arise as people with chronic and unpredictable conditions seek financial support from insurance plans, in both the public and private sectors. There is a complex ethical dilemma regarding disclosure of health information, and an agreement that the system itself often provides disincentives to return to work (ie. danger of loss of benefits if you return to work, with no means to re-access benefits if the return to work is not permanent). A common fear was expressed as, “I’m feeling fine now, but I am afraid of what might happen if I go back to work and then I get sick again.”

The claims process is very complicated and laborious and there is consensus that it needs simplification. If a claimant’s health status is changing frequently (unwell/very unwell/now feeling better) ‘new’ forms must be constantly filed to reflect changes in health status. There is a requirement to continually prove (or re-prove) your illness. This becomes unwieldy not only for the individual, but also his/her health care provider(s), especially the family physician, who often functions as ‘gatekeeper’ for both the public and private sector insurance providers.

“My patient is feeling better right now, and would like to return to work… If he does return, however, he will be cut off from his long-term disability benefits. [Consequently] he has decided not to return to work because the fear is too great… I think return to work would help his self-esteem – he has suffered from depression – if going back to work doesn’t work out, there’s a real sense of failure.”

Dr. David W. Grossman
College of Family Physicians of Canada
There is also a perceived lack of understanding on the part of many government assistance assessors and private insurance claim adjudicators in regards to the unique circumstances of claimants living with episodic illness.

II e) Legislation and Policy
There was acknowledgement of the need for barrier free legislation and an enabling environment for people living with the unique challenges of an episodic illness. Human rights legislation was also seen as an important vehicle for affecting and enforcing change.

II f) Education
The theme of education came up repeatedly throughout the day, including the need for greater awareness at many levels: the person living with the illness; the caregiver(s) and family of the person; healthcare providers; employers; insurance companies and funders; and, policy makers at various levels of government, etc. regarding the unique needs of people living with episodic, unpredictable illness and disability.

Suggested Actions
The closing session of the forum was used by participants to brainstorm the following possible next steps:

1. Articulate why lifelong episodic illness is unique or different from other chronic illness/disability.

2. Undertake shared work on developing useful common definitions.

3. Define similarities pertaining to long-term episodic illness among disability groups and define common goals re: policy, research and programming.

4. Create flexible alliances to address public education, public action, and support.

5. Explore organizational support for ongoing collaboration.

6. Investigate funding sources to support collaborative work in regards to episodic disability issues.

7. Encourage an environmental scan re: programs and strategies (Canada and abroad) that address long term, episodic illness in an integrated manner.

8. Encourage research re: early intervention and relapse prevention.
9. Encourage research on the economic benefit of best practices (i.e. cost savings of effective management of episodic illness).

10. Encourage a comprehensive review of existing studies pertaining to labour force involvement of people living with episodic illness/disability.

11. Advance the agenda on workplace accommodation/workforce involvement

12. Advocate for change with insurance providers (public and private) regarding current claim management and criteria. Re-establish a formal means of communication with the “Disability Insurance Committee” of the Canadian Life and Health Insurance Association (CLHIA).

13. Consider forming a national consumer-provider task force to address insurance policy issues.

**Evaluation of the One-Day Forum by Participants**
The general response of participants was very favorable, with a sense that the project was effective as a first step in exploring issues common to people living with lifelong and episodic illness. There was unanimous agreement that future cross disability work of this nature should continue.

“We got further into complex issues than I thought possible… a good start…”

*Rick Kennedy
Canadian Mental Health Association*

Those organizations that were unable to participate requested copies of the final project report, and have asked to be included in future cross disability initiatives.

**EMERGING THEMES**

Through Phase One and Phase Two of the project, participants identified many common issues:

a) Definitions  

b) Care, Treatment, and Support  

c) Workplace Issues  

d) Income Security and Support  

e) Legislation and Policy  

f) Stigma and Prejudice  

g) Education
These emerging themes present a complex array of issues for analysis. When asked to define ‘disability’ and ‘rehabilitation’ in the context of their experience, participants consistently identified both broad, general disability issues as well as specific issues unique to episodic illness.

The broad, general disability issues seemed too general and overarching in scope to consider within the confines of this project, and yet participants continued to identify these “big” issues as important to the well being of people living with episodic illness.

On the other hand, “specific issues unique to episodic illness” were difficult to explore in great depth, perhaps due to the wide range and diversity of participants, but also in part because the big general issues consistently emerged in discussion.

As the Cross Disability Project Advisory Committee analyzed and discussed the project outcomes, an Advisory committee member living with episodic illness offered the following perspective:

“... for most people living with episodic illness, the big general issues are their day to day struggles, [and] these are the people that the service providers (ie. participants at the forum) are dealing with – so it follows that these big issues are, in a sense, the “episodic” issues that they know and have experience to talk about.

Until the big general issues are dealt with it will always be a struggle to [neatly define those issues “specific” to episodic illness]. To use an HIV analogy: in Africa, it is difficult to think about prescription meds when clean drinking water, food and decent shelter are daily struggles – or closer to home, for the HIV+ drug addict in Vancouver’s downtown eastside, HIV is far down on their list of health concerns coming after such things as food, shelter, drugs, drug rehab, dental destruction, social alienation, ongoing abuse since childhood, fear for their lives including thefts, and so on and on.

I think we are doing a disservice if we take the attitude that because these “big general issues” are either too big to deal with or too common to everyone that they don’t have a place in the discussion on what is unique about the episodic lifelong condition(s).

I’d like to turn this around and look at it another way – that is, how does someone with an episodic illness cope with or manage the day to day big general issues that is [different or] unique from other people living with illness facing these same struggles? Is it that one day you can walk up your 2 flights of stairs to your apartment and the next day you can’t, but there is no one there to carry you up because you didn’t see this coming around the corner and have the help you require arranged? Is it that for the last 16 months your welfare benefits cover

Looking Beyond the Silo

Page 11
your monthly living expenses (just barely I might add) but this month an unforeseen illness forced you to go buy over the counter medications and completely wiped out your food budget 9 days into the month? And so on…”

Tom McAulay
person living with HIV
CWGHR member
Cross Disability Project Advisory Committee member

PROJECT ANALYSIS

In analysis of the Cross Disability Project data, a conceptual model was developed to illustrate the wide array of issues identified throughout the project. See Figure 1.0.

The first circle (lower left) represents those issues pertaining to people living with disabilities that are “permanent” in nature. That is, they are lifelong and relatively consistent, such as cerebral palsy, spinal cord injury, etc., and include invisible disabilities such as cognitive impairment, learning disabilities, etc. Examples of important issues in this circle include: barrier free legislation; employment and education equity; income security; assistive devices; long term care and support; independent living; barrier free access, etc.

The second circle (lower right) represents those issues pertaining to people living with “episodic” illness or disabilities such as multiple sclerosis, cancer, mental illness, arthritis, fibromyalgia, etc. Examples of important issues in this circle include: being well/unwell; able to work/not work/part-time work; unpredictable nature of the condition; specific insurance issues; changing vocational rehabilitation needs; exorbitant drug costs due to new research, etc.

The area of overlap between the “permanent” and “episodic” circles (a) represents common issues relevant to both groups – as well as demonstrating the concept that many people live in the overlapping zone of both circles – for example, the person with diabetes (“episodic”) who has had a foot amputated (“permanent”), or the person with bipolar disorder (“episodic”) who has limited mobility due to osteoarthritis (“permanent”).

The third circle represents the Canadian Working Group on HIV and Rehabilitation and represents all issues pertaining to HIV and rehabilitation. This circle overlaps with both the other circles, indicating that people living with HIV share many common concerns with both the “permanent” (b) and “episodic” (c) disability groups.

The dark shaded area of overlap between the three circles (all) represents those issues affecting the lives of people in all three circles. These are often overarching general issues such as: care and treatment, effects of health care
Figure 1.0  Conceptual Model of Cross Disability Issues

CWGHR
HIV & Rehab

Permanent Disability
- Blindness
- Cerebral Palsy
- Down’s Syndrome
- Stroke
- Spinal Cord Injury
- Amputation
- Traumatic Brain Injury
- Invisible

Episodic Disability
- Multiple Sclerosis
- Cancer
- Mental Illness
- Crohn’s & Colitis
- Arthritis
- Diabetes
- Fibromyalgia
- Cystic Fibrosis
reform, availability of health care providers, social determinants of health, national standards of care, social justice, human rights, palliative care, “disability” definitions, etc.

This conceptual model can be used to guide future cross disability work by providing a framework for conceptualizing the issues faced by people living with disabilities, including people living with HIV. As such, this model may be used as a tool to help identify potential partners for collaboration on certain issues.

**PHASE III: MEETING WITH DR. CAROLYN BENNETT**

The initial work plan of the project included meeting with politicians/policy makers to discuss cross disability issues defined in Phases I and II of the project. As the project unfolded, it became clear that the most effective option available was to meet with Dr. Carolyn Bennett, Member of Parliament, and Chair of the Sub-Committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, Government of Canada.

A meeting was held between the CWGHR Project Advisory Group and Dr. Carolyn Bennett on Tuesday, February 12, 2002, in Toronto.

Those in attendance included:
- Dr. Carolyn Bennett, M.P., Government of Canada
- Stephanie Nixon, Co-Chair, CWGHR
- Tom McAulay, CWGHR member
- Elisse Zack, Executive Director, CWGHR
- Peggy Proctor, CWGHR Cross Disability Project Coordinator
- Peter Crighton, CWGHR staff

The purpose of the meeting was to discuss common themes pertaining to lifelong episodic illness arising from the CWGHR Cross Disability Project. It was also hoped that Dr. Bennett might suggest strategies in regards to affecting systemic change on pertinent issues.

Dr. Bennett was very receptive to discussion of the Cross Disability Project and encouraged future collaboration between disability groups on common issues. She appeared well aware of several of our concerns in regards to disability pensions and insurance company policies. She emphatically stated that certain insurance policies and practices must be addressed, and that she is a firm proponent of “citizen engagement” in terms of stakeholder consultation in important policy discussions.
She suggested ways CWGHR might collaborate with other groups to identify problems and propose changes. She encouraged disability groups to support the proposed “Social Union Framework” currently being discussed in government circles. She also suggested that disability groups be prepared to speak before parliamentary committees using compelling real life stories that illustrate significant problems with existing policy on various issues.

The CPP tribunal will soon be seeking input under the direction of Commissioner Peter Smith, and this would also be an appropriate place to present a collective case.

An interactive website will soon be up and running to facilitate electronic consultation on behalf of the Sub-Committee on the Status of Persons with Disabilities. Dr. Bennett encouraged feedback via the website from CWGHR and other cross disability project partners.

Dr. Bennett congratulated CWGHR on their initiative in undertaking this collaborative project, and encouraged future cross disability work.

LOOKING BEYOND THE SILO

This project provides an important foundation for exploring cross disability issues pertaining to lifelong episodic illness. There has been expressed commitment from a number of organizations to participate in future collaborative work, and this bodes well for future endeavors.

A line of communication has been opened with Dr. Carolyn Bennett, Chair of the Sub-Committee on Persons with Disabilities, which could develop into a very productive and effective relationship in terms of policy discussion on cross disability issues. Further meetings and communications with policy makers from various levels of and departments in government will also enhance the ability to affect change on policy issues.

The key to successful future collaborative work will be the ability to identify and attract the right people from the right organizations at the right time to tackle various issues. This process will take time, and a concerted effort at building relationships among key groups. CWGHR is well positioned to assume a leadership role in future work, given the multi-sectoral and multi-disciplinary nature of the organization.

Community based organizations, governments and people dealing with specific illnesses tend to work within their silos, often unaware of similar work going on in many other silos. The challenge is to know when to pause, step outside your own silo, and join with other silo folk to form some new work crews.
## Interview Schedule

Note: All interviews were conducted by Peggy Proctor, Project Coordinator

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Date of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gerard Yetman</td>
<td>Canadian AIDS Society</td>
<td>January 23, 2002</td>
</tr>
<tr>
<td>Kris McDonald</td>
<td>Multiple Sclerosis Society of Canada</td>
<td>January 30, 2002</td>
</tr>
<tr>
<td>Beth Easton</td>
<td>Canadian Breast Cancer Foundation</td>
<td>February 7, 2002</td>
</tr>
<tr>
<td>Francine Knoops</td>
<td>Canadian Psychiatric Association</td>
<td>February 4, 2002</td>
</tr>
<tr>
<td>Rick Kennedy</td>
<td>Canadian Mental Health Association</td>
<td>February 2, 2002</td>
</tr>
<tr>
<td>Donna Klaiman</td>
<td>Canadian Association of Occupational Therapists</td>
<td>January 31, 2002</td>
</tr>
<tr>
<td>Dr. David Grossman</td>
<td>College of Family Physicians of Canada</td>
<td>February 4, 2002</td>
</tr>
<tr>
<td>Sean B. Rourke</td>
<td>Canadian Psychological Association</td>
<td>January 31, 2002</td>
</tr>
<tr>
<td>Dr. Carole Miles</td>
<td>Centre on Disability Studies</td>
<td>February 7, 2002</td>
</tr>
<tr>
<td>Tova Sherman</td>
<td>Reach Nova Scotia Association</td>
<td>January 25, 2002</td>
</tr>
</tbody>
</table>
CWGHR CROSS DISABILITY PROJECT

Key Questions / Discussion Template for Interviews

I. Desired Outcomes of the Project:
1. To initiate dialogue among Canadian disability groups – particularly groups representing individuals living with conditions that are chronic, episodic and cyclical in nature.
2. To define some common “disability and rehabilitation” issues among people living with conditions which are chronic, episodic and cyclical in nature.
3. To explore the concept of cross-disability partnerships and/or future collaboration.

II. Objectives:
1. To host a successful one-day forum which facilitates dialogue:
   - Amongst groups representing individuals living with conditions that are chronic, episodic and cyclical in nature (including a cross-section of consumer-based and provider-based groups)
   - Between the aforementioned groups and funders / policy makers
2. To share information regarding program and policy issues affecting people living with conditions that are chronic, episodic and cyclical in nature.
3. To develop an awareness of the potential for influencing cross-disability policy and programming decisions in both the public and private spheres.
4. To facilitate potential partnerships and/or potential collaborative work.

THE INTERVIEW QUESTIONS:

1. What do the terms “Disability” and “Rehabilitation” mean in the context of people living with

2. What are the key issues / concerns / gaps / barriers in terms of “disability” and “rehabilitation” from the perspective of the people you work with?

3. Are there examples of programs &/or initiatives that are “working well” (or have worked well) for your organization / stakeholders?

4. Are there examples of projects you can think of demonstrating effective collaborative work (past or present) intended to influence program or policy change?

5. We are interested in exploring how various groups go about building community capacity at the grassroots level… How have
you engaged or encouraged community response to important issues in your organization? What do you see as key to getting people actively involved?

6. Would you like to suggest anyone else (individual or group) that could / would make a significant contribution to this type of gathering gathering?

7. Thank you for accepting our invitation to attend the one-day forum:
   • What do you hope to get out of the gathering?
   • What do you hope to share with others during the gathering?

8. We are in the process of panning the day… Do you have any suggestions regarding any particular format for the day (for example: free-flowing discussion, lecture, small groups, etc.)

9. Do you have any other comments or suggestions?

Thank you for your kind time and attention!

Peggy Proctor
Phone (306) 966-6574
Fax: (306) 966-6575
Email: Peggy.Proctor@usask.ca
## “Success Story” Examples from Key Informant Interviews

<table>
<thead>
<tr>
<th>NAME</th>
<th>EXAMPLES</th>
</tr>
</thead>
</table>
| Gerard Yetman  
Canadian AIDS Society | - Collaborative work between CAS and the Hemophilia Society of Canada in the blood transmission era  
- Response of CAS and HSC to “hot issues” in the blood handling and tracking system  
- Legal and justice agenda was promoted with the Keever commission due to collaborative efforts of so many people  
- End result was a new blood handling system in Canada  
- Another examples is CAS work with curriculum development for Schools of Social Work across Canada and the Canadian Social Work Association |
| Kris McDonald  
Multiple Sclerosis Society of Canada | - Ontarians with Disabilities Act – legislation passed in 2001 with the MS society working on that campaign  
- The MS Society Committee for Social Action do advocacy and lobby work |
| Francine Knoops  
Canadian Psychiatric Association | - Canadian Alliance on Mental Health and Mental Illness serves as a consensus body for advocacy and has issued a joint policy paper “Call for Action”  
- Is intended to be inclusive of all mental health stakeholders |
| Rick Kennedy  
Canadian Mental Health Association | - Support for students with psychiatric disabilities in post-secondary education – raising awareness that not all disabilities are physical – students need special accommodation(s) in order to be successful at university  
- ‘Roots for Real Work’ project that involves return to meaningful employment for people living with mental illness  
- ‘Inclusion in Community’ project that encourages people living with mental illness to go out and serve on various Boards of Directors (ie. YMCA, etc.) in their communities  
- Canadian Alliance on Mental Illness and Mental Health (CAMIMH) which encompasses professional, consumer, family and community perspectives  
- Collaboration with Dietitians of Canada on S.A.D. |
<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Contributions</th>
</tr>
</thead>
</table>
| Donna Klaiman                             | Canadian Association of Occupational Therapists  | - Quebec CLSC Model – multidisciplinary team approach  
|                                           |                                                  | - LCOA Active Living Coalition – the Diabetes Project (Health Canada) re: risks of Diabetes  
|                                           |                                                  | - CAOT soon to conduct a national forum with Canada Mortgage and Housing to look at issues of barrier free design in housing  
|                                           |                                                  | - HRDC sector study on home care – CAOT and Home Care Association lobbying that respite care be recognized as part of the continuum of home care  |
| Dr. David W. Grossman                     | College of Family Physicians of Canada           | - Community Advisory Panels at St. Michael's Hospital provide a “community forum” to advise the hospital  
|                                           |                                                  | - The clinic he works in operates as a large multidisciplinary team, with an effective team approach to care  |
| Sean B. Rourke                            | Canadian Psychological Association               | - Current research he is involved in a controlled trial doing “rehab” with people suffering cognitive impairment and seeing positive results  |
| Dr. Carole Miles                          | Centre on Disability Studies                     | - The concept of “self-managed care” in the context of home care services within the public health care system in the province of Manitoba  |
| Tova Sherman                              | Reach Nova Scotia Association (Access to Justice for Nova Scotians with Disabilities) | - The 9 / 4 Program, which promotes employment opportunities for people living with disabilities |
### CWGHR CROSS DISABILITY PROJECT  
February 2002

#### INVITED PARTICIPANT LIST

<table>
<thead>
<tr>
<th>NAME</th>
<th>ORGANIZATION</th>
<th>CONTACT INFORMATION</th>
</tr>
</thead>
</table>
| Gerard Yetman       | Canadian AIDS Society               | Gerard Yetman, Manager  
National Programs  
Canadian AIDS Society  
Phone: 1-800-884-1058 (x 121)  
Fax: 613-563-4998  
Email: gerardy@cdnaids.ca |
| Pamela C. Fralick   | Canadian Physiotherapy Association  | Pamela C. Fralick  
Chief Executive Officer  
Canadian Physiotherapy Association  
2345 Yonge St., Suite 410  
Toronto, ON M4P 2E5  
T: (416) 932-1888 (x 14)  
1-800-387-8679  
Fax: (416) 932-9708  
Email: pfralick@physiotherapy.ca  
http://www.physiotherapy.ca |
| Kris McDonald       | Multiple Sclerosis Society of Canada (representative) | Kris McDonald  
Disability Consultant  
3231 Eglinton Avenue East, Suite 704  
Scarborough ON M1J 3N5  
Phone: 416-264-0626  
Fax: 416-264-4886  
e-mail: krisal@axxent.ca  
Deanna Groetzinger  
Senior Communications Officer  
MS Society of Canada  
250 Bloor Street East, Suite 1000  
Toronto ON M4W 3P9  
Tel: (416) 922-6065  
Fax: (416) 922-7538  
Email: deanna.groetzinger@mssociety.ca |
<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mara Koven</td>
<td>Canadian Breast Cancer Foundation</td>
<td>National Special Projects Manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Canadian Breast Cancer Foundation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>790 Bay Street</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Suite 1000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Toronto, ON M5G 1N8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T: (416) 596-6773 X325</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:mkoven@cbcf.org">mkoven@cbcf.org</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="http://www.cbcf.org">www.cbcf.org</a></td>
</tr>
<tr>
<td>Francine Knoops</td>
<td>Canadian Psychiatric Association</td>
<td>Director, Professional Affairs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Canadian Psychiatric Association</td>
</tr>
<tr>
<td></td>
<td></td>
<td>441 MacLaren #260</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ottawa ON K2P  2H3</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:fknoops@cpa-apc.org">fknoops@cpa-apc.org</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>t: 613 234 2815 x238</td>
</tr>
<tr>
<td></td>
<td></td>
<td>f: 613 234 9857</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="http://www.cpa-apc.org">www.cpa-apc.org</a></td>
</tr>
<tr>
<td>Rick Kennedy</td>
<td>Canadian Mental Health Association</td>
<td>Director of Marketing and Development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>National Office</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Canadian Mental Health Association</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2160 Yonge, 3rd Floor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Toronto ON M4S 2Z3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T: (416) 484-7750</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fax: (416) 484-4617</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Email: <a href="mailto:rken@cmha.ca">rken@cmha.ca</a></td>
</tr>
<tr>
<td>Donna Klaiman</td>
<td>Canadian Association of Occupational Therapists</td>
<td>Director of Education and Development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Canadian Association of Occupational Therapists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>CTTC Suite 3400</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1125 Colonel By Drive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ottawa, ON K1S 5R1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T: 1-800-434-2268 ext 229</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tel: 613-523-2268 ext 229</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fax: 613-523-2552</td>
</tr>
<tr>
<td></td>
<td></td>
<td>email <a href="mailto:dklaiman@caot.ca">dklaiman@caot.ca</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="http://www.caot.ca">www.caot.ca</a></td>
</tr>
<tr>
<td>Catherine Lewis</td>
<td>Canadian Diabetes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
<td>Address</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Dr. David Grossman          | College of Family Physicians of Canada (representative) | St. Michael's Hospital  
407 - 70 Richmond Street East  
Toronto ON M5C 1N8  
T: (416) 864-6060 x2753  
Fax: (416) 864-5485  
email: DavidW.Grossman@UToronto.ca | Christine Wackermann  
Health Policy Coordinator  
The College of Family Physicians of Canada  
2630, avenue Skymark Avenue  
Mississauga ON L4W 5A4  
Tel: (905) 629-0900  
Fax: (905) 629-0893  
Email: cw@cfpc.ca  
www.cfpc.ca |
| Sean B. Rourke              | Canadian Psychological Association (representative) | St. Michael's Hospital  
Inner City Health Research Unit  
407 - 70 Richmond Street East  
Toronto ON M5C 1N8  
T: (416) 864-6060 x2753  
Fax: (416) 864-5485  
email: sean.rourke@utoronto.ca | John Service  
Executive Director  
Canadian Psychological Association  
151 rue Slater Street, Suite 205  
Ottawa ON K1P 5H3  
Tel: (613) 237-2144 (x22)  
1-888-472-0657  
Fax: (613) 237-1674  
Email: jservice@cpa.ca  
www.cpa.ca |
| Nadine Henningsen           | Canadian Home Care Association                    | Nigerian Henningsen  
Executive Director  
Canadian Home Care Association |                                                 |
<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Address/Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Carole Miles</td>
<td>Centre on Disability Studies (representative)</td>
<td>Carole Miles Redwin, Box 262, Landmark MB, R0A 0X0, (204) 355 4228 phone or fax, email <a href="mailto:camiles@mb.sympatico.ca">camiles@mb.sympatico.ca</a></td>
</tr>
<tr>
<td>Judy Marshall</td>
<td>Canadian Association of Rehabilitation Professionals (CARP)</td>
<td>Judy Marshall, Executive Director, CARP National, 201 Consumers Toad, Suite 302, Toronto ON, M2J 4G8, (416) 494-4700 (x204), 1-888-876-9992 (x204), (416) 494-9139, Email: <a href="mailto:judy@carpnational.org">judy@carpnational.org</a>, <a href="http://www.carpnational.org">www.carpnational.org</a></td>
</tr>
<tr>
<td>Stephanie Nixon</td>
<td>Canadian Working Group on HIV and Rehabilitation (CWGHR)</td>
<td>Stephanie Nixon, Co-Chair, Canadian Working Group on HIV and Rehabilitation (CWGHR), 333 Sherbourne Street</td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
<td>Toronto, ON M5A 2S5</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Tom McAulay</td>
<td>Canadian Working Group on HIV and Rehabilitation (CWGHR)</td>
<td></td>
</tr>
<tr>
<td>Elisse Zack</td>
<td>Canadian Working Group on HIV and Rehabilitation (CWGHR)</td>
<td></td>
</tr>
<tr>
<td>Michael J. Howorth</td>
<td>Crohn’s and Colitis Foundation of Canada</td>
<td></td>
</tr>
<tr>
<td>Dr. Barbara Whylie or</td>
<td>Canadian Cancer Society</td>
<td></td>
</tr>
<tr>
<td>Heather Logan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jackie Manthorne</td>
<td>Canadian Breast Cancer Network</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
<td>Contact Information</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Pam Murray            | The Arthritis Society                             | Pam Murray  
V.P. Marketing and Communications  
The Arthritis Society, National Office  
393 University Avenue  
TORONTO ON M5G 1E6  
Tel: (416) 979-7228 (x375)  
Fax: (416) 979-8366  
Email: info@arthritis.ca |
| Lorna Stevens         | Neutropenia Support Assoc. Inc.                   | Lorna Stevens  
Neutropenia Support Assoc. Inc.  
P.O. Box 243, 905 Corydon Avenue  
Winnipeg MB R3M 3S7  
Tel: (204) 489-8454, 1-800-663-8876  
Email: stevensl@mb.sympatico.ca  
www.neutropenia.ca |
| Laurie Beachell       | Council of Canadians with Disabilities            | Laurie Beachell  
National Coordinator  
Council of Canadians with Disabilities  
926 – 294 Portage Avenue  
Winnipeg MB R3C 0B9  
Tel: (204) 947-0303  
Fax: (204) 942-4625 |
| Carole J. Barron      | The Canadian Council on Rehabilitation and Work   | Carole J. Barron  
Executive Director  
The Canadian Council on Rehabilitation and Work  
Tel: (416) 260-3060 (x222)  
1-800-664-0925 (x222)  
Fax: (416) 260-3093 |
| Eugenia Repetur Moreno| Canadian Association of Social Workers            | Eugenia Repetur Moreno  
Executive Director  
Canadian Association of Social Workers  
383 Parkdale Avenue, Suite 402  
Ottawa ON K1Y 4R4 |
| Daniel Lapointe | Hemophilia Society of Canada | Daniel Lapointe  
(Sarah Quigg, Admin Assistant) | 
(Sarah Quigg, Admin Assistant) | Executive Director  
Hemophilia Society of Canada  
625 President Kennedy Avenue  
Suite 1210  
Montreal PQ H3A 1K2 | 
Tel: (514) 848-0503 (x224) | 1-800-668-2686 | Fax: (514) 848-9661 | 
Tel: (613) 729-6668 | Fax: (613) 729-9608 | Email: casw@casw-acts.ca | www.casw-acts.ca |
Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS:
A Qualitative Study

Project Undertaken By

The Canadian Working Group on HIV and Rehabilitation

Project Investigators
Robin Weir, R. N., Ph.D.
Joan Crook, R. N., Ph.D.
Christine Vanditelli-Chapman

October, 2003

Financial support provided by
The Office for Disability Issues, Human Resources Development Canada (HRDC)
# TABLE OF CONTENTS

Prologue................................................................................................................................iv
Abstract ..................................................................................................................................viii
Background...........................................................................................................................1
Current State of Knowledge.................................................................................................2
Purpose of the Study.............................................................................................................5
Methods.................................................................................................................................5
  Recruitment of Participants .....................................................................................5
  Design .......................................................................................................................7
  Ethical Issues ........................................................................................................9
  Analysis ................................................................................................................9
Findings.................................................................................................................................10
  Demographics ......................................................................................................10
  Emerging Themes ..............................................................................................12
  Reflections on the diagnosis ........................................................................13
  Learning to Live .................................................................................................14
    Riding the Roller Coaster of everyday life .............................................16
    Re-establishing a public face .................................................................18
    Redefining self ..........................................................................................20
  Rebuilding Relationships ............................................................................22
    Family ...........................................................................................................24
    Significant others ......................................................................................26
    Friends .........................................................................................................27
    Health care professionals ..........................................................................32
  Finding a way to feel productive ................................................................34
    Work .............................................................................................................35
    The Conundrum: All or nothing at all ......................................................39
Summary...............................................................................................................................41
Conclusion ............................................................................................................................45
Acknowledgements...............................................................................................................48
References.............................................................................................................................49
Epilogue................................................................................................................................52

Appendices

   Conceptual Model of Cross Disability Issues
   Information Sheet
   Consent form
   Interview Guide
The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, charitable, nonprofit, multi-sector, organization that promotes innovation and excellence in rehabilitation in the context of HIV disease. In Canada, the profile of HIV disease is changing. At one time, HIV infection caused an often rapid decline in health, leading to death. While there is still no cure for HIV disease, today new drugs can slow disease progression and help people to live longer.¹ As HIV is complex, and experience and research are leading to new knowledge, people living with HIV disease, their families, caregivers and those involved in treatment, education and policy, face many challenges as a result of the unpredictable and episodic nature of the illness.

CWGHR conceptualizes rehabilitation in its broadest sense of reinsertion or full return to society for those living with HIV disease and its accompanying challenges. To achieve our mandate and goals, CWGHR develops rehabilitation resources, new knowledge, and promotes awareness in a multi-sector collaboration with partners in the HIV/AIDS sector, rehabilitation professionals and with disability groups on issues of common concern.

Living longer with HIV often means dealing with impairments, activity limitations, and participation restrictions² that range from moderate or inconvenient, to severe and debilitating.

These challenges manifest themselves in physical, psychological, and social forms. As a result, they require a series of concerted and collaborative efforts in rehabilitation support and services.

**Background on research into “episodic” and cross disability issues**

Health care providers, institutions, and organizations often separate different disease groups into distinct “silos” (e.g., Multiple Sclerosis Society, Cancer Society, Arthritis Society, Canadian AIDS Society, etc.). These groups tend to operate autonomously, despite having overlapping experiences and common concerns.

As HIV disease has evolved into a longer term and often medically “manageable” condition for many people, CWGHR has had a growing sense that collaboration with other disability groups would be both informative and beneficial. It was felt that other “consumer” and “provider” groups with experience in episodic illness might make effective partners in the effort to affect change.

CWGHR conceived of a multi-phase Episodic / Cross Disability Project that would engage various disability groups and service providers in a discussion of commonalities between their “silos” and allow groups to explore possible collaborative work. There was also the intent to meet with policy makers to share collective concerns pertaining to episodic illness, as part of the project.\(^3\)

“Phase I” of this project entitled “Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions” was completed in March 2002. It explored issues of similarity between the experiences of people living with HIV-related disability and people living with other chronic, episodic and unpredictable illness and/or disability. Results of this project

---

\(^3\) Proctor, P. (March, 2002). Looking Beyond the Silo: Disability Issues on HIV and Other Life-long Episodic Conditions, Final Report to the Canadian Working Group on HIV and Rehabilitation (CWGHR).
demonstrated a keen interest from a number of different organizations to participate in future collaborative work, and a list of suggested actions that would lend themselves to joint endeavours. Phase I also included a meeting with Dr. Carolyn Bennett, MP and Chair of the Parliamentary Sub-committee on the Status of Persons with Disabilities to discuss common themes pertaining to lifelong episodic illness emerging from the Project.

In “Phase II”, the main objective was to help CWGHR further define and better describe the episodic nature of HIV. Because there are many unknowns with respect to the episodic course of HIV illness (e.g. What are the impacts of living with uncertain or alternating periods of illness and wellness? Is the impact cumulative over time?), it would be beneficial to better understand the experience of living with HIV before continuing work with other disability groups.

A new advisory committee was struck by CWGHR to guide the direction of Phase II and to provide leadership to the research project. The Advisory Committee members were:
Kelly O’Brien; Physical Therapist, Project Coordinator of Phase II Episodic Disability Project, Department of Physical Therapy, University of Toronto, Toronto, Ontario.
Tom McAulay; CWGHR member and person living with HIV disease.
Vivia McCalla; Registered Nurse with the Home Hospice Community Program of Casey House, Toronto Ontario.
Peggy Proctor; Physiotherapy consultant, Saskatoon, Saskatchewan
Patty Solomon; Ph.D. P.T. Faculty of Health Sciences, McMaster University, Hamilton, Ontario
Peter Williams, Program Director, PHA Program, Ontario AIDS Network, Toronto, Ontario
Kate Reeve; Education Coordinator, CWGHR
Elisse Zack; Executive Director, CWGHR
Phase II was designed to seek out and listen to people living with HIV (via focus groups across the country) to learn more about their lived experience with the disease, especially in regards to the uncertain, unpredictable, episodic and fluctuating nature of the condition over time. Kate Reeve acted as the lead facilitator in all of the focus groups and Drs. Robin Weir and Joan Crook were hired as lead investigators.

From the outset of this phase of the Project, Advisory Committee members struggled with the use of appropriate language to use with focus group participants in asking them to describe their own experience(s). It was agreed that the word “episodic” may not be the best term, although this term had been increasingly used in previous CWGHR work. The committee chose to incorporate additional words that might help participants connect to our understanding of episodic and frame their own experiences with words that had meaning for them. This “other language” included “roller coaster”, “unpredictable”, “fluctuating”, “uncertain”, and “up and down”. It was hoped that more appropriate terms would be found through the Project itself to describe the episodic experience of living with HIV. Please refer to Appendix C of this report for a copy of the Interview Guide used in the focus group interviews.

The following report is a description of Phase II of this project. Results of Phase II will have implications for CWGHR’s work on rehabilitation programs and policy issues and inform the direction of this work in Phase III.
Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS:
A Qualitative Study

ABSTRACT

Purpose: The purpose of this study was to examine the reality of living with HIV/AIDS, particularly the uncertain, unpredictable, episodic and fluctuating nature of this disease and the “roller-coaster-like” trajectory of that reality.

Methods: A grounded theory approach was used to explore the psychosocial processes that occurred over time for PHAs. Participants were recruited across Canada through outreach linkages with partner agencies of ASOs in a variety of geographic areas to ask them questions about their particular experiences in living with the unpredictable episodic illness. A qualitative approach was used in the form of small group, audiotaped, in-depth discussions led by a trained facilitator and co-facilitator.

Analysis: Transcriptions from the taped discussion groups underwent thematic analysis by multiple researchers to look for patterns of regularities, recurring ideas and experiences that linked or distinguished participants’ perspectives.

Results: Such knowledge provided an important foundation for exploring cross-disability issues pertaining to life-long episodic illness.

Uncertainty seemed to be a central feature of the life stories revealed by the participants living with the complexity of their illness, its unpredictable and ambiguous trajectory and the
complex and unproven efficacy and safety of treatments. The challenge was to find a balance between personal resources and environmental supports to find meaning to their lives.
BACKGROUND

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sectoral and multi-disciplinary working group formed in 1998 with a mission to promote improved quality of life for Canadians living with HIV disease through a national, co-ordinated multi-sectoral response to rehabilitation in the context of HIV. Its mandate includes the following two roles: a development and advisory role and a project and research funding role (Proctor, 2002).

As HIV disease has become a more lifelong, unpredictable but medically manageable condition, CWGHR identified the need for more collaboration with other disability groups in order to identify commonalities in their experiences and to share collective concerns.

As part of their research work and part of a larger CWGHR project, funded by the Office for Disability Issues (ODI) through Human Resources Development Canada (HRDC), a research project entitled Looking Beyond the Silos (CWGHR, 2002) was designed to bring people together to define disability and rehabilitation issues that were similar between people living with HIV related disability and people living with other chronic, episodic and unpredictable illnesses and/or disabilities. In addition, its purpose was to determine key aspects about the experience of living with the episodic life-long condition of HIV/AIDS.

Phase I of this project consisted of 3 components that included key informant interviews (N=10), with representations of national organizations primarily non-HIV groups dealing with life-long episodic illness/disability; a national one-day forum with invited key organizations (N=13), representing health care providers, rehabilitation specialists and volunteer groups; and a meeting between the CWGHR advisory group and the Federal Chair of the Sub Committee on the Status of Persons with Disabilities (Dr. Carolyn Bennett) regarding cross disability concerns.
A number of common issues were identified by the participants, which included: definitions of terms, care, treatment and support, workplace issues, income security and support, legislation and policy, stigma and prejudice, and education. These issues and themes confirmed the complexity of the question and interpretation and led to the development of a conceptual model to illustrate the various aspects or dimensions of disability (Appendix A) that would guide future cross disability work and to identify potential partners for collaboration (Proctor, 2001).

While this project provided an important foundation for exploring cross disability issues pertaining to life-long episodic illness, it was realized that there was a gap in our knowledge and understanding concerning how someone with HIV “copes with or manages the day to day struggles” that the unpredictable, and uncertain episodes of illness created for them. Therefore, prior to conducting further cross disability research, it was decided that the experiences of people with HIV/AIDS must first be elaborated.

A project Advisory Committee was established by the Canadian Working Group on HIV and Rehabilitation (CWGHR). Persons representing academia, PHAs, Community-Based AIDS Organizations (ASOs) across Canada guided the researchers in the development and conduct of the study.

**CURRENT STATE OF KNOWLEDGE**

The decrease in AIDS related mortality and morbidity is due to significant advances in the clinical care of people infected with HIV. The use of highly active antiretroviral therapies (HAART), including protease inhibitors (PIs), has been effective in suppressing HIV viral replication and reducing the incidence of opportunistic infections (Moatt et al, 2000). As a result, a growing number of HIV-infected persons remain without any clinical symptoms of
HIV-related morbidity and persons with AIDS are living longer and staying in better physical condition.

With earlier detection and more effective early intervention (Gallo, 1996; Siegal and Knauss, 1991) prolonged survival may mean high levels of uncertainty for longer spans of time for HIV-infected persons (Brashers et al, 1999). This uncertainty plays an important role in the illness experience due to the ambiguous patterns of symptoms, complex systems of treatment and care, insufficient information about diagnosis and unpredictable disease progression and prognosis (Brashers et al, 1999). AIDS has therefore become a chronic, progressive disorder requiring intensive medical management (O’Connell and Levinson, 1991)*. Unlike acute illness, a chronic condition is not an episode in a life, but rather it tends “to become the person’s very life (Pierret, 2000). Medication issues are prominent in this process. Whether or not to start the medication regimen is the first question to be addressed. Then having to take a large volume of medication with restrictions, such as with or without food or water or taking 2 hours before or after meals, structures their day around pills and serves as a reminder that they are unhealthy. Severe gastrointestinal side effects, lipodystrophy, hypercholesterolemia, diabetes and neurological disease accompany the decrease in opportunistic infections and hospitalization rates (Tiamson et al,2002; Bullers, 2001). These often crippling conditions are characterized by acute phases alternating with relative calm spells (Goldman, 2000). In place of the symptom-diagnosis-treatment-healing model, a different model has emerged that signals open, uncertain and unpredictable mental and physical challenges associated with the disease and the rapidly changing information about the illness and its treatment (Pierret, 2000). Because of the uncertain course and often complicated multi-system treatments, the mobilization of a network of family,

* The term “progressive disorder” may be interpreted and used differently by other authors and disability groups.
friends, health care professionals and services are required for their management. Living with a chronic disease requires a different view of the self and the meaning of the illness and one’s life (Scandlyn, 2000). Many long term survivors have described the reorganization their lives have had to undergo as they realized that if they were going to die it might not be soon. In many respects, the uncertainty of chronic illness is as challenging as the knowledge that you will die (Scandlyn, 2000). One author and person living with AIDS (Goldman, 2000) describes his life as a “compromise between side-effects and an HIV regimen that seems to be keeping me alive”. He describes this limbo state as a process of sustaining a body that will never be well but “may very well continue to be”.

Over the past twenty years, the ways in which illness has been conceptualized by medical sociologists has shifted from an “outsider’s” perspective of illness to the “insider” or subjective experience of the sufferer. While outsider views, like the sick role, illness behaviour and sickness careers have made an important impact on medical sociology, they have failed to reveal how illness is experienced and managed by those who have it (Conrad, 1990). Work is beginning to accumulate on the “insider” perspective on the chronic illness experience and includes concepts such as uncertainty, careers, stigma, as examples (Conrad, 1990).

Strauss et al (1984) have further conceptualized the illness experience in terms of the types of work that must be accomplished in all aspects of the person’s life. They describe the variety of different kinds of work including: illness trajectory work (crisis work, symptom control work, regimen work) as well as other tasks such as every day life work and biographical work (Corbin and Strauss, 1985). How emotions are managed, especially with pain and exacerbations of illness and how they affect illness are largely unexplored issues ((Register, 1987). Central to the illness experience may be the meaning people attribute to it and how they...
make sense of what is happening to them and to their bodies (Culnan, 1987). As some research has shown (McGuire and Cantor, 1987), issues of meaning may affect how people experience their illness and what they do about it.

There is a paucity of study and understanding about how people living with AIDS address their meaning of illness, particularly given this altered illness trajectory, that is the consequence of the disease, new treatment and care.

PURPOSE OF THE STUDY

The purpose of this second phase of the original cross disability study was to examine the experiences of people living with HIV/AIDS in regards to the uncertain, unpredictable, episodic and fluctuating nature of this disabling condition and the roller coaster-like trajectory of that reality. The findings are located within the sociological traditions of Corbin and Strauss (1986) in their work on illness trajectories in chronic illness. This conceptual orientation is consistent with CWGHR’s interest in studying a wide range of chronic illnesses and will allow the eventual examination of how episodic, uncertain and unpredictable episodes of illness are shared or not among other chronic conditions.

METHODS

Recruitment of Participants

Following approval by McMaster University Research Ethics Board, potential participants were recruited through the co-ordinating efforts of the Education Co-ordinator of the Canadian Working Group on HIV and Rehabilitation (CWGHR). She had access to a national population through her work in planning and conducting regular workshops, across Canada, for
people living with HIV/AIDS (PHAs) and the many disciplines addressing rehabilitation issues in HIV/AIDS.

Partner organizations with CWGHR, such as AIDS Service Organizations, across Canada were advised of the study purpose and eligibility requirements of participants through written information (Appendix B) and through direct contact with CWGHR personnel. They were asked to advertise the project and the request for volunteer participants. Information sheets that described the study and its purpose provided the telephone contact number of the Education Co-ordinator of CWGHR who confirmed with the respondents their willingness, eligibility and interest in participating. Once eligibility had been confirmed, the co-ordinator advised the respondents of the date, time and place of the focus group.

Groups were scheduled at various sites across Canada on the basis of co-operative networks of agencies that were willing to participate in the recruitment process. The selection of geographic sites provided an urban/rural perspective within the selected participants.

Theoretical sampling was used to designate potential study participants. Eligibility criteria included that the potential participants:

a) could speak and understand English

b) were living with HIV/AIDS

c) had at least one HIV related illness or were a long-term HIV/AIDS survivor (more than 10 yrs diagnosed with HIV)

These criteria allowed the selection of subjects who could illuminate the phenomenon (i.e. the episodic experience) being studied. For this study, 6 groups of 6 - 8 consenting participants were chosen to take part in the in-depth facilitator led discussions. Consenting and eligible study participants were asked to sign an informed consent form (Appendix B) prior to
the beginning of the focus group and to provide basic demographic information including their age, gender and length of time living with HIV/AIDS. Each participant received $25 for his or her participation.

Design

As we were interested in understanding the lived experiences of a person living with AIDS, we employed a phenomenological and grounded theory method of inquiry. This study focused on using the grounded theory method for studying how the symptoms and exacerbations of their illness affected their psychosocial and daily life management of their disease. Through the focus group format, this method provided an opportunity “to see the work through the eyes of the target group” (Stillman, 1991). Through the communicative benefits of group dynamics (Stillman, 1991) the focus group method was useful to explore social and communication issues and examined the cultural construction of experience by tapping into people’s assumptions and framework to draw out how and why they thought as they did (Kitzinger, 1984). Research questions were developed to explore the meaning and reflections of a particular experience and to stimulate discussion that would illicit accounts of the effects of uncertainty and unpredictability of episodic symptoms and illnesses on their lives. Participants were asked a variety of open-ended questions. Probe and follow-up questions were included to clarify issues and to validate researcher interpretations. These questions were tested with a volunteer group of support workers in an ASO, prior to the study, for clarity and relevance and refined with the feedback (Appendix D). The grounded theory approach was used to explore the social processes that occurred over time within phases or stages with the goal of contributing to theory. The
A qualitative approach was in the form of small group, audio taped, in-depth discussions led by a trained facilitator and co-facilitator.

To maintain consistency in group methods and data collection, all groups were facilitated by the same trained facilitator while the co-facilitator varied across groups. At the end of each session, the facilitator and co-facilitator debriefed together in a private location with a review of their impressions and field notes of the session to compare their notes. The audiotapes from the in-depth interviews were transcribed verbatim, and facilitators and co-facilitators had the opportunity to check the accuracy of their content.

The role of the facilitator was to stimulate and guide the group. She was aware of the dynamics of the group and was able to exercise a mild unobtrusive guide to the flow of the conversation. Maintaining group enthusiasm and interest for the topic plus a sense of timing for the mood of the group and the appropriateness of discussion alternatives were essential.

The co-facilitator made written field notes in an attempt to capture brief comments of the participants – especially those comments that might be quotable. This note taking did not interfere with the spontaneous nature of the group interview but captured the central points of the discussion. They served as a backup should the tape recorder have failed to function or background noise drown out individual voices on tape.

The tape recording equipment was set in plain sight before the meeting began. The importance of the recorder was mentioned at the beginning of the group discussion and was introduced as a tool to help capture everyone’s comments and to assure participants that no names would be included in reports. Participants were encouraged to speak one at a time to avoid “garbling” on the tape.
Ethical Issues

Written, informed consent was obtained by the group facilitator from each participant prior to each group discussion (Appendix B). Consenting participants did not need to sign their own name to protect their confidentiality. Only the research team had access to the interview tapes and typed transcripts. Tapes were destroyed once they were transcribed. Transcriptions of focus groups were kept in a locked location, accessible only to the research team until the final report of the study was produced. All responses are confidential. Any quotations used in any report for publication are attributed anonymously. Audiotapes were not available to participants for review in order to ensure the confidential nature of individual comments on the tape. Consenting subjects were advised that they could terminate their participation in the study at any time (i.e. leave the group).

Potential and consenting participants were advised that the purpose of the group was not to provide counselling but rather to explore participants’ experiences. Should the group discussion have stimulated sad feelings and reflections to the extent that a member would need to leave the group, the co-facilitator provided access to appropriate resources. Partner agencies in the particular area of the focus group provided relevant backup staff resources for to the focus group facilitator to refer to should any of the participants require assistance.

Analysis

Data obtained from the group discussions were transcribed and entered into the NVIVO computer program for qualitative analysis. The researchers used latent content analysis (Babbie, 1995) which involved an independent review of the group transcripts as a whole for an overall understanding and to identify general categories of content. The researchers then met and
reviewed their independent lists to develop a central set of preliminary categories followed by repeated reading of the texts to look for patterns of regularities, recurring ideas and experiences that linked or distinguished participants’ perspectives. Key ideas were assigned code names, which were then grouped into descriptive categories. After extensive review, these categories were grouped under themes which reflected concepts to which the groupings were attached. Subsequently, the original transcripts were reviewed and coded using the categories and themes. Differences between authors in coding were resolved by mutual agreement based on a review of transcript segments.

**FINDINGS**

**Demographics**

Six focus groups were conducted across Canada between March 7 and April 16, 2003. The majority (86%) of participants were middle-aged, male, long-term survivors of HIV/AIDS. We attempted to include participants from rural and urban areas through the choice of cities and knowledge of areas that each ASO served. Study participants were from a variety of ethnic groups and had a range of educational backgrounds with ¾ of the sample having completed high school and beyond.

There seemed to be three different categories of participants: those diagnosed many years ago who had ‘grown up’ with the progression of the disease and its treatment with drugs and therapies and who had contracted HIV through sexual relations; those who had contracted HIV by drug use through sharing of needles and were diagnosed within the past 6 years; and those who contracted the illness in other ways, such as through tainted blood transfusions, or from a partner who had a tainted blood transfusion.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Totals (N=44)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Years)</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>28 - 77</td>
</tr>
<tr>
<td>Mean</td>
<td>43.08</td>
</tr>
<tr>
<td>SD</td>
<td>3.27</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td><strong>Length of Time since Diagnosis (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>4 - 20</td>
</tr>
<tr>
<td>Mean</td>
<td>12.07</td>
</tr>
<tr>
<td>SD</td>
<td>0.93</td>
</tr>
<tr>
<td><strong>Description of current living area</strong></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>24</td>
</tr>
<tr>
<td>Urban</td>
<td>15</td>
</tr>
<tr>
<td>Rural</td>
<td>5</td>
</tr>
<tr>
<td><strong>Identify with a particular ethnic group</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
</tr>
<tr>
<td>Not answered</td>
<td>2</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>High school/some college/courses</td>
<td>15</td>
</tr>
<tr>
<td>College</td>
<td>13</td>
</tr>
<tr>
<td>Post-College Diploma</td>
<td>1</td>
</tr>
<tr>
<td>University Degree</td>
<td>3</td>
</tr>
<tr>
<td>Incomplete or N/A</td>
<td>11</td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>3</td>
</tr>
<tr>
<td>Very Good</td>
<td>16</td>
</tr>
<tr>
<td>Good</td>
<td>16</td>
</tr>
<tr>
<td>Fair</td>
<td>7</td>
</tr>
<tr>
<td>Poor</td>
<td>1</td>
</tr>
<tr>
<td>Not answered</td>
<td>1</td>
</tr>
</tbody>
</table>
Emerging Themes

The initial questions about the experience of living with the “ups and downs” of their disease, produced categories of information which included: a) learning to live, b) re-establishing a public face and rebuilding relationships, and c) finding a way to be productive. The first category (a) emerged from participant’s discussion of the impact of their diagnosis of HIV and how they coped. The other 2 categories (b,c) represent the challenges and their experiences with reconstructing their lives.

During the analysis of the data, it became clear that, while specific individual experiences differed, there was an emergence of common experiences and themes. Participants were linked by more than a disease as they shared a special bond, through the group process that they were not alone in their experiences, or how they were feeling, and learned that what they were experiencing was “normal”. Themes that became common across the groups included reflections on their diagnosis and the symptoms and side effects that they experienced, to struggles about presenting and revealing a public face, to the importance of the definition of the disease for self and the redefinition of self, to the challenges relating to relationships, to issues about paid work and returning to work.

Most of the participants of this study (70%) had an HIV positive diagnosis for more than 10 years. They were from an era in medical history when the only thing related to being HIV positive was most certainly death. They were from a time when the first thing that you did after being diagnosed was to begin to make funeral arrangements, detach yourself from now meaningless time constraints and limitations and live for the moment because you did not know how many more you had to live. They were also from a time when there were great advances in medical treatment of HIV disease, turning the tide from the certainty of death to the potential to
live. What follows is how the participants lived out those moments, with the ups and downs, the
gains and the losses, and the challenges of living with a recently defined chronic illness.

**Reflections on the diagnosis**

As mentioned above, most of the participants were diagnosed many years ago, during the
time when treatment and drug regimes were in their infancy, and the knowledge that the
diagnosis of HIV positive surely meant a death sentence. The diagnosis of death impacted
people in many ways. Some went right out and prepared their funeral arrangements so that their
family and friends did not have to cope with that:

“made all my plans, like the funeral, did the will, notified the family…the whole
shebang”;

while others took the diagnosis as a release from the everyday responsibilities of living:

*there was a certain freedom in that you were going to go…you weren’t responsible for
anything…and you weren’t capable…but you didn’t mind ’cause you couldn’t handle it
anyway.*

All informants talked about how the diagnosis made them redefine their outlook on life and so
rather than working and planning for the future which they now ‘know’ they will not have, they
began to live in the moment, one day at a time, as if everyday was their last.

While living everyday as their last seemed to mean a “duty-free” outlook on life, it was in
fact quite the opposite. Living everyday as the last meant that many deferred decision making to
their partner, or others in their lives, since the decisions were not going to affect them anyway.
This was most poignantly illustrated when one participant talked about purchasing things and not
having to worry about warranties because they themselves would expire long before the warranty
did:
“the beginning part is that phase where you don’t care about buying appliances or when you buy the appliances you don’t care about the warranties...and then when you get over that and you do care about the warranties in the back of your mind...you realize...”

Deferring decision making to significant others in their lives, in a sense meant giving up some control, only to have to struggle to regain that control months, sometimes years later, once they internalized the fact that they were going to live. Living in the moment meant not making plans or commitments, not investing in oneself, or in relationships with others, or as one participant explained it:

“I go through the motions of life but am not really living”.

Learning to live

“The diagnosis” seems like a logical place to start the story, and yet it was not an overriding theme throughout the discussion. The discussion focused more around the impact of being HIV positive on the emotional, physical, financial and practical aspects of their lives, and the “bumps” in the road that made their experience unique to people diagnosed HIV positive. Being diagnosed with a disease that is supposed to kill you is difficult enough to deal with, but then learning that you have been sentenced to life is a concept that is not as easy to accept as it might seem.

With the improvement of drug regimes and the management of acute episodes of illness related to being HIV positive, so did the life expectancy of those diagnosed. These advancements meant that those diagnosed had to re-evaluate their outlook on their life and life expectancy. They had initially resigned themselves to living one day at a time, ‘as if tomorrow would never come’:

“it’s hard to go from expecting to die and then all of a sudden realizing, well, maybe that’s not going to be the case...it’s a hard transition to make...to do that turnaround was like you’d been reborn...and it was really scary”
With the change in the trajectory of their illness from a certain death to an uncertain future of chronicity, each participant was challenged now by the choices to be made. S/he could either continue to ‘live’ as s/he had been since diagnosis, one day at a time, going through the motions of living, but not really being alive, or, s/he could accept that this was something that s/he was going to have to live with for the rest of his life, and figure out a way to incorporate all that comes with being HIV positive into his life:

“you’ve been so long getting to that point...that when you did realize that you were going to have to take hold of yourself...I found it awful...I felt right out of place...I mean you’ve lost all your self-assurance...I mean all of that was gone...and I started out having to relearn really, how to talk to people.”

Learning how to live with this longer lasting illness trajectory rather than an imminently fatal one was not an easy adjustment. This meant that the participants now had to try to reclaim their place in society, the place that they had relinquished when diagnosed. This was quite a challenge as sometimes this realization did not come for years, and some still struggle with it today. Reclaiming their place in society meant that they now had to rebuild relationships, re-establish a public face, find a way to be ‘productive’ society members, and ultimately learn to manage their lives armed with the knowledge of medication, fluctuating symptoms and the realities of living with a chronic illness.

The work that goes into day-to-day living with HIV is not always recognized, for the day-to-day effort and concentrated, complicated ongoing activities it takes to maintain the semblance of a ‘normal’ life and do the things that ‘normal’ people do:

“...and when depression zaps your ability, first all you’re feeling...is it even worthwhile to bother and second, your capacity and energy to do the work of day-to-day living...has left you open for all sorts of things...so if you’re not able to look after yourself...it just makes you realize what a complicated business it is getting from day to day, taking the right medications, eating the right food, getting enough sleep...that even if your life is healthy in all its aspects, it doesn’t happen all by itself...”
Riding the Roller Coaster of Everyday Life

The onset, or triggering of symptoms became a big focus for most participants. They found themselves living with this fear always in the shadows, which sometimes meant major lifestyle changes to manage symptoms or side effects:

“but you don’t know when you’re going to get sick or how long you’re going to be sick for…it’s very unpredictable...for me it just comes out of nowhere. I can be sitting on the couch and my girlfriend will look at me and say ‘what’s wrong?’...and all of a sudden it will just happen...it will be there.”

With such uncertainty of symptoms and side effects, the very fabric of social life was in limbo:

“you don’t even think of making plans because you just don’t know if you’re getting up off this down or, you know...and when you’re really getting down, there’s people who don’t understand...”

A further source of uncertainty concerned how to even interpret the symptoms or side effects that they were experiencing. Was it only a cold or headache or an upset stomach, or was it the precursor to another episode of illness?

“...and people coughing when you’re in a public vehicle or something...I have a fear that I never had before...you know it is rude that you blew in my face...now I actually feel tightening in the chest and you remind yourself of the danger that you’re facing...and it’s not...some of it is rational...a lot of it isn’t...and you’re living in those kind of fears that really are nonsense...but they’re really part of who you are these days.”

While knowledge might be gained overtime about the course of some of these episodes of illness, there was always the fear lurking in the background of whether or not this was the time that they would not get better:

“all the way through and I’m sure there was probably somewhere in my head...I was going...ok...is this the beginning of the end, kind of thing...especially if it’s a long period where you don’t have the energy and you don’t have that get up and go...you start to wonder...is this that moment where it’s switching?”

The beginning of the end was seen as a downward tumble often prompting participants to seek out medical interventions in attempts to halt the avalanche. For some it was clear that when
the end was in sight they would “just end it” instead of having to endure prolonged suffering. Those who were making the decision to end their lives when the symptoms felt unmanageable to them, were participants who were diagnosed more recently and said they were well aware of the potential and limitations of the current drugs. Participants who were veterans seemed more willing to try new and different medications in order to prolong their lives. The veterans reported that they had the historical knowledge and experience of when HIV was an imminent death sentence, and therefore had placed more hope and faith in new medical procedures and drugs. The challenge for all participants was the sorting out of regular everyday symptoms versus symptoms that needed attention.

For some, the fear was not only “if and when” to seek medical assistance for managing their symptoms, but also “where” to go for such assistance:

“we live in a rural area...there is nobody where we are...it’s very redneck...so you don’t want to tell nobody we’re HIV there...but being out there when there’s really not a lot of support of community access to the knowledge of HIV and AIDS...then where do you go from there?”

Coping with these uncertainties required some participants to reframe their expectations and experiences:

“I think that I am trying to achieve a state of less control...when I say less control I mean accepting unpredictability that anything can happen at any time...and being fine with that.”

Similarly, to manage the side effects of their medication regimen, many resolved their conflict with acceptance of what they believed was a trade-off of side effects versus health:

“I just have to put up with the side effects. If I want to stay on good therapy...I have to put up with the side effects.”
The struggle to find effective medications was one that was ongoing. Participants talked about the need to change medications because their body ultimately became immune to specific medications, meaning they therefore had to go through the adjustments all over again:

“When I first went on to the previous therapy I noticed that I had to let my body adjust to these medications, and of course there's side effects along with that. And just recently, within the last couple of months, I've been switched to another therapy because the other therapy was becoming ineffective and my body's still adjusting now”.

Another participant told about dealing with the difficulty of medication changes and the challenge of the time it took the body to adjust:

“Yeah. They've changed my medications three times on me because my body's immune to it. So now I'm on my third and I'm just adjusting to it now. So yeah it's been a roller coaster for me too”.

Medication changes had the potential to be viewed as a positive intervention, yet the changes were surrounded by uncertainty and, for the patient, the time of adjustment might have gone unrewarded if the medication proved to be an ineffective addition to their original regimen:

“I think the roller coaster only really occurs when I switch drugs because I ask the question, are these drugs going to work and if so...what side effects will I get?"

Yet despite all of the struggles and side-effects participants acknowledged that most times it was worth the struggle because they found:

“health-wise, that once you do go on to the therapies your health does increase. You do better once your body has adjusted”.

Re-establishing a Public Face

All participants, working or not, young, old, male, female, discussed the concept of having to put on different masks depending on with whom they were interacting. The effort that went into “looking and participating” as members of society was one of the most difficult and
challenging efforts. The challenge of normal participation in society meant the management of their resources (energy level, symptom control, emotional strength) so that they were at their optimum place when they engaged in “the real world”.

For those in the paid workforce, there was a lot of discussion around the emotional work of needing to wear the mask of normalcy, as they did not want most of their co-workers to know that they were HIV positive. Participants revealed their diagnosis to only a select number of co-workers in their attempt to maintain and manage their public identity in the face of the stigma that still surrounds such a diagnosis.

The greatest challenge in terms of resource management and choosing to participate in society was the varying levels of fatigue and energy loss. Participants discussed the symptom of fatigue and limited energy:

“I think that my ups and downs may not be as dramatic as some people’s…but they’ve certainly been there and for me, it’s mostly a matter of energy level. I can put out a fair amount of intellectual and physical energy for a fair period of time but it’s you know…it is like a battery that is sometimes charged and sometimes not and when it runs out, it runs out…there’s no earthly way that I can do anything with it…it’s another one of those examples that gets met with different reactions because when I say, man I really don’t feel like getting out of bed today, others just say, yeah, don’t we all…”

Trying to “parcel” out their energy resource and meet their own expectations required significant work and planning. There were times when participants had to make trade-offs, which sometimes impacted their health in a negative way; hence always requiring re-evaluation and concern:

“like right now I’m really busy (working)...and so I’m not doing the things that were really good for me, like yoga three times a week and going to the gym three times a week and all those kinds of things...it was like oh I can be busy and I can keep these things up... but I would immediately sacrifice my own self care in order to be there and be busy because that really boosts the self-esteem... it just seems like I have to pick one or the other...I can’t seem to find a balance of both...”
The pressure for participants to manage their limited energy resources was influenced by their great performance. They had become so efficient at picking and choosing their interactions and participation in society that there was almost never any doubt that they “should” be full participants. In other words, they were so good at convincing people that they were fine that others’ expectations of them did not falter. This meant that once others tuned into their limited output, they then became the target of judgement for being lazy for choosing not to participate, or do something extra whether at work or play. These judgement calls meant either taking the time and effort to explain, or what some might say, expose themselves, or keeping their diagnosis and challenges to themselves and ultimately having to deal with the emotional backlash of others:

“I have to really push myself to get out of the house because there are some days that I just don’t want to ... it’s got to the point where I’ve actually cut down my work hours...and we are allowed to pick our work for 3 months and I take the least amount of hours that I can and I don’t even work overtime anymore. When I first started there I think it was a stretch of about 2, 3 months that I worked every day without a day off. I can’t do that anymore. And my boss still is calling. He doesn’t know but the company doctor knows and human resources but my boss he’s always calling me can you work extra, can you do this. Thank God I’ve got an answering machine so I let that take it”

Redefining self

As discussed above, all participants discussed the challenge to redefine their sense of self once they decided that they were going to accept the challenge of living with this longer lasting state of illness. Redefining self was a necessity if they were going to attempt to reclaim a place in society for they were now looking at the world through the lenses of the disease. Learning what it meant to live with a chronic illness occurred through managing their daily lives. For some, developing new ways of thinking about themselves, lent a sense of control and belonging:
“right now I just think of it as my best friend. I go to bed with it, I wake up with it…there’s no shaking it, so, in order to take care of myself, I’ve got to nurture and love it. That’s my attitude…it’s helpful…it’s my best friend.”

Whereas for others, their illness remained a continuing source of stress and challenge:

“I regard HIV as a thief…it stole from me. It still steals from me. So on the good days, the up days, the thief has not come in…the windows aren’t broken…nothing’s happened…I’ve gone through the whole of the good day waiting for the other shoe to drop…but I recognize that at any minute the window might break.”

From the point of diagnosis to the point of re-entrance into society, the world that they chose to construct was different for each participant, just as the experience of symptoms and side effects were individualized. Participants recognized that how one deals with these issues is somewhat dependent on “who you were before the diagnosis”. So individuals who had developed coping mechanisms through their other life experiences were able to utilize them to deal with the issue at hand. This also meant that those who had other issues in their lives, whether physical or emotional, still had to manage their pre-existing conditions on top of the management of the “new” diagnosis.

Many participants discussed the fact that the HIV positive diagnosis seemed to magnify other issues in their lives, depression being impacted the most. Participants shared the fact that often it was the depression that was the most difficult to deal with rather than the physical symptoms:

“I mean when you’re dealing with a physical illness you conditioned yourself from it. It’s not a shame or a stigma to have a broken leg or a cold…but if you are suffering from depression then you’re a weakling and a loser…and if only you were a better stronger, you know, tougher person...”

Depression was a huge issue for most participants. Most felt that their depression was perhaps the greatest challenge that they faced as they recognized that all of the other losses influenced their mental health and desire to interact with others and society. Those who identified
depression as a challenge were able to find inspiration from their relationships with others who in their opinion were managing their HIV status and, therefore, able to live a positive and happy life. The issue of depression and impact on the sense of self was one that weaves its way through all of the intricacies of living with HIV. Because of this infiltration, it is important to keep in mind that unlike other symptoms that seemed to come and go, depression was one that was forever present, actually or “in the wings”, influencing or impacting on every experience.

Rebuilding Relationships

Participants at every stage of illness and diagnosis had to make decisions regarding to whom they were going to allow access and the amount of access to their “HIV positive world”. In making these decisions they had to take 3 factors into consideration: access, choice and control. Participants had to make decisions regarding whom they were going to allow access to their “HIV+ world” and the amount of access. They allowed different people into their lives at different levels of intimacy and at least attempted to maintain control of their relationship with others. Finally there was the concept of choice. This referred to whether the people in the participants’ lives chose to accept the access that they were given and how they chose to act or react. While participants made every attempt to control access they did, at times, find themselves in situations where that control had been taken out of their hands.

There seemed to be four distinct categories of relationships in the participants lives: family, significant others, friends and professionals (medical and employment related). Within these groups there were varying types of access given, as well as varying responses or choices made by ‘the other’. Similar to an average person’s life, it seemed that there were very few others who were provided full access, that is, allowing someone to come and go as they pleased,
and to witness the ups and downs of everyday life. Most participants had people in their lives who fell somewhere in the continuum between full and no access.

Deciding on levels and types of access was not a constant. Since situations, symptoms and relationships were ever changing, they often had to be ‘re-evaluated’. Therefore maintaining and forming relationships for these participants was a constant process of measuring investments, risks and losses. Different levels of investment in relationships depended on what stage they were at in their life with HIV. Participants who were diagnosed many years ago, at a time when treatments were not as well known or advanced, made the decision to invest little to nothing because they were not going to be around much longer. These participants, whom we call veterans, did not feel that they were going to live long enough, so they stopped investing in relationships and involving themselves in other peoples’ lives. Part of their lack of investment played out in their withdrawal from decision-making:

“the first 6 years it was pretty shaky and I sort of gave up and thought I was going to die and didn’t. I’m in a long-term relationship and I didn’t voice my opinion what to do with the house or anything like that. So I sort of just withdrew the decision-making”.

As they came to the realization that they were going to live, they started to realize what they had given up and now had to work on re-establishing bonds, trust and their social status:

“now …after 6 years of it...I’m trying to reclaim it back”.

As participants described their relationships, we gained an intimate view of how they decided who gained access to their lives, and the struggles that they went through in making those decisions. We also learned about the challenges they had in attempting to control different types of access in their relationships. And finally, they revealed both the positive experiences, and the raw emotions when having to cope with the choices the people in their lives made with the access they have been given.
Family

Family situations for participants varied. Some participants were involved in long-term relationships prior to and following diagnosis, whereas others were still in search of such a relationship. Some participants had immediate and extended family active in their lives, while others described relationships that were strained or absent. Access, or the issue of boundaries and the filtering of information proved to be a challenge that consumed both time and precious energy.

Participants who had established family relations, whether it was with significant others or other immediate family, generally reported that they experienced positive support in their relationships:

“I’m lucky. I have family: my daughter and grandchildren and my son-in-law is a wonderful human being. That’s very important. I’m loved and they need me and I need them but they need me. Then you see that is very, very important. And they really understand”, “…and just the way I was treated by my family I wasn’t really coddled like I was on my last days or whatever, I was just treated as a member of the family when at that time people were pulling their kids away from people who were HIV positive”.

While many participants had great support and relationships with family, there was a great deal of discussion around having/wanting to “protect” them from worrying:

“I don’t see why I should tell them. They have enough worries”, “my family are completely protected from my ups and downs. I would not let them see or know of a down if I could help it”.

For these participants, protecting their families meant saving their loved ones grief and worry. Other participants protected their families from bad episodes, not as an attempt to save them from emotional upheaval, but rather to save themselves from the reactions of others:

“It’s a huge amount of work to be constantly smoothing out and saying I’m not going to drop dead, I’m going to be okay...get out of my face, please.”
Maintaining others’ personal health through the filtering or withholding of information, for some participants, was one way that they protected themselves and attempted to maintain control over choices that family members made with the more open access initially provided:

“you don’t want to show too much of your symptoms because you’re trying to maintain other people’s health. And even though you have a need to talk about it, you can’t because of how other people are going to deal with it”.

Some participants said that, in some of their family relationships, the access that they initially had given to their lives had to be re-evaluated because of some of the choices that family members made. When the main involvement of a relationship became focused on illness, participants became overwhelmed. In order to protect themselves from this type of relationship focus they learned to limit access, often keeping day-to-day symptoms to themselves:

“they get very concerned if I even just say I’m tired. Well why are you tired, what’s wrong? I feel like they’re jumping on me and I’ll just say, chill out, I’m just tired”.

When the shift from open access to more limited access happened, family members reacted with increasing concern:

“Concern is wonderful but at some point it becomes ... I have to say almost pathological. It really does get to the point where it’s like they don’t want to hear that they don’t need to be needed”.

There were some participants who re-evaluated family access and instead of reducing it, increased it, but only after having to educate them:

“my mother and sister, when they first found out I had it, they didn’t even want me to visit. I’d go out and visit, they put hot water and javex in the sink if I used their cup or a fork or spoon. So I got 6 months into having it and turned around and I said, come up here, I’ve got all the information, I said, here, I won’t talk until you read all this information and see where you stand. So now they give me all the support I need”.

The other extreme of family relations that our participants talked about focused on strained relations, or no relationship at all. Some participants explained that they had little to no
contact with their families prior to, or following diagnosis, so there was not much change. Other participants talked about the strain that the diagnosis put on their family relations:

“*I don’t need the BS about being HIV positive from you so I’m going to write you off*”.

Significant others

While participants discussed the value of the support they received from their family and friends, there was the acknowledgement that there was nothing that could replace the love, support and relationship of a significant other:

“*well you know your family loves you and stuff but it’s different when you have a partner or a girlfriend or a boyfriend*”.

Some participants were in long-term relationships at the time of diagnosis. These participants did not report any rifts in the relationship as a result of being diagnosed HIV positive. Participants who were not in long-term relationships talked about having great difficulty in finding and maintaining intimate relationships:

“I try to find a girlfriend and you’ve got to tell them that you’re HIV and it’s just I can’t get a girlfriend or nothing, it’s just crazy. It’s like you’re alone all the time. I’ve really had a rough time”.

Some participants have given up on finding a partner because they were not willing to get hurt again:

“*once we got too close; I don’t need to be hurt further. I don’t want to be disappointed*”.

Participants who were still searching for a partner, talked about the fact that they needed to ease their potential or new partner into the realities of HIV:

“And even still when I start to date somebody new for the first time, if they’re not positive, then I kind of break them in slowly into my HIV. I don’t tell them how long I’ve been positive or how long I’ve been out of work and I don’t let them see the pills right up front. I sort of ... it’s like a stages thing”.

They talked about easing them in slowly in order not to frighten off the potential partner.
While some participants thought the slow approach was best, others believed that telling all, right up front would help to protect them from loss when the time finally came for them to reveal their status. These participants talked about being honest all along, but somehow realized through experience, that the intellectual understanding of the effects of HIV and AIDS was easy enough to discount until the relationship reached the point of physical intimacy:

“...they don’t have an understanding of what’s going on even though they try. They say things like I’m ok with it, until you’re like in bed naked and then all of a sudden that ugly virus and those body fluids are right in their face literally and they 180 on you in the middle of sex. I find that really difficult to deal with”.

Many participants discussed the loss of physical intimacy and the impact that this loss had on their lives overall. The impact of the loss of physical intimacy meant, for most participants, feelings of physical isolation and loneliness. While they acknowledged that the intellectual and emotional intimacy they enjoyed enriched their lives, they still felt the loss of touch and the impact of that loss on their relationships and their sense of self:

“You’re living in a don’t touch me but touch me. There is an intimacy intellectually of what used to be physical and it seems to me that you’re only living half because to me to be whole, you have to be the whole pie or none of it. And I’m living there in a lifetime of just half a pie and I have to be able and successful with it, and I’m not happy with it and I don’t grieve it. I’m passed that but it’s forever there. It’s the reality that it’s no longer possible”

Friends

The discussion around friendships focused on four different issues: the current status of friendships, challenges to opportunities to meet friends, finding and creating opportunities, and building and maintaining a support system.

The loss of friendships and the forming of new ones were a focus for some participants. The loss of friends meant two different things: the loss or death of friends, mostly from the
disease; or the loss of friends who could not handle the realities of their diagnosis. Some participants lived through a time when all of their friends were HIV positive, and they had to bury most of them:

“I was diagnosed 18 years ago, just over 18 years ago...so I was the second person in my circle of friends...that circle of friends I’ve buried”.

Another participant poignantly described the consequences:

“sad thing is that you spent your teens and 20s developing what I call your friendship web, your infrastructure...and then this virus comes around and wipes them all out...and by the time you realize, by the time it’s all over, you’re all alone...”

As a result of the emotional losses participants have had to face through burying friends, some made the decision that they would not have new friends that were HIV positive:

“most of my friends died, I vowed not to have positive friends again”.

This decision was made in order to protect themselves from the losses and from a reminder of their potential realities. Most found it difficult to keep this promise to themselves as they continued to seek out new relationships.

The other kind of loss that participants talked about was the loss of friends who reacted to either the diagnosis or the circumstances surrounding it. What follows is a description about what happened when participants gave their friends access to their lives and information surrounding their diagnosis, and the choices that they made. Participants described how they felt that friends who were not HIV positive, or had not experienced symptoms, had a more difficult time understanding the ups and downs:

“Yeah I do understand that when you’re talking to people, especially people that are negative, when you’re trying to tell them you’re having a bad day and all they want to do is go out and party and have fun, they don’t get it at all”.

Participants talked about friends leaving at different points in their lives. Some had friends leave as soon as they found out about the diagnosis:
“I found out who my true friends were and found out who weren’t. It was a very painful experience”.

Others talked about friends who said they were okay with everything until symptoms and side effects became visible:

“they see me, like all of a sudden I look different now, and they don’t want to come near you”.

Dealing with the loss of friends was difficult, but those friends who stuck around provided participants with support through the ups and downs, and on a daily basis:

“those who were very receptive to me, they were very supportive and I still have them as friends to this day. They’ve been very supportive at that time when I was really, really sick”.

Many participants talked about the difficulties in making friends and the challenges to opportunities. Some of the challenges to opportunities to meet new people included: stages of life, ‘normal’ social conversations/social icebreakers, fluctuating symptoms and disclosure.

Some participants acknowledged that they were at an age when they should already have had their group of friends:

“as I get older, like most people, my life has been departmentalized; and there’s a whole section of friends that don’t exist any more. And I might have had a hundred friends, I have three – that’s different”.

Part of this challenge was because of their early departure from the work world:

“your age group are already established, their lives are full. You’re not 20 anymore when you have a lot more time. You’re in your late 30s, your 40s, your 50s, and people in your age that you expect to be able to socialize and connect with because they’re from your generation, well their lives are full”.

The challenges to meeting people seemed to be mostly a result of our participants not being comfortable with their social place, and how it compared to ‘the norm’. Because many of them were not working they found it difficult to be in an environment where meeting new people meant small talk and social icebreakers:
“I absolutely hate going to social events or dinner parties, that kind of stuff, where people don’t already know me and what my life is like because they inevitably...somebody turns and says, so what do you do for a living? So I hate that question with a passion to the point that I’ve told my friends if I’m going to be the new person at the table, don’t invite me, I don’t want to go”.

Along with the lack of comfort with social status, participants also struggled with revealing to new friends that they were HIV positive:

“They’re either afraid of us or they’re not. I mean I’ve certainly worried myself over this a considerable amount, disclosure or not disclosure, whether it’s for friends or for sexual partners. Either they’re going to react positively or they’re not. They’re going to accept it or they’re not. And whether I worry about it, it’s not going to make any difference about it and my experience has taught me that the sooner they know the truth about you the better. The sooner I get it over with the better it is”.

While in most cases participants discussed the loss of friends as a result of choices made by other people, in a few cases, participants revealed that they were the ones who had to end the relationship:

“early on when I had friends in the 80s that thought HIV was the biggest sin in the world, or the face of the earth, I figured I didn't need them for friends anymore. I was probably better off without them”, “I had some friends that I finally had to choose to get rid of in my life. I mean they were negative in subtle ways. I mean it’s like I’ll try and quit smoking, but oh here have one. Just little things like that that I just realized, you know what, this is not in my path of healing, remove the negativity from your life, and since then ... I mean it was hard, I cut them out”.

These participants felt that in order to promote healing and acceptance of their diagnosis they had to get rid of negative influences, and people that had the potential to drag them down.

Much of the discussion surrounding friendships, and loss of friendships had to do with lack of understanding and willingness to cope with the effects of a friend being HIV positive. Friends seemed to be categorized as either HIV positive or HIV negative. Participants talked about not wanting to have friends that were positive because there was too much to lose, but having friends that were negative seemed to lead to more misunderstanding. Ultimately most
participants ended up realizing that they needed to find a place where the challenges discussed above did not exist and they were able to “just be themselves [sic]”.

In attempting to address the issue of finding new friends they described the different ways they attempted to find and create new social opportunities. The first, and perhaps most obvious suggestion for meeting new people who may be able to provide understanding were support groups. Some participants talked about attending support groups when they were first diagnosed, but found that they had outlived their usefulness after a while:

“I’ve been out of the support group environment...where people are 10 years down the road....I just wanted to find out where do I fit in. Do I fit in from being a newbie...to being 10 years down the road”, “I find the support groups out there up the whazoo but they’re all about how to deal with various illnesses that are going along at this point in time and coming out with your HIV...or whatever”.

Participants felt that there were very few opportunities for people who were HIV positive to meet and suggested that:

“I’d like there to be more opportunities for positive people to get together for social reasons”.

Some participants said that there were a few groups that provided this opportunity, but added that for most who attended, it was a social outing, and therefore was often difficult to continue to pursue friendships with people outside of the group, or meeting situation:

“I mean I meet positive people here all the time but it’s really hard for me to turn the people I meet here into friendships, social event kind of things”.

Ultimately participants found that the best way to meet people, and to fill in the time that was once filled by work, was to volunteer. Many participants found that volunteering gave them the opportunity to feel like they were contributing to society again. This participation in organizations surrounding HIV/AIDS meant more than just filling in time; for some it meant that they had to re-evaluate their choice to not get involved with people who were positive in order to
protect themselves. Eventually these participants came to accept that it was in these types of organizations, and the people that work for them, that they felt they belonged.

A feeling of belonging and trust created a foundation for the building and maintenance of friendships. While many participants experienced some challenges when it came to friends, many reported that they had great friends who were very supportive:

“I’ve been pretty sick in the past so…and then I’ve gone through a couple of years or 3 or 4 years where I’ve been pretty well…and then, now I’m not well again so people are kind of rallying around me so I feel like I’ve got some good support”, “They’re still there. I mean sometimes I have to kick them out”.

Friends who had a positive attitude and who were active in participants’ lives also encouraged participants to maintain their healthy status. They talked about being inspired to stay healthy not only for themselves, but for others in their lives. They said that it was much easier to hide when there was no one who had access to the everyday challenges of their world. When others were also invested in their health, they then coped and could focus on others’ investment to help get them through:

“There was a sense when you’re by yourself like you say, it’s easier to make yourself miserable and hide the fact that you’re not eating and sleeping properly whereas when you have somebody in your life then there’s a sense of I want to be strong and healthy not only for me, but for my relationship as well”.

Healthcare professionals

The final categories of relationships discussed by participants were those with healthcare professionals. As illustrated through the discussion of relationships, participants spent some time evaluating and re-evaluating who they gave access to and how much. The discussion of control in regard to the medical profession varied quite a bit. Some participants stated the they were in control: “I decide what pills go in my mouth”, whereas other felt that this was the one
relationship where control was tenuous. Participants talked about being stripped of control as they found themselves needing to give the medical profession “full access” in order to be assessed and treated for the disease, symptoms and side effects. In this situation, what was important to them was ‘the need’ to relinquish control and provide access rather than ‘the want or desire’ to:

“I’ve been in emerg and you have that little curtain between you and the person next door and then they bring in the other doctor, this is Mr. So and So, he’s HIV+, has this and that.”

Now anyone within hearing range of their cubicle has the knowledge as to why they are there and what they are being treated for.

The consequences of such knowledge confirmed the fear:

“...and I had nurses come in and it’s like...poking me six times because they were shaking so bad to try to take a blood sample...and it was just humiliating...anything that happened to you it was suddenly related to HIV...”

“And it was like I just didn’t feel like a person anymore, anytime I had to have medical attention...and I’ve never been sick from any HIV-related problems ever.”

Other medical relationship issues also had something to do with control, but focused on control of medical information, medications and treatments rather than with control of access to participant’s everyday world. Participants experienced their relationships with doctors individually depending on their stage in the illness and personal circumstances. Some participants talked about taking control over their illness by researching treatments and bringing this information to their doctor. Others talked about placing trust in their physicians as they had decided to leave the prescribing choices and decision making up to them.
Finding a Way to be Productive

Loss of paid employment became an issue for many participants. Along with loss of employment came financial difficulties. This meant for most the need for reliance on income support. Some saw that relying on such income support gave them a chance to stabilize their symptoms, and gave them time to learn how to incorporate other symptoms into their daily lives. While income support was seen by some as a chance to “check out for a while and focus” on themselves, for others such support felt like a prison sentence:

“And even if we stayed on disability our income doesn’t really increase at the rate of the cost of living increases so we’re progressively becoming poorer and poorer, and I find that really frustrating. My working friends, whether they’re positive or negative, I mean even the positive ones who sucked it up and stayed in the workforce, their income has increased over the last 10 or 15 years. I feel like I’m just socially not able to do all the things that they’re able to do because I don’t have the money and so as much as my friendships aren’t based on income, at the same time if you can’t do the things that they’re doing you fall out of the friendship loop pretty quick.”

Participants were very vocal about the fact that living in poverty was perhaps one of the biggest issues for PHAs:

“Like those are huge issues, poverty issues…it’s actually the initial reason why I went to join the study…was for the $25…honestly…because poverty I think is the number one issue PHAs are dealing with and we need people to listen to that because…I mean there is the fear that you can’t go back to work because of the fear I need this money for my drugs, rent and all this stuff…

And so the experience of poverty had its own consequences:

“I find that makes me feel sub human…I mean I went through a move just recently…seeing a mattress in the garbage and having to drag it home because I have no furniture…I don’t feel human…I feel less than human…like I feel like I’m a scavenger, crawling around on the ground. That’s what you get reduced to.”

Participants expressed their fears of living into old age and in the state that they had been living in:

“I feel like I’m a bum off the street sometimes, and I never had to live like that in my life…so it’s been a huge adjustment for me to find myself after all these years. I thought
I would be somewhere now and have a half decent life by this time because I turned 49 this year. I thought my life would be different and to think that I might have another 20 years of scraping by...”

In addition to living with the ups and downs and stress of the disease, participants also made it known that having to live a life of poverty impacted on their ability to cope, and took away the little energy reserves that they had:

“Trying to have control is not having income and money and food as I was saying before...that kind of control, that is very difficult to maintain. When you're on social services in this province it isn't, it isn't making you a very good living. People find other ways to supplement their income or food bank or wherever you can. But that...I mean if we had enough to maintain a quality of life through income would probably make things easier. If I didn't have to worry about food in the cupboard and bills getting paid and having enough pot to smoke, I think I wouldn't worry about whether or not I was going to get sick next week”.

It is clear that living in poverty, as described by the participants, impacted on their sense of self as well as their sense of value and place in the world. While participants held hope of returning to the paid workforce in order to relieve themselves of the economic constraints of government income, in the next section we learn of the challenges and barriers that prevented them from doing so.

Work

Paid work plays an integral part of almost everyone’s everyday world. A career fulfills many needs including personal achievement and satisfaction, economic needs and societal needs. Because paid work is such an integral part of our North American culture, in many ways it has come to be a defining part of self, and measurement and recognition of normalcy. Some participants in this study continued to be employed, while the majority of them did not. Because paid work was such a defining factor in their lives, participants felt that:
“being HIV you are a nobody now because you can’t go to work because what employer is going to want to hire you when you can only maybe work 30 hours a week if you’re in that able level...or a day where I can only work 3 hours today”.

Whether participants continued to work or not, they all were able to talk about issues surrounding a work identity, income, and the unknown aspects of the future.

Those that continued their employment identified their fears and challenges surrounding work somewhat differently than those who were not employed. Working participants talked about their fears of having to give up paid work one day, which for them would mean giving up a large part of their identity. The motivation to continue working for them was that it provided a distraction from HIV. These participants felt that to lose that would be difficult, as they would not know how to fill in the time. For some, however, the motivation to continue working was purely practical in that they needed to continue to support themselves and their medical needs, so they:

“work to pay your bills...you’re sick inside but yet you got to be on the outside looking like you’re well and physical and capable of doing it and meanwhile it’s very stressful... And when you have a bad day and you got to be up at 6:00 in the morning...”

The participants who continued to work identified a number of challenges to their continuation including management of their work identity, fears of the future, and the potential for dramatic change in their health status. All of the participants who were still working explained that they were very careful at work, and only shared information regarding their HIV status to select individuals:

“And not everybody knows about my status...with whom I work with...or whatnot...They don’t always need to know...”

This sometimes became a challenge for those participants who were symptomatic, or were on medications:
“I’ve done it for years...working and having...like a problem...like I would need to go to the bathroom to take my pills ‘cause I was working then and the public and everything.”

This group also discussed their fears of the future and the potential of not being able to maintain their lifestyle due to loss of income. But the most distressing part of the future for these folks was the fear of not being on a drug plan and therefore not being able to afford their medications:

“it’s always in the back of my mind will I be covered as long as I’m here. You know what I mean? There’s an insecurity that there’s no way you can deny it.”

The potential for the loss of resources for medication costs is one that all the participants could relate to, and those who were presently on medication seemed to feel that reality just a little bit more, acknowledging that they knew where they had been, and they did not want to go back.

For those who were no longer working, there was a lot of reflection on their past working life, especially in relation to losses and choices when it came to work. Many of the participants talked about having to make the choice of working or being healthy:

“you can’t afford to take that chance because ultimately your health is more important than just making money. I gave up all that. It’s survival, that’s all there is to it. It’s just pure survival.

The choice, or need to leave work for many came down to a choiceless-choice:

“I literally had to decide at one point to do something about it because if I didn’t I was going to die, and that just wasn’t an over-dramatization at all. That was just a certain fact.”

Leaving work, therefore, meant recognition of the unmanageability of symptoms and side effects of medications, and an attempt to regain control. The need to leave work in order to regain some sort of manageable health status meant that these participants had to give up a part of how they defined self, their work identity:

“my sense of self-worth is really wrapped around being employed and being part of the workforce so I find that challenging.”
This journey for better management of life with HIV was an ongoing one, but as they experienced some sort of stability they could not seem to help but think about the life they once had:

“I would love to have the energy I had back before I was diagnosed”.

When participants talked about the need and want to return to work these ideals were outweighed by the risks and challenges they identified. The risks were defined by potential losses and the challenges by barriers that they felt were insurmountable. The participants identified two distinct and defining risks that influenced their decision regarding going back to work: the risk of getting sick, and the risk of loss of benefits and income from either private or government sources. The challenges identified by participants included the societal expectations of workers and lack of suitable positions for people who needed flexibility and understanding built into their work role.

Because this group of participants had to leave work in order to better manage and maintain their health status, they were very open about their fears of relapse and the unknown effects returning to work might have had on their health:

“the last time I went back to work…it just caused a total collapse of my cocktail…I mean I want to go back to work in some ways but in other ways it’s like what happens if that happens all over again”.

Despite these very real fears of a relapse, this did not seem to be the overall deciding factor in terms of returning to the workforce. The most prevalent fear of returning to work was that if something did happen and they were not able to continue to work, then they would have given up the security of their current source of income, whether it be government or private disability funding.

Participants who were on disability pensions from their employers feared that:
“there was a risk that if I did go back to work, they could cut me off 2 months down the road saying, you’re not doing your job right, goodbye, and then I’d really be screwed”.

The fear of potential loopholes in government disability benefits also kept people dependent:

“it was difficult enough to get onto disability benefits and then even more difficult to get additional benefits by tweaking legislation and using it to get more funds. If I went back to work they would close my life and I would lose all of that and the way legislation is now you’d never get it back”.

The fear of losing government income and medication coverage was unquestionably the greatest risk impacting participant’s decisions regarding work:

“there is the fear that you can’t go back to work because of the fear I need this money for my drugs, rent and all this stuff…but if we went back to work...we might feel better in health...we may not need the drugs”.

All participants on government income came to the conclusion that they were not willing to take the risk of going back to work, so that they would be able to maintain their benefits. These participants felt that the government needs to “get the...red tape regulation changed”. It was clear that if there were some kind of a guarantee that if they tried to work and had a relapse or were not able to work full time, that the government would reinstate benefits. Then they would be more willing to return to work:

“I feel healthy enough that…I have an opportunity to take a full-time job but I’m scared, I’m always scared something is going to happen. It’s going to take me so long to get back on disability that you know it’s frustrating. And yes you do want to work and you think...ok this is going to be great...I can have a nice full-time job but I’m too scared that something is going to happen. My body’s already given out on me now in the last little while so it’s like should I or shouldn’t I, and I’m going no”.

The Conundrum: All or nothing at all

In the above discussion regarding work, there seemed to be an all or nothing attitude. From this perspective, you either worked, or you did not; there was no consideration of the number of hours worked or talk about full or part time options. It ultimately became clear that
this all or nothing attitude was not because there was a lack of desire to work, but rather it was a result of the stringent structure of our workforce:

“I’m not able to do everything like a normal person does...some days I’m fine, I can do a lot, but there’s other days I just curl up in bed and stay there for the whole day”.

The participants acknowledged that there was no place for someone who could not be consistent. The unpredictability of the illness on a daily basis, according to the participants, made it impossible for them to return to work even though they had periods of time when they felt that they were healthy enough to work:

“I’ve often thought about I don’t want to be retired really and my health is often good enough that I feel like I could work but I don’t know if I could work consistently”.

It was clear that participants who felt healthy enough to work had the desire but not an accessible work structure to support them.

Returning to work might be partially about making money and getting themselves out of a life of poverty, but there seemed to be more value placed on the emotional impact of working or, more clearly, not working:

“there are emotional risks attached to that of not working, to not be productive, and to not feel you’re doing something useful with your life”.

There was a lot of discussion around forced retirement, or having to retire too young:

“It just hit me like a ton of bricks and I thought I’m already retired and I have another 25 years to go before I officially retire and I found that to be just overwhelming and the thought that today was going to be exactly the same as 25 years from today...it sent me into a huge depression. It took me awhile to get out of it. And I attribute it to the fact that you know I’m living a retired person’s life and I don’t like it”.

Other participants reiterated that being retired at such a young age made thoughts of the future challenging and bleak:

“we don’t have milestones...I don’t have milestones and I find that difficult to deal with because if you don’t have those milestones to pull you through your time...then every day
does start to look like the same one...one after the other. So I find that that’s what I’m missing is milestones and goals”.

The management of illness whether on an hour-to-hour, day-to-day, or month-to-month basis was really what returning to work came down to. In order to manage illness, participants needed to be able to afford and take medications, be able to achieve and maintain basic standards of living, including a roof over their heads, food on the table, and the management of symptoms and side effects in their everyday life. Participants felt that there was no available space for them in the workforce of today that would allow them to manage illness and contribute to society, and at the same time feel secure that if they suffered a relapse or episode they would be supported without having to “fight to get back on disability”. A few participants created their own space in the workforce, working under the table when their health allowed:

“when my body...I hear my body ok, I have to take a nap today. Today is not going to be a day where I can work 16 hours and do it. I mean today I can only get 3 hours done. I’m aware of that. I listen to that. That’s worked for me and I haven’t gotten sick again, luckily. But I guess for me that’s how it works for me”.

SUMMARY

When a disease is terminal, the experiences of major ups and downs seem to fit the dramatic events that herald the progression of an illness’ trajectory. Re-experiencing that illness’ change from an imminently fatal condition to a longer lasting fatal condition seemed to require or result in a redefinition of the meaning of those peaks and valleys and while they may have occupied significant moments in time, they eventually appeared to become shadows that accompanied the experiences of everyday living.

Our focus group questions and probes were designed to guide participants to reflect on their episodes of illness and symptoms in a more defined way, but what they revealed in their
discussions and through their stories was something quite different. Rather than selected or a series of dramatic episodic events, there was instead a continuing vigilance of attending to signals, anticipated and actual, that implied to them, deterioration and/or debilitation. The everyday ebb and flow of one participant’s illness experience was described as “feeling good, feeling like crap, feeling good”. While some participants did talk about major episodes or events in the experience of their illness, we were most overwhelmed by the day to day struggle that they talked about and the ongoing challenge to pursue living in the face of uncertainty of what the next moment, next day or next year would bring:

"so you don't know what's going to happen or when its going to happen...HIV is the driver as far as the out of control elevator because you don't know what floor you're going to land on and sometimes you'll land on the floor that you've pressed the button for..."

At the same time we learned from others that the ups and downs of their everyday life were experienced as "ripples or bumps":

"I'm fine...other than a roller coaster...it's more like you go down and then up and then you sail on one level, and you go down again...but you come back up and once again it's smooth...it's not like woo, woo all over the place..."

In posing the question of "ups and downs", we assumed that participants experienced and measured "ups" but we discovered that most of the participants did not use this term. As one participant said:

"When is it up?...it always is...I mean ever since I was diagnosed it's always gone the one way...I mean really in all seriousness, your up is that it stays on a plateau..."

...and another in response to the question said:

"..and I have to really stop and reflect on times that I have these ups and downs... as you ask questions...because I don't think about them as being ups or downs...I just look at it as being part of life because no matter what, being HIV positive or not, we are all going to have the roller coaster of life..."
Whereas variability was experienced by some participants, others emphasized the unpredictability of the illness:

“Like when you think you are going to fart and you have explosive diarrhoea...or you don’t know if you should sit on the toilet or puke in the sink.”

The impact of the unpredictability on the participants’ life was generally to withdraw:

“I can’t go anywhere or do anything”

or:

“gotta stay inside just because you can’t go out because you’re scared...”

For another participant:

“When you’re feeling like that, you don’t want to eat, you don’t want to deal with people, you don’t was to deal with meals”

The uncertain course of HIV and its treatment threatened to limit the participants' freedom and cloud their future planning:

"it means once you experience something then there...like if you get involved in something and then you get ill and you can’t see it through, then you're more hesitant to get involved again just in case you get ill and have to stop again...."

In response to this challenge, they had to educate themselves, be patient, accept their illness, talk to others, know their limits or as one participant said:

"...it's adapt or perish...you have to keep going forward...you have to keep going forward because if you stand still, you know...you'll be torn to pieces...you have to go forward..."

Crossing all the themes of these discussions was the struggle for balance against the seeming chaos of their circumstances:

"...yeah...I have been living day to day for so long...and I can't stand living day to day any more...I want...I need some sense of direction...some sense of overall balance against the chaos that keeps life fun...the right kind of chaos..."
Another participant described...

"it changes every aspect of who I am...I mean my every....., everything that I say...everything I experience is on a different flavour and in some ways...I do grow stronger and in other ways I grow weaker...it's sort of like you gain one thing and you lose another...and it's finding...I think for me...it's finding the balance between that...

And so, out of lives that were "problem saturated" with little life beyond their disease (Robinson, 1993), they summoned their reserves and persevered in a reorientation of their stories:

"it is not a matter of obsessive control over the details...it's a matter of having the big picture...and the right amount of the right kind of, the kind of chaos and unpredictability that makes life rich and interesting.. while trying to deal with the best you can with the frightening bit that can open up at any moment...the ability to sort of take, you know, the gifts of life...whether they're thrown at you and try to side step the dangers...and to know...you know you've got some sort of purpose and head towards it...."

These participants articulated the struggle and the different transitions that were accomplished, most clearly:

"...well control, you see, depends on personality...I mean there are some personalities that are more controlling than others naturally...there are some people that are quiet and more reserved and actually take a different approach...there are people who are sometimes depressed and there are people who never had a day of depression...some of that is...each one of us is made a little differently...but one thing is for certain...we all do have some common threads...all...yeah... just live day by day and hope it gets better before it gets worse...

As Charmaz (1995) suggests, through their struggles, ill people paradoxically grow stronger in self and they “adapt to impairment. They suffer bodily losses but gain themselves”. Their journey leads to another level of self-awareness and their position relative to their situation and their place with others and at this point they may even find themselves giving “solace and comfort to the healthy”.

As one participant concluded:

"I know my final thoughts are...just don't let it get to you up here... there's still just so much hope for even a better future than what we even have now...or what we've had
for...well for anybody who's been infected for at least 10 years...I mean if you start taking a look at what it was like 10 years ago and now...I mean there's an awful lot of hope and don't give up...maybe you'll be a little nervous about the therapies and stuff like that...but don't give up on yourself..."

CONCLUSION

Uncertainty seemed to be a central feature of the experiences reported by these participants in living with the complexity of their illness, its unpredictable and ambiguous trajectory and the complex and unproven efficacy and safety of treatments (Mishel, 1990). In telling their stories they revealed the many ways they coped with the dangers and threats they experienced in living with this disease. The challenge for most was to attempt to find some balance between their personal resources and their environmental supports, when for many, personal resources were limited (e.g. energy, depression) and environmental supports (e.g. financial, work, family, friends) were absent or minimal. Nonetheless, they faced the challenges and managed the complex interplay of the uncertainty with their emotional distress by seeking some coherence and meaning to their lives.

The analysis focused on the day to day experiences of living with HIV/AIDS and as the analysis suggests PHAs are still confronting many of the psychosocial challenges as in the pre HAART era, although in different guises. While AIDS is being reclassified as a “chronic illness”, we need to continue to value and build upon what we have learned about people’s everyday efforts to cope with the illness, since it can be seen, through this analysis, that many of the same issues remain relevant as the epidemic continues.
LIMITATIONS

Caution must be exercised in the interpretation of this study’s findings. First, the sample was drawn from small groups of volunteering PHAs in selected areas across Canada, who are by no means representative of the PHA population. Participants came from ASOs and this bias may have influenced the nature of their characteristics and life experiences as well as their willingness to participate.

Neither the transcripts nor the interpretive analysis were reviewed by the participants for accuracy. While this decision was reasonable, as a way to ensure the protection of their anonymity and their belief in that protection, the decision could reduce confidence in the validity of the interpretation.

How the authors created the stories of the participants should reflect but not necessarily reproduce the participants’ stories (Charmaz, 1990). Our conclusions are an attempt to offer concepts that preserved the context of the story, and the person’s character within it. To this end, our active codes and subsequent categories attempted to represent the images of the reported experiences (Denzin & Lincoln, 2000). As noted by Glaser and Strauss (1967, p23) “in discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from the category is used to illustrate the concept”. The quotes that appear in this paper were selected examples of the responses provided by the participants that were judged by the authors to fit the various conceptual categories which emerged during data analysis.

When using qualitative methods, it can be seen that the researchers brought the general perspectives of their disciplines, their own philosophical, theoretical and methodological tendencies, their particular research interests and their own life experiences. Hence the questions that were developed, the data collection methods and what issues and focus they saw within the
data, obviously shaped the analysis. Thus the decisions that we made throughout the research process have shaped this product.

**IMPLICATIONS FOR FUTURE RESEARCH**

As this analysis implies, it was not only the unpredictable episodes of illness that challenged HIV/AIDS sufferers, but also it was the management of the multi-layered uncertainty (personal, social and medical sources) through adjustments in identity, relationships, knowledge and physical and psychological well being.

What was needed was a fit between the needs and resources of the person and the demands and resources of the environment. Proactive individualized multidisciplinary interventions targeted at the individual (treat depression, vocational training) and/or the environment (flexible work hours, supportive housing) could be developed to identify and strengthen available resources.
ACKNOWLEDGEMENTS

Our sincere thanks to all the participants who generously offered their time and shared their personal and moving stories. In addition, we are grateful to the Project Co-ordinator, Kelly O’Brien, the organizer and facilitator of the focus groups, Kate Reeve, along with the various co-facilitators who guided the groups and for the co-operation of all the personnel in the ASOs who helped make the study happen. Many thanks to the Advisory Committee members, Tom McAulay, Peter Williams, Patty Solomon, Kate Reeve, Vivia McCalla, Peggy Proctor, Kelly O’Brien and Elisse Zack for their investment in this project and their commitment to its completion. Finally, many thanks to Leah Heikoop for her skill in producing the final document.
REFERENCES


Proctor, P. Looking Beyond the Silo: Disability Issues on HIV and Other Life-long Episodic Conditions, Final Report to the Canadian Working Group on HIV and Rehabilitation (CWGHR), March, 2002.


Epilogue: Reflections of the Advisory Committee

The purpose of this section is to provide the reader with some overall reflections of the advisory committee on the how this report from “Phase II” of the Episodic Disability Project fits with the report from Phase I (Looking Beyond the Silo). It also includes some thoughts on future implications for rehabilitation programs and policies pertaining to episodic illness in the context of HIV.

Definition of “Episodic”:

- One of the themes that emerged from the key informant interviews held in Phase I of this project (Looking Beyond the Silo) was the need to establish relevant definitions pertaining to lifelong and episodic illness. We had hoped that results of Phase II might help to establish a definition of “episodic” to help us better conceptualize and describe the unpredictable and roller-coaster-like experience of living with HIV. Many factors contribute to the “episodic” nature of living with HIV beyond the biological impact of the virus, its effect on the immune system, and the resulting illnesses. For example: anticipating new side effects with every change in treatment, possible changes in employment, adjusting to new living arrangements with changes in income and health status, and coping with changing support systems as friends die and/or friends and family react to a person’s vulnerable health and periods of illness and wellness over time. It did not seem possible to create a new definition of “episodic” disability that would capture the complexities of what these participants shared in their stories.
• Some participants seemed to have a sense that HIV is supposed to be, or will become, episodic. So while they themselves may not have experienced a major episode, or series of episodes, the impending threat of HIV taking control and their not knowing what will happen has a significant impact on how life is lived and how it is perceived and described. This highlights the ongoing unpredictability associated with the illness, the ongoing uncertainty of the potential for an episode to arise and the uncertainty of how one will cope with an episode if and when one arises.

Comparing Results of Phase I and II:

• One of the objectives of the Phase I Looking Beyond the Silo project was to conduct key informant interviews with representatives of various national organizations working on other lifelong and episodic illnesses to identify similar disability and rehabilitation issues. A few of these themes that emerged from the Phase I key informant interviews also emerged from the focus group discussions of persons living with HIV in Phase II. For example, workplace issues and income security were two themes that emerged from the Phase I key informant interviews. Similarly, issues surrounding work and finding a way to be productive were themes that emerged from the Phase II focus group discussions with persons living with HIV. This highlights areas of importance related to workplace and income support issues for persons living with HIV, as well as other lifelong and episodic illnesses and helps to identify areas in which to focus future policy and program development.
Implications for Future Work on Rehabilitation Policies and Programs:

- Beyond what makes HIV unique, the committee believes that the impact of living with HIV has much in common with other lifelong, episodic conditions and that alliances would be effective in facilitating change at the policy level. It is the hope of this committee that this report will facilitate future partnerships and further research to facilitate change that provides a better quality of life to people living with lifelong, episodic illness. This may require a redefinition of terms and/or the creation of new terms to accurately reflect the experience of people living with episodic disabilities / conditions so that points of common experiences may be determined based on their own experiences and priorities.

- As stated above, it was intended that this report might provide a clear definition and understanding of the term “episodic”, reflecting the experience of living with HIV. While it may not have done that entirely, it has provided insight and new understanding that suggests further research in this area. For example, more work could be done to focus on the cumulative impact of living with an episodic illness. Is there an “erosion effect” over time? Do people living with an episodic illness redefine or reframe ‘episodic’ from the dramatic to a more common, manageable experience of ripples and bumps as a coping mechanism?

- The results from Phase I and II of the Episodic Disability Project have provided a comprehensive knowledge base. This information will serve as a springboard from which CWGHR will launch Phase III of the Project. Phase III will involve moving from research into community development and knowledge transfer with the initial development of a network of organizations working on episodic disabilities or conditions.
The goal will be to embark on an action plan to promote changes to rehabilitation programs and policies to better address the needs of persons living with HIV and other lifelong and episodic illnesses.

CWGHR will incorporate this research along with other project findings into our educational materials and workshops to enhance our existing resources on rehabilitation in the context of HIV. It is through this ongoing work that CWGHR will continue to promote excellence in rehabilitation as an integral component of the care, treatment and support of people living with HIV.
APPENDICES
Appendix A

Conceptual Model of Cross Disability Issues
Appendix A

Conceptual Model of Cross Disability Issues

Permanent Disability
- Blindness
- Cerebral Palsy
- Down's Syndrome
- Stroke
  - Spinal Cord Injury
  - Amputation
  - Traumatic Brain Injury
  - Invisible

Episodic Disability
- Multiple Sclerosis
- Cancer
- Mental Illness
- Crohn's & Colitis
- Arthritis
- Diabetes
- Fibromyalgia
- Cystic Fibrosis

CWGHR
HIV & Rehab
Appendix B

Information Sheet
You are being invited to participate in a focus group.

**Who is doing the focus group?**
The Canadian Working Group on HIV and Rehabilitation (CWGHR) and 2 researchers from the Community-Linked Evaluation AIDS Resource (CLEAR) Unit, McMaster University, Hamilton. CWGHR is a national, autonomous, multi-disciplinary working group with the mission to enhance the quality of life for Canadians living with HIV disease by facilitating the development, awareness and access to rehabilitation services.

**Why are we doing the focus group?**
While people with HIV/AIDS are living longer, they are living with the unpredictable and fluctuating nature of the illness. As a result, we are trying to learn from you the reality of living with HIV/AIDS in relation to the uncertain, unpredictable and fluctuating nature of this disease and the “roller-coaster” like trajectory of that reality; those episodes of feeling ill, then better, those peaks and valleys, ups and downs that occur. A better understanding of these experiences will lead to the development of relevant HIV rehabilitation programs and policies to ultimately better meet the needs of persons living with HIV/AIDS.

**What are we asking participants to do?**
You are invited to take part in a 1 – 1 ½ hour focus discussion group with 5-8 PHAs. This is not a counselling group, but rather is a group to discuss issues regarding your experiences with an episodic illness. You will be asked a series of questions to discuss the experiences that you have living with HIV. After the focus group discussion, you will be asked to complete a short questionnaire based on your personal characteristics. An honorarium of $25.00 will be provided to thank you for your participation.

**How will the information be used?**
The focus group discussion will be later converted into a written format from the audiotape. The notes will then be analyzed for common themes that emerge related to the experience of living with a lifelong episodic illness.

**How is my privacy protected?**
Your participation in the focus group is voluntary. The focus group will be audiotaped. The tapes will be transcribed at McMaster and any identifying information (e.g. first name) will be removed. The tapes will be destroyed after transcription.

**How can I participate?**
If you are interested in learning more about the study or if you wish to participate, please call Kate Reeve at CWGHR in Toronto, 416-324-4183.

A summary of the results will be available to study participants at the completion of the study through the local AIDS organization.
Appendix C

Consent Form
Appendix C

Unpredictable Episodes of Illness in the Experiences of People Living with HIV/AIDS

Consent Form

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is doing a study about the day-to-day experiences of people living with AIDS. We would like to meet with you to try to understand your experience over time with your illness. We are particularly interested in understanding those episodes of feeling ill, then better, those peaks and valleys, ups and downs that occur. This is not a counselling or therapy group, but rather we want to learn from you how you cope with these episodes and manage your every day life.

I understand staff from CWGHR are going to be meeting with small groups of people living with HIV/AIDS to discuss these experiences. The group discussion will last about one and one-half hours and will be led by 2 facilitators who will assist the group to discuss the relevant issues.

I understand I am being asked to participate in one of these groups. All information that I discuss in the group is confidential. My name will not be recorded or used to identify my comments. The group discussion will be audiotaped and the tape will be subsequently transcribed by secretaries unrelated to the project. No individual will be identified in the transcription. The audiotape will be destroyed after transcription. The results of the study will be made available to CWGHR and presented in-group form (that is, no individual will be identified).

I can choose at any time to leave the group discussion. My participation in this group will not affect any services I presently receive. If I decide to withdraw from the study, I understand that the information I provided about myself will be removed from the study record.

If I have any questions about this group, or my participation, I may make a collect call to Kate Reeve at CWGHR in Toronto, 416-324-4183.

The study will take about 6 months to complete. If I am interested in receiving the results of the study, I can call the above phone number.

Yes, I understand the purpose of the focus group and the expectations for my participation.
Yes, I agree to participate in this tape-recorded discussion group.

Signature _____________________________________________
Print Name _____________________________________________
City of Residence _____________________________________________
Witness Signature _____________________________________________
Witness (printed name) _____________________________________________

I will receive a signed copy of this form.
Appendix D

Interview Guide
Appendix D
Unpredictable Episodes of Illness in the Experiences of People Living with HIV/AIDS
Interview Guide

With earlier detection and effective drug treatments, more and more people infected with HIV are living a long time with their disease. We are meeting with you to try to understand your experience over time with HIV/AIDS in relation to the uncertain, unpredictable and fluctuating nature of this disease and the “roller-coaster” like course of that reality. We are particularly interested in understanding those peaks and valleys, ups and downs, that occur, those episodes of feeling ill, then better. We would like you to discuss with us the impact these episodes of feeling ill then better have on your life.

Describe your experiences that made you think that you were right for this discussion group (i.e. that you could relate to what we were trying to understand about your illness).

Consider how these peaks and valleys impact on all aspects of your life. For example:
- work life
- finances
- relationship with family of origin, partners and outlook on life

Probes:
- How has living with the “roller-coaster” affected your outlook on life?
- Has the anticipation of a new/impending critical event affected your outlook on life?
- If you have had multiple ups and downs with your illness, how has this impacted the way in which you anticipate a new critical event? How has this affected your outlook on life?
- How do these ups and downs relate to changes in your perspective on life?

Let’s talk about the unpredictability of the disease.

Probes:
- How do you deal with the uncertainty when your symptoms are quiet?…present?
- When you don’t know how long you will respond positively to the treatments, how do you cope with that uncertainty?
- Some PHAs have told us that they can now plan ahead. Do you have any comments to make about looking forward, planning ahead, even dreaming about the future?
It may be difficult when there are ups and downs, and many episodes of illness/wellness, that roller-coaster-like course to feel you have control over the direction of your life.

Probes:

- What is the impact on having numerous “episodes” on the way in which you cope with your illness?
- What do you think contributes to your having control over your life?
- How did your ideas about control change over time, over the course of your illness?

Do you have anything else you wish to say about living with the “roller coaster” like course of your illness?

Probe:

- Do you have any other way of describing these episodes?
This document is intended to highlight some of CWGHR’s reflections on the results and implications from the research paper Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study. This was a second phase of cross disability research intended to examine the experiences of people living with HIV/AIDS (PHAs) in regards to the uncertain, unpredictable, episodic and fluctuating nature of this disabling condition and the roller coaster-like trajectory of that reality. A qualitative methodological approach was used in the form of six small group, audiotaped discussions led by a facilitator and co-facilitator. Participants were recruited from AIDS Service Organizations in a variety of geographic settings across Canada to investigate their experiences living with an episodic and unpredictable illness. Transcripts from the audiotaped discussions were analyzed using grounded theory techniques to determine how the episodic nature of HIV affected their psychosocial and daily life management of their disease. The findings are located within the sociological traditions of Corbin and Strauss (1986) in their work on illness trajectories in chronic illness. This conceptual orientation is consistent with CWGHR’s interest in studying a wide range of chronic illnesses and will allow the eventual examination of how episodic, uncertain and unpredictable episodes of illness are shared or not among other chronic conditions. The full report of this project, and the report from the preceding first phase of this project are available from the Canadian Working Group on HIV and Rehabilitation website at www.hivandrehab.ca.

**Defining Episodic**

With the advent of new treatments people with HIV and access to these new medications are living longer lives. While there is still no cure for HIV disease, and ultimately it is still fatal, it is often considered a life long or chronic condition. When a disease is terminal and imminently fatal, the experiences of major ups and downs, or episodes, seem to fit the dramatic events that herald the progression of an illness' trajectory. Re-experiencing this illness' change to a longer lasting fatal condition seems to require or result in a redefinition of the meaning of the episodes experienced. While they may have been significant in the moment, they eventually seem to become just another bump in the road, part of the many complex experiences of everyday living with HIV.

**Implication:** Instead of pursuing one comprehensive definition of episodic it seems more prudent to foster an understanding that there is an episodic continuum that people experience. This may have specific implications in communications between people living with HIV and health care professionals who may be using the word episodic with
very different understandings. This difference in understanding would impact assessment, and therefore care, treatment and support decisions.

**Not just episodes of physical illness**

It is important to note that when participants discussed episodes, the ups and downs in life, that impacted their health and well-being, it was more than physical bouts of illness. Having to change treatment regimes, disclosing their status to people, change in work status, financial changes, and shifts in mental and emotional health, such as depression, also figured prominently as part of the burden of living with an episodic and unpredictable illness.

**Implications:** When assessing the health and well being of PHAs it is critical to explore all factors affecting health and well being beyond the physical to include the functional, psychological, social and vocational life domains as well. Furthermore, it is important to acknowledge the complex interpersonal relationships people living with HIV may have with friends and family, and how these relationships influence their life domains, thus impacting their overall health. The holistic, comprehensive and individualized approach, while acknowledging the complexities of HIV is critical in delivering effective rehabilitation care facilitate optimal quality of life for persons living with HIV.

**Living under threat of siege**

Participants stories revealed that there is a cumulative impact from the stress of living with constant uncertainty that comes with HIV and its treatment. While there is still a need for further research into this phenomenon, the following themes emerged here.

- A constant vigilance is required, attending to signals, anticipated and actual, that may indicate deterioration and/or debilitation. There is a day-to-day struggle to meet the ongoing challenge to pursue living in the face of uncertainty of what the next moment, next day or next year would bring.
- As the unpredictable course of HIV and its treatment encroached on the freedom of participants and clouded their future, some described withdrawing and isolating themselves from friends, family and society. During times of better health and feeling well people may decide to emerge from withdrawal and rebuild a public image and social network. There were various reasons people became isolated and there were many stories of people having to rebuild their public persona and create new social networks.
- In addition participants reported that the people close to them were also affected by this cumulative stress. This sometimes had a negative impact on their relationship further isolating the person with HIV.

**Implications:** When assessing the health and well being of PHAs it is critical to acknowledge the underlying unpredictability, and the impact that this ongoing stress of
Living with HIV

Session Outline

• Living with the consequences of illness and treatment
• Perspectives of HIV as an episodic illness
• Experiences of HIV related impairments, activity limitations and participation restrictions
• Issues across the health/social care continuum

Working with People Living with HIV

There are no new impairments, activity limitations or participation restrictions; but new disease processes in a unique context:
  – Cyclical nature
  – Co-morbidities
  – Social determinants of health
  – Diversity of people, culture, identity, values and beliefs
### The HIV Community/ies

- Highly-evolved community-based movement
- Possess expertise in how best to help/reach/serve people living with HIV infection
- Excellent opportunities for partnerships with respect to clinical care, education and research

### Discussion
unpredictability may have on the health and well-being for persons living with HIV. It is important that rehabilitation services are available for persons to access at any point in their illness given the unpredictable nature of the illness. Rehabilitation may help persons to adopt strategies to help cope with the unpredictability of the illness, thus contributing to improving self-esteem and social integration, which may improve overall health.

**HIV and Work**

The unpredictable nature of living with HIV is juxtaposed to the usually rigid policies and culture of the workplace and income support programs. This climate makes it prohibitive for PHAs to attempt to stay in, and/or return to, the workforce even though many who are not working expressed a desire to work. Fears include:

- the possible negative impact of full time work on one’s health
- not being able to get appropriate time off to attend to health needs
- having to disclose status and face the resulting discrimination and prejudice that still surrounds HIV.
- losing medical coverage
- losing part of their identity.
- loss of income leading to a life of poverty.

**Implications:** More research is needed to investigate the effect of flexible return-to-work and benefits programs to better serve persons living with HIV in relation to the episodic and unpredictable nature of the illness. In the meantime, it is important that rehabilitation service providers acknowledge the complexity of the decision-making process pertaining to return-to-work, and facilitate linkages to appropriate services that relate to an individual’s personal goal regarding vocation.
Rehabilitation Roles

Session Outline

• Definition of Rehabilitation
• Expanded Role
• Rehabilitation Response
• Rehabilitation Roles

Definition of Rehabilitation

• How do you define rehabilitation?
  ➢ By practice area
  ➢ Discipline specific
  ➢ Client centred
Rehabilitation is…

…about giving people the tools to do what is meaningful to them

The Maze Of Rehabilitation Services In The Context Of HIV/AIDS

What Rehabilitation Services In The Context Of HIV/AIDS Should Be
The Rehabilitation Response


Challenge

How to create an inclusive framework that will emphasize a multi-dimensional, multi-disciplinary perspective on services for those with HIV?
– Medical “rehabilitation” and role in other chronic illnesses

Conceptual HIV/AIDS Rehabilitation Framework

Disability: In any life domain, is identified as any body impairment, activity limitation or participation restriction identified as an issue by a person living with HIV/AIDS.
- Body impairment
  - Activity limitation
  - Participation restriction (ICF, WHO 2001)

Rehabilitation = a dynamic process, including all prevention and/or treatment activities and/or services that address body impairments, activity limitations and participation restrictions for an individual

Person Living with HIV/AIDS

Physical body systems

Functional daily activities

Psychological spiritual personal growth

Social community leisure/recreation

Vocational practical

Cultural/Religious Organizations

Private Sector

Complementary & Alternative Health

Family & Friends

Government

ASOs & CBOs

Health Sector

Person Living with HIV/AIDS
Key Messages from the Framework

- Demonstrates broad rehabilitation domains and service issues for persons living with HIV
- Overarching issues:
  - Stigma and Discrimination
  - Multi-Systemic
  - Episodic
- Demonstrate the broad role for rehabilitation among a variety of stakeholders

Purpose & Objectives

To explore the knowledge, attitudes and practices of selected health care provider groups concerning rehabilitation for people living with HIV/AIDS (PHAs)
- To describe rehabilitation professionals’ extent and nature of involvement in the provision of HIV and rehab services to PHAs in Canada
- To explore HIV specialists’ extent and nature of involvement with rehabilitation and perceptions of rehabilitation issues for PHAs in Canada

Methods

Nationwide Postal Survey

- Rehabilitation professionals with or without experience with PHAs who worked clinically in the past year
  - Physical therapists (PT)
  - Occupational therapists (OT)
  - Speech-language pathologists (SLP)
  - Physiatrists
- HIV specialists who worked in HIV clinical setting in the past year
  - Dieticians
  - Nurses
  - Pharmacists
  - Physicians (GPs, ID specialists, psychiatrists)
  - Psychologists
  - Social Workers
Methods
Sampling Frame and Sampling

Rehabilitation Professionals
- Random sample (n=2105)
- Sample pool - National association lists (voluntary)
- Supplemented with provincial/territorial regulatory body lists (mandatory) where available
  - Over 30% of final sample pool was generated from the provincial/territorial lists

HIV Specialists
- Known population (n= 793)
- National association lists (e.g. CANAC, Canadian Collaborative HIV Pharmacists Network and College of Physicians and Surgeons)
- Supplemented with snowball sampling.
  - 6% of final sample from snowball sampling

Survey Instruments

- Developed in collaboration with national advisory committee
- Two surveys (HIV and Rehab) in English and French
  1) Current practices and services provided
  2) Levels of knowledge and educational needs
  3) Attitudes and perceptions of rehabilitation in the context of HIV
  4) Perceptions of emerging HIV rehabilitation professional and service delivery issues.
  5) (Rehab Survey) Additional section for those who had served PHAs

Data Collection

- Dillman’s Tailored Design Method
  - Pre-notice letter ~ 1 week prior
  - First survey mailing
    - cover letter, survey, post-paid return envelope, refusal card
  - Thank you/reminder postcard ~1 week after survey
  - Second survey mailing ~ 3 weeks after first survey
Rehabilitation Professionals

Response Rates

2,105 mailouts, less 99 return to sender = 2,006
- Responses 1,492 (74%)
  • Ineligible 198 (10%)
  • Refusal 236 (12%)
  • Completed survey 1,058 (53%)
    (58% of eligible respondents)

Respondent Characteristics

- Profession
  • PT 47%
  • OT 41%
  • SLP 9%
  • Physiatrist 3%
- Gender
  • Female 88%
  • Male 12%
- Average years in practice 14.5
- Community Size
  • Metropolitan (>500,000) 43%
  • Urban (100,000 - 500,000) 32%
  • Rural (<100,000) 25%
- Region
  • Ontario 53%
  • Alberta 13%
  • BC 10%
  • Prairies 10%
  • Atlantic 9%
  • Quebec 5%
  • NWT, Yukon, Nunavut <1%
- Northern Region 8%
- Work Setting
  • Client’s home/home care 29%
  • Hospital – inpatient 22%
  • Hospital – outpatient 21%
  • Private practice – individual 19%
  • Private practice – group
### Rehab Professionals' Knowledge: HIV Training and Awareness

- 27% reported receipt of training in HIV/AIDS as part of rehabilitation health degree education
  - Mean hours of HIV/AIDS education: 12 hours
- 48% reported 'no' to 'little' HIV rehabilitation awareness of others in their workplaces
- Current personal level of HIV knowledge:
  - Somewhat knowledgeable
  - HIV associated disability: 61%
  - Transmission of HIV infection: 60%
  - Diagnosis of HIV infection: 60%
  - HIV psychosocial aspects: 60%
  - HIV prevention: 54%
  - HIV epidemiology: 46%
  - HIV pathogenesis: 38%
  - Episodic course of infection: 30%
  - Treatment medications: 30%
  - HIV related policy issues: 20%

### Rehabilitation Professionals' Current Practices in HIV

- 61% RP had never knowingly served an HIV positive client
  - Would work with this client group: 27%
  - Would not work with this client group: 27%
  - Unsure: 46%
- Of the 39% RP who had ever served an HIV positive client
  - Mean number of PHAs seen in previous year: 4 (s.d. 18)
  - < 25% of rehab issues were HIV related: 75%
- Importance of their profession for PHAs
  - Not at all important: 4%
  - Somewhat important: 40%
  - Very important: 46%
  - Don't know: 10%

### Rehabilitation Professionals' Attitudes & Perceptions

- Rehab Professionals and PHAs:
  1) RPs currently possess adequate knowledge and skills to assess and treat PHAs: 55% disagree
  2) RPs who provide service to PHAs need specialized training in HIV/AIDS: 57% strongly agree
  3) Working with PHAs is similar to working with individuals with other chronic illnesses: 43% agree
  4) Many RPs are uncomfortable with the idea of working with PHAs: 42% agree
  5) Serving PHAs is more demanding than serving clients with other chronic illnesses: 48% disagree

* Based on scale: 'strongly agree', 'agree', 'disagree', 'strongly disagree', 'don't know'
Rehabilitation Professionals’ Attitudes and Perceptions

• Issues:
  1) Community-based agencies such as ASOs have a large role in rehabilitation in the context of HIV/AIDS 42% agree
  2) Most rehabilitation services received by PHAs are funded by government 71% don’t know
  3) Currently, most PHAs have to pay for their own rehabilitation services 75% don’t know
  4) Rehabilitation services are less available to PHAs compared to people living with other chronic illnesses or conditions 48% don’t know
  5) Rehabilitation services are primarily needed for PHAs at palliative stages of illness 52% disagree
  6) I personally feel that rehabilitation for PHAs should be a larger priority 38% agree/39% dk

* Based on scale: ‘strongly agree’, ‘agree’, ‘disagree’, ‘strongly disagree’, ‘don’t know’

In Summary

• Despite the role rehabilitation professionals have to play in the care and treatment of people living with HIV, only a minority currently serve PHAs
• HIV specialists currently provide limited rehabilitation-related services for PHAs and refer to a range of rehabilitation services
  – Need for further education and development in the field of rehabilitation in the context of HIV
  – CWGHR Capacity Building Project - Interprofessional Education for Rehabilitation Professionals

Acknowledgements:
National Advisory Committee

• Evan Collins
• Louis-Marie Gagnon
• Barney Hickey
• Jim Marianchuk
• Arlis McQuarrie
• Christopher Sulway
• Elisse Zack
Acknowledgements:
Funding

- Project funding:
  - Canadian Working Group on HIV and Rehabilitation (CWGHR)
  - Canadian Institutes of Health Research (CIHR)
- Fellowship funding:
  - Canadian Institutes of Health Research (CIHR)
  - The Ontario HIV Treatment Network
- HIV Studies Unit funding:
  - The AIDS Bureau, Ontario Ministry of Health and Long-Term Care and Faculty of Medicine, University of Toronto

Rehabilitation Roles

- Person specific (Nixon & Cott 2000)
- ADL & IADL (Stanton et al 1994, O’Dell 1993)
- Evaluation of swallowing dysfunction (Halvorsen et al 2003)
- Communicative functioning, feeding and swallowing skills (McNelly 2005)

Rehabilitation Roles

- Cognition, role changes, environmental assessment, facilitating occupational performance (Fish & Rudman 1998)
- Neurodevelopment, pain management, exercise, cardiorespiratory function (O’Dell 1993, Galantino 2001)
Further Rehabilitation Roles

- From your experience
- Related to other episodic illnesses

How Can We Think More Broadly about Rehabilitation in the Context of HIV and other Episodic Illnesses?

Characteristics

- Fluctuating periods of wellness and illness "ups and downs", "good days" and "bad days", "roller-coaster"
- May be super-imposed on permanent disability or a terminal illness (e.g. HIV: health fluctuates but ultimately living with a terminal illness)
- Often involves multiple systems: neurological, cardiorespiratory and/or musculoskeletal
Statistics for Episodic Illnesses

• Estimated 56,000 people living with HIV in Canada at the end of 2002
  • 12% increase from 49,800 in 1999

• Estimated 55-75,000 living with MS in Canada

• Estimated 498,000 living with COPD in Canada in 1998/99
  • Will likely increase due to aging population

“Strength in Numbers”

common disability and rehabilitation issues ➔ better understanding of:

• How persons with episodic illness move through the continuum of care
• Enhanced goal setting with persons with episodic illness
• Facilitate access to health care and PT services by persons with episodic illness
• Program or policy changes to better meet the rehabilitation needs of persons with EI (e.g. return to work policies – CPP, ODSP, etc.)

Summary

• New opportunities for rehabilitation
• Need for increased response
• Education
• Partnerships
REPORT SUMMARY

POLICY ISSUES ON REHABILITATION IN THE CONTEXT OF HIV DISEASE: A BACKGROUND AND POSITION PAPER

June, 2000
This paper has been approved by CWGHR and was developed through the CWGHR Project Advisory Committee. The Advisory Committee members are Ron Bowie, Kathy Dickson, Ethel Heald, Nancy Lawand, Arn Schilder, Roger LeClerc, Tom McAulay, and Elisse Zack. The researcher for the paper was Russel Ogden.

CWGHR gratefully acknowledges the financial support of the Care, Treatment and Support Program, HIV/AIDS Division of Health Canada for the development of this paper.

CWGHR also gratefully acknowledges the financial and/or in-kind support of: The Life and Health Insurance Companies in Canada, GlaxoWellcome in partnership with BioChem Pharma, BC Centre for Excellence in HIV/AIDS, Human Resources Development Canada, and St. Michael’s Hospital, Wellesley Central Site.

CWGHR recognizes and appreciates the outstanding commitment and effort of Russel Ogden in the research and development of this paper.

© The Canadian Working Group on HIV and Rehabilitation
Room 680, Bruce Wing,
St. Michael’s Hospital, Wellesley Central Site
160 Wellesley Street East
Toronto, Ontario
M4Y 1J3 Canada
REPORT SUMMARY

Who is CWGHR?

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sector and multi-discipline working group. CWGHR was formed in 1998 with a mission to enhance the quality of life for Canadians living with HIV disease by facilitating the development of rehabilitation programs and resources, promoting innovation and excellence in the field and by generating awareness of, and access to, rehabilitation services.

CWGHR has a dual mandate: a development and advisory role, and a funding role for projects and research. Its members include people living with HIV disease, community based HIV organisations, national professional organisations working with HIV and rehabilitation, relevant divisions of government, and private sector businesses and organisations.

What is Meant by Rehabilitation?

Perceptions have changed about HIV disease being a progressive, deteriorative and terminal illness with no effective treatment. It is increasingly viewed as a chronic-terminal condition that can be managed through antiretroviral medications. Nevertheless, there can be serious limitations to antiretroviral medications, including sometimes debilitating side effects from toxicity and resistance to therapy.

For the many persons with HIV disease who have benefited from antiretroviral therapies, there remain a number of impairments, disabilities and handicaps that are barriers to active participation in society. Indeed, the cyclic nature of HIV disease is a constant reminder that leading a relatively normal life often means reliance on a range of techniques of rehabilitation that can involve specialists from a variety of health care and social fields.

Given the relative infancy of HIV disease and the very recent development of life-extending treatments, rehabilitation is just beginning to play an important role in the
continuum of HIV care. A challenge for care providers will be the development, promotion, integration, and coordination of rehabilitation techniques into the mainstream of HIV care and service.

CWGHR places the term “rehabilitation” in a broad context in order to describe a range of techniques or interventions that can be applied to maintain, restore, or enhance aspects of health and quality of life. To provide a framework for rehabilitation in the context of HIV disease, CWGHR has adopted the World Health Organization’s *International Classification of Impairments, Disabilities and Handicaps* (World Health Organization, 1980). The concepts of impairments, disabilities and handicaps include health-related experiences that are not covered by the concept of disease.

*Impairments* are defined as any loss or abnormality of anatomical, physiological or psychological structure or function, such as weakness, impaired cognition, or fatigue. *Disabilities* are defined as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, such as difficulty walking, bathing, or getting dressed. *Handicaps* are defined as disadvantages for a given individual resulting from an impairment or a disability impacting on environmental barriers. These disadvantages may relate to work or to other societal roles and relationships.

In the context of HIV disease, rehabilitation can be viewed as a range of services that individuals may choose to rehabilitate themselves when they experience an impairment, disability, or handicap caused by their illness. The goal of rehabilitation is to slow deterioration by improving, restoring or maintaining activities and participation in daily life. Ultimately, rehabilitation aids an individual to optimise independence and quality of life, while minimising health and income support costs.

---

1 The World Health Organization first published the *International Classification of Impairment, Disability and Handicap* (ICIDH) in 1980. In 2000, the ICIDH-2 is being published (see World Health Organization, 1997). In this version, the term ‘disability’ is being replaced by ‘activity’ and ‘handicap’ is being replaced by ‘participation’ in order to avoid the negative connotations associated with the original terms.
Therefore, the goals of rehabilitation are centred on the person living with HIV disease. Many different people and organisations can be involved in the rehabilitation process. First and foremost, the individual is often involved personally in self-care activities that minimise impairments, disabilities and handicaps. The individual’s circle of friends and family may also play a role in this process.

Rehabilitation services may also be delivered by health care and social service professionals, including physiotherapists, occupational therapists, physicians, nurses, speech-language pathologists, social workers, psychologists, pharmacists, dieticians, and others. These services are often delivered by an interdisciplinary team of professionals and may be provided in a variety of environments, including inpatient and outpatient hospital settings, community clinics or in an individual’s home. Finally, rehabilitation activities may also be delivered through AIDS service organisations or other people working in the HIV community. Examples of such rehabilitation activities include recreation and support services such as dance or yoga classes, food banks, or mobility equipment exchanges.

**Literature on Rehabilitation in the Context of HIV Disease**

The body of literature on rehabilitation in the context of HIV disease is relatively small, with a heavy emphasis on vocational issues. This is not surprising given the relative infancy of HIV disease and the recent clinical advances in its treatment. A growing number of articles also address professional development, community development, and policy reform to improve the quality and scope of rehabilitation services for persons with HIV disease. To date, empirical research tends to be exploratory and usually is based on relatively small population samples.

At the program and policy level, a number of recent initiatives have begun to focus on the needs of persons with HIV disease with respect to disability and quality of life issues, disease prevention, and health promotion. Often, there is theoretical recognition that the complex physical and psychosocial impacts of HIV disease require a coordinated, integrated, and multidisciplinary approach. Although there are recent
examples where such theory is being applied to practice—such as the CHAP Program at Casey House in Toronto, or the Dr. Peter Centre in Vancouver—the programming is still too new to be evaluated.

In Canada, other disability organisations have developed models for addressing rehabilitative needs that are shared by many persons with HIV disease. For example, the Multiple Sclerosis Society has sponsored empirical research, developed an employment guide, and produced a self-help wellness manual for its members. The Arthritis Society, in cooperation with the pharmaceutical industry, has developed a self-management program for pain control and lifestyle improvement. These kinds of initiatives have the potential to be extended to persons with HIV disease.

**Purpose of the Background and Position Paper**

The research process for this paper involved a literature search and over 50 key-informant interviews with CWGHR members, their referred contacts, persons living with HIV disease, professional agencies, members of AIDS service groups, and academic and government institutions. This purpose of this paper is to: i) provide background on policy issues concerning rehabilitation in the context of HIV disease, ii) identify key players and guide CWGHR’s planning in addressing these issues, and iii) inform potential research and project areas.

Following a review of the issues identified in the research process for this background and position paper, the CWGHR membership determined 28 recommendations for action. These are reproduced at end of this Summary. In general, there is a need for greater professional development for practitioners working in areas that are HIV related. Many health care professionals have never received formal education about HIV disease, yet they often find themselves working in related areas of rehabilitation. Interdisciplinary models of integrated service need to be identified and best practice standards of rehabilitation service delivery need to be established. In addition to barriers in accessing rehabilitation services, persons living with HIV disease encounter numerous vocational and income support issues that are often complex because
of the cyclical nature of HIV disease and partial disability. With respect to these issues, there is a need for research, education, and advocacy. Indeed, many persons with HIV disease lack knowledge about what to expect from rehabilitation, so they are poorly positioned to advocate for services.

HIV, both as disease and disability, is of immense importance because of its economic, medical, social, ethical, and political impact. The challenge for CWGHR and the rehabilitation community is to foster coordination and cooperation across public and private sectors to promote solutions in education, research, and service so that rehabilitation techniques can be established as integral to the care for persons with HIV disease. Fundamental to this process is that there be a client-centred focus. This means that goals must be multidisciplinary rather than discipline specific, and that the wishes and values of the client must be incorporated and evaluated with clients’ input.

The emergence of CWGHR, recent shifts toward models of multidisciplinary and client-centred care, and a number of unique research initiatives all speak to a convergence of interests dedicated to enhancing the quality of life for persons with HIV disease. In Canada, rehabilitation in the context of HIV disease is at a critical and formative period. Cooperation across sectors of government and private industry, HIV/AIDS organisations, persons with HIV disease, health care professionals, academe and other disability groups is needed because rehabilitation issues are inter-related and require a coordinated approach.
Recommendations for Action\textsuperscript{2,3}

Research

1. Given that a variety of comprehensive, interdisciplinary models of integrated service for people living with HIV disease exist, it is recommended that these models be identified and evaluated for best practice standards of rehabilitation service delivery in the context of HIV disease.

\textit{Sphere of influence:} Researchers; practitioners; educators.

\textit{Potential partners:} Provincial and national professional organisations.

2. Given the complexity of impairments, disabilities and handicaps that people living with HIV/AIDS may experience, it is recommended that accurate and appropriate assessment tools be developed.

\textit{Sphere of influence:} Researchers; practitioners; educators.

\textit{Potential partners:} Provincial and national professional organisations.

3. Given that the field of rehabilitation in the context of HIV/AIDS is so young, it is recommended that strategies be explored for encouraging interdisciplinary research in this area.

\textit{Sphere of influence:} Researchers; HIV/AIDS research funders; practitioners.

\textit{Potential partners:} Provincial and national professional organisations.

\textsuperscript{2} These recommendations should be considered with regard to the context of all people with HIV disease, with reference to gender, age, culture and other relevant background. The “potential partners” named in this section are suggestions only; there may be additional appropriate partners. CWGHR recognises and acknowledges the different functions of both HIV consumer and/or disability groups, and AIDS service organisations (ASO’s). The identification of various community-based HIV organisations and their respective roles in effecting change should proceed according to such roles and mandates. CWGHR’s involvement as a partner will vary with different issues and various organisations will be appropriate to give leadership in relation to specific recommendations. The recommendations are not listed in accordance with any specific priorities for action.

\textsuperscript{3} In the sphere of influence and potential partners categories, “practitioners” include relevant health care and social service professionals. “Educators” include people working in relevant undergraduate and graduate programs, and “researchers” refers to researchers associated with these professions. “Professional organisations” refers to local, provincial, and national bodies, including general associations and HIV/AIDS organisations (i.e. College of Family Physicians of Canada, Canadian Physiotherapy Association, Canadian Association of Physical Medicine and Rehabilitation, Canadian Association of Occupational Therapists, Canadian Association of Social Workers, Canadian Nurses Association, Canadian Association of Nurses in AIDS Care, Canadian Psychological Association and Dieticians of Canada, Canadian Association of Speech Language Pathologists and Audiologists).
4. Given that there is a lack of reliable empirical research into the existing arrangements and requirements for active living for persons with HIV disease, it is recommended that a comprehensive survey into the socio-demographic characteristics and health status of Canadians with HIV disease be conducted. The survey should investigate arrangements for active living, use of and satisfaction with existing services and caring professionals. It should explore differences in service provision and availability in rural and urban locations, and it should measure the degree of satisfaction with quality of life as experienced by persons with HIV disease so that rehabilitation professionals and organisations can better determine ways to enhance quality of life.

Sphere of influence: CWGHR (through a request for proposals).
Potential partners: Community-based HIV organisations.

5. Given that return to meaningful activity is a goal of rehabilitation for people living with HIV/AIDS, it is recommended that research be undertaken to understand the impact on individuals when this goal is achieved.

Sphere of influence: Researchers.
Potential partners: Researchers; community-based HIV organisations; practitioners in primary care.

6. Given that the simple, local, and multi-discipline approach of the Vancouver MAT/DOT (Maximally Assisted Therapy/Directly Observed Therapy) program has the capacity to establish important care and support relationships with marginalised persons with HIV disease, it is recommended that the outcomes of the program be evaluated to determine if there are lessons that could be of benefit to similar populations, nationally. Additionally, the capacity of such a model to be integrated with services such as stable housing, psychosocial support, methadone programming and heroin substitution should be explored.

Sphere of influence: BC Centre for Excellence in HIV/AIDS; researchers.
Potential partners: CWGHR (through a request for proposals); Vancouver AIDS service organisations.

7. Given that issues of “engagement” and “therapeutic alliance” are currently being researched as important variables in the delivery of rehabilitation services to “difficult” multi-challenged populations, it is recommended that similar research involving gay men with HIV disease should also be conducted.

Sphere of influence: Researchers and research funders.
Potential partners: CWGHR (through a request for proposals); Health Canada.

---

4 This research is taking place at the Dr. Peter Centre in Vancouver.
8. Given that access to and effectiveness of rehabilitation is often difficult for people living with HIV disease who are chemically dependent, it is recommended that research be undertaken into harm reduction models of health care, or where research exists, appropriate action be taken.

*Sphere of influence:* Researchers and research funders.

*Potential partners:* CWGHR (through a request for proposals); Health Canada; HIV/AIDS Legal Network.

**Professional Practice and Education**

9. Given that health care and social service professional students may not receive adequate comprehensive education in the area of rehabilitation in the context of HIV/AIDS, it is recommended that gaps in undergraduate and graduate education be identified and addressed.

*Sphere of influence:* Educators and practitioners in academic and clinical settings.

*Potential partners:* Provincial and national professional organisations.

10. Given that many health care and social service professionals currently working in the area of rehabilitation in the context of HIV/AIDS have never received formal education about HIV disease, it is recommended that continuing education needs are identified and addressed.

*Sphere of influence:* Educators and practitioners in academic and clinical settings.

*Potential partners:* Community-based HIV organisations; Provincial and national professional organisations.

11. Given the advantages of early rehabilitation intervention, it is recommended that primary health care providers be educated about these advantages and be given guidance in how to make appropriate referrals.

*Sphere of influence:* Educators and practitioners in academic and clinical settings.

*Potential partners:* Community-based HIV organisations; Provincial and national professional organisations.

12. Given that the role of rehabilitation for infants and children living with HIV/AIDS is a relatively new and growing field, it is recommended that relevant issues in rehabilitation education, practice and research are explored.

*Sphere of influence:* Educators, researchers and practitioners in paediatrics.

*Potential partners:* Provincial and national professional organisations.

13. Given the advantages of early rehabilitation intervention, it is recommended that AIDS service organisations and the broader HIV community be educated about these advantages and be given guidance in how to make appropriate referrals.

*Sphere of influence:* Community-based HIV organisations; practitioners; educators.

*Potential partners:* Canadian AIDS Society; community-based HIV and professional organisations.
14. Given the increase in older people with HIV disease and that specific treatments prescribed for normal ageing processes will have implications for medical interventions for HIV disease, it is recommended that AIDS service organisations prepare their education and programming to include the needs of older people. Partnerships with organisations that serve older people need to be developed in order to ensure that older people with HIV disease and their care providers are able to benefit from community HIV services.

*Sphere of influence:* Health Canada; Community-based HIV organisations; Canadian AIDS Society.

*Potential partners:* CWGHR; AgeWise.

15. Given that HIV/AIDS affects diverse populations, such as people from First Nations, it is recommended that implications for rehabilitation education, practice and research be explored with regard to the unique needs of such populations.

*Sphere of influence:* Practitioners, educators and researchers.

*Potential partners:* Community-based HIV organisations; First Nations communities; provincial and national professional organisations.

16. Given that some professional organisations working in the area of rehabilitation in the context of HIV/AIDS do not have current position papers recognising the significance of their roles in the field, it is recommended that these organisations be identified and encouraged to do so.

*Sphere of influence:* Professional organisations.

*Potential partners:* Canadian AIDS Society; CWGHR.

17. Given that rehabilitation in the context of HIV disease is part of a social movement to enhance care for persons living with HIV disease, it is recommended that researchers, community-based organisations, other partners/stakeholders, and persons living with HIV disease collaborate to ensure that their mutual projects are published and widely disseminated.

*Sphere of influence:* CWGHR.

*Potential partners:* The Canadian AIDS Society; Community-based HIV organisations; professional organisations of health and social service workers; academic institutions; internet publishers.
Vocational Issues & Income Support Issues

18. Given that some aspects of group insurance policies have been identified as barriers to successful rehabilitation efforts (see Elliott, 1999), it is recommended that such aspects be identified and that research be undertaken to develop solutions that could include further engagement of partners to overcome or minimise such barriers, with advocacy being undertaken as necessary.

Sphere of influence: Federal Department of Finance; provincial regulatory bodies; private health insurance companies.

Potential partners: AIDS Committee of Toronto, Canadian Life and Health Insurance Association; Canada Pension Plan.

19. Given that medical advances are changing the nature of HIV disease, it is recommended that advocacy be undertaken for innovative rating structures to make all forms of insurance more accessible to people living with HIV disease.

Sphere of influence: Disability insurers.

Potential partners: HIV/AIDS Legal Network; MS Society.

20. Given that the CPP disability program has been criticised by disability groups for inadequacies in its definition of disability, contribution rules, and processing of applications and appeals as well as for its lack of an effective transitional vocational rehabilitation program which recognises chronic and cyclical disability, it is recommended that a review of the implications of the CPP disability program be undertaken and that areas for reform be identified and addressed.

Sphere of influence: Human Resources Development Canada/Canada Pension Plan Disability Benefits Program.

Potential partners: HIV/AIDS Legal Network; Canadian AIDS Society; Council of Canadians with Disabilities.

21. Given that the Guide to Insurance Benefits is intended to be updated periodically, it is recommended that amendments include the following: i) information about risk-benefit issues concerning long term disability and return to work; ii) contact lists about current programs offering detailed benefits counselling (e.g. Employment Action at ACT); iii) working pages and checklists to assist readers in determining the kind of coverage they may require, if any; and iv) information about sub-standard insurance (rated life insurance) and partial disability insurance.

Sphere of influence: The Canadian AIDS Society.

Potential partners: Community-based HIV organisations; MS Society; Canada Pension Plan.

22. Given that the recent bankruptcy of Eaton’s revealed a legal loophole in self-insured long term disability plans, it is recommended that there be legislated reform to

---

5 Income support issues and vocational issues are a shared category because it is common for persons with HIV disease to fluctuate between employment and unemployment. More specifically, “vocational issues” relates to recommendations related to helping people become or stay employed. “Income support” relates to all people, whether employed, employable or not.
ensure that all long-term disability benefits provided by employers have protection similar to that of regular pension plans (see p. 36).

**Sphere of influence:** Relevant government departments.

**Potential partners:** Provincial governments; unions; professional organisations; Canadian Labour Congress; Canadian AIDS Society; HIV/AIDS Legal Network; Community-based HIV organisations.

23. Given that many persons with HIV disease are already employed, it is recommended that information and assistance be provided to employees and employers about disclosure of HIV status, workplace accommodations, health and life insurance benefits, access to provincial drug programs and access to legal counsel.

**Sphere of influence:** Canadian AIDS Society.

**Potential partners:** HIV/AIDS Legal Network; community based HIV organisations; CWGHR; provincial disability support programs; provincial health and social service ministries/departments; HRDC; Canadian Human Rights Commission; employers; unions; Provincial disability support programs.

24. Given that analysis is needed to determine what makes it possible for a person with HIV disease to stay in the workplace and what systemic barriers make it difficult to sustain work, it is recommended that employer associations, insurance industry, governments, unions and AIDS service organisations come together to find common ground in accommodating the medical needs of persons with HIV who work.

**Sphere of influence:** (none, per the group)

**Potential partners:** HIV/AIDS Legal Network; Canadian AIDS Society; provincial AIDS service organisations; Canadian Labour Congress; HRDC; professional organisations; insurers.

25. Given that progressive employment practices set examples for improved industry standards, it is recommended that a national AIDS in the workplace manual be developed to promote standards for workplace policies and accommodations for persons with HIV disease. It is also recommended that a program be established for employers to be recognised for their best practices with respect to HIV/AIDS in the workplace.

**Sphere of influence:** Canadian AIDS Society; HIV/AIDS Legal Network.

**Potential partners:** Community-based HIV organisations; Conference Board of Canada; Fraser Institute; Canadian Labour Congress; European AIDS and Enterprise Network.6

---

6 The European AIDS and Enterprise Network recently initiated a program for employers to nominate themselves in three categories: HIV and AIDS policy regarding employment and workplace; supporting people living with HIV disease in remaining or returning to work; and HIV education for the work force.
26. Given anecdotal reports across disabilities regarding terminations of CPP disability benefits, it is recommended that research be undertaken to explore the scope and nature of such terminations and that any necessary advocacy be undertaken. *Sphere of influence:* Canada Pension Plan/Human Resources Development Canada. *Potential partners:* HIV/AIDS Legal Network; Canadian AIDS Society; Community-based HIV organisations; MS Society; CWGHR.

**Other**

27. Given that the HIV/AIDS Legal Network has recently begun a major project to identify legal and policy issues in HIV care, treatment and support, it is recommended that CWGHR collaborate with the Network to determine common interests and potential partnerships on issues relating to disability and rehabilitation. *Potential partners:* Health law institutes; Canadian AIDS Society; centres for bioethics.

28. Given that the wellness approach is widely recognised within the AIDS/disability movement, is client centred and empowering, and provides a framework for professionals and support groups to focus discussion and set priorities, it is recommended that a resource and/or education program for health promotion be developed for persons with HIV disease to manage issues that could include: pain management, fatigue, adherence, access to care, support and treatment programs. *Sphere of influence:* Canadian AIDS Society; Community-based HIV organisations. *Potential partners:* Multiple Sclerosis Society; Council of Canadians with Disabilities; Canadian Association of Occupational Therapists.
Executive Summary

Context
The conditions and diseases associated with HIV infection continue to change. Since the introduction of highly active antiretroviral therapy (HAART) in 1996, people in developed countries living with HIV/AIDS who are able to access and tolerate HAART are living longer. HIV disease increasingly is perceived as a chronic, episodic condition rather than a terminal illness. This chronicity is mirrored by the increased prevalence of people living with HIV/AIDS (PHAs) living with disability, and an increased role for rehabilitation. In Canada, rehabilitation in the context of HIV disease is at a formative stage. A recent study that documented the prevalence of impairments, disabilities, and handicaps among PHAs in British Columbia found a remarkably high prevalence of disablement. However, no complementary work has investigated rehabilitation in the context of HIV from a service provider perspective.

The Study
The purpose of this study was to describe the knowledge, attitudes, and practices of selected health care provider groups concerning rehabilitation services for PHAs in order to provide baseline data for program and policy development. Specific objectives were to:

1. Describe the extent and nature of involvement of rehabilitation professionals in HIV service provision to PHAs in Canada; and
2. Describe the extent and nature of involvement of HIV specialists in rehabilitation in Canada.

With the support of the Canadian Working Group on HIV and Rehabilitation (CWGHR) and in collaboration with a national advisory group, a rehabilitation framework in the context of HIV/AIDS was developed to provide a broad conceptual understanding of service domains and issues. This framework provided the basis for the development of two survey instruments, developed and pretested with the assistance of the national advisory committee. A nationwide Canadian survey funded by the Canadian Institutes of Health Research (CIHR) was conducted with a sample of selected rehabilitation professionals and the known population of HIV specialists. The rehabilitation professionals included physical therapists, occupational therapists, physiatrists, and speech-language pathologists who may or may not have been working in the area of HIV/AIDS. The HIV specialists included physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), nurses, dieticians, pharmacists, social workers, and psychologists working in the HIV field. The survey was administered to the selected health care providers via mail using the Dillman Tailored Design Method.

Results
Results presented in this report describe the knowledge, attitudes and practices of HIV and rehabilitation provider groups in four areas:

A) Current Practices in HIV Rehabilitation
B) Training, Knowledge & Workplace Awareness in Rehabilitation and HIV
C) Views on Professionals’ Roles in HIV Rehabilitation, and
D) HIV Rehabilitation Service Delivery Issues.

Rehabilitation Professionals Summary: For rehabilitation professionals, the response rate was 71%, with 1,058 usable surveys produced. The majority of the respondents were female (88%) and averaged 14 years in practice. Sixty-one percent indicated that they had never knowingly served an HIV positive client. Of these, 27% indicated they would like to work with this client group (27% would not, and 46% were unsure). Of the 39% who had knowingly served an HIV positive client, the mean number of PHAs
served in the past year was 4. Only 27% had received training in HIV/AIDS as part of their rehabilitation education. Forty-eight percent reported no or little awareness of HIV rehabilitation within their workplaces. The majority of rehabilitation professional respondents indicated that their profession was somewhat (40%) or very important (46%) to PHAs, but only 19% agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat PHAs. Fifty-three percent disagreed that serving PHAs is more demanding than serving clients with other chronic illnesses or conditions. However, 50% agreed that many rehabilitation professionals are uncomfortable with the idea of working with PHAs. Forty-one percent indicated that there were service barriers specific to HIV that might prevent PHAs from having their rehabilitation needs met such as stigma, lack of available funding, and lack of education health providers.

**HIV Specialists Summary:** Among the HIV specialists, the response rate was 55% with 214 eligible surveys produced. Respondents included nurses, physician, social workers, pharmacists, psychologists, and dietitians who had worked in an HIV clinical setting within the past 12 months. Respondents averaged 16 years in practice and had seen a mean of 53 HIV positive clients within the last month. Ninety percent were from metropolitan or urban areas. Sixty-two percent indicated that under half of their HIV caseload was rehabilitation-related, where rehabilitation was defined as services and activities that address or prevent impairments, activity limitations, and participation restrictions. Within the last year, 86% had referred HIV positive clients to social workers, 85% had referred to community-based AIDS service organizations, 50% to physiotherapists, 35% to occupational therapists, 32% to physiatrists, and 10% speech-language pathologists. The most important rehabilitation issues in the context of HIV were seen to be income supports (85% indicated ‘very important’), prevention (83%), chronic poverty (81%), housing (80%), employment (76%), and stigma (74%). The majority of reasons for referral to rehabilitation services were to address issues including social service assistance (85%), income support (80%), drug coverage assistance (79%), psychosocial issues (76%) and housing support (74%). Seventy-five percent indicated that their profession was ‘very important’ in the rehabilitation of PHAs. Ninety-four percent agreed or strongly agreed that rehabilitation professionals who provide service for PHAs need specialized training, and only 44% agreed or strongly agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat PHAs.

**Conclusions and Service Implications**
Despite the role that rehabilitation professionals may play in the care and treatment of PHAs, only a minority currently serve HIV/AIDS clients. Those who had served PHAs had seen only a small number of PHAs in the past year, and reasons for which they served their HIV clients were primarily for rehabilitation issues unrelated to their HIV status. HIV specialists currently provide limited rehabilitation-related services for PHAs. However, they refer to a range of services that do provide rehabilitation services for PHAs. HIV specialists refer PHAs primarily for social participation restrictions and consider community-based supports and social workers to be crucial for PHAs. Study results suggest that there is a need for increased information for, and education of, rehabilitation professionals, HIV specialists, PHAs, and other health and service providers who may refer to rehabilitation professionals on the role of rehabilitation in the context of HIV/AIDS. There is also a need for more collaborative practice among health care professionals to better meet the rehabilitative needs of PHAs.

**Acknowledgements**
The research team would like to acknowledge the national advisory committee for their guidance throughout the course of the development, implementation and interpretation of results of this survey. Advisory committee members include: Evan Collins, Louis-Marie Gagnon, Barney Hickey, Jim Marianchuk, Arlis McQuarrie, Christopher Sulway and Elisse Zack.
HIV and Rehabilitation: The Canadian Providers’ Survey

Introduction
The conditions and diseases associated with HIV infection continue to change. Since the introduction of highly active antiretroviral therapy (HAART) in 1996, people living with HIV/AIDS (PHAs) who are able to access and tolerate HAART are living longer, which is largely the case in developed countries. For those individuals, HIV disease increasingly is perceived as a chronic, long-term condition rather than a rapidly, terminal illness. This chronicity is mirrored by the increased prevalence of PHAs living with disability, and an increased role for rehabilitation. In Canada, rehabilitation in the context of HIV disease is at a formative stage. It is critical that baseline information on the understandings and state of rehabilitation in the context of HIV be collected in order to foster cooperation across health care professional groups, HIV/AIDS organizations, PHAs, sectors of government, private industry, and academe. A recent study that documented the prevalence of impairments, disabilities, and handicaps among PHAs in British Columbia found a remarkably high prevalence of disablement. However, no complementary work has investigated rehabilitation in the context of HIV from a service provider perspective. To this point, little is documented about rehabilitation services in the context of HIV/AIDS. Thus, it is important to seek better information about the provision of rehabilitation services to more effectively develop the rehabilitation field for PHAs. The aim of this research project was to describe professionals’ current knowledge, attitudes, and practices concerning rehabilitation services for PHAs to provide baseline data to inform programs and policy.

Background – Developmental Study
In a position paper, the Canadian Working Group on HIV and Rehabilitation (CWGHR) identified a major gap in knowledge about the provision of rehabilitation services for PHAs. CWGHR is a national, autonomous, multi-sectoral and multi-disciplinary working group, established in 1998, to facilitate a national, coordinated response to emerging rehabilitation needs in the context of HIV/AIDS. CWGHR funded the developmental phase of this project. This phase involved the development of 1) an HIV/AIDS conceptual rehabilitation framework to encompass the broad domains of rehabilitation services and issues, and 2) two survey instruments designed to collect information on HIV rehabilitation services in Canada. Development of the conceptual framework and survey instruments involved consultation and collaboration with a national advisory committee including people living with HIV/AIDS and representatives from various health care provider groups and service organizations across Canada (Appendix A).

Conceptual HIV/AIDS Rehabilitation Framework and Survey Development
The framework was based on information gathered from an extensive review of the literature, consultations with the Advisory Committee, and interviews with thirteen key informants from across Canada who had knowledge and expertise in HIV/AIDS rehabilitation. This framework was deliberately constructed to be broad in scope in order to conceptualize rehabilitation-related services for PHAs in new and innovative ways. For the purposes of the study, rehabilitation was defined using the International Classification of Functioning, Disability and Health (ICF) as all prevention and/or treatment activities and/or services that address body impairments, activity limitations and participation restrictions experienced by an individual.

The framework includes two intersecting components. First, from the perspective of those living with HIV/AIDS, are issues and disabilities associated with living with HIV. Second, from the service
provision perspective are concepts of rehabilitation, traditional and non-traditional rehabilitation services, and their potential place within the context of HIV/AIDS. At the centre of the model the concepts of rehabilitation and disability meet. Details of the framework are published elsewhere. 5 6

Given the broad scope and inclusiveness of the framework, it potentially allowed for exploration of a range of attitudes and perceptions from multiple health service provider groups, including informal care providers, community groups, and others. In order to keep the current study manageable, a decision was made to focus on traditional rehabilitation provider groups (physical therapy, occupational therapy, physiatry, and speech-language pathology) and HIV specialist groups (physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), nurses, dieticians, pharmacists, social workers, and psychologists working in the HIV field). However, the surveys developed from the framework for these groups were inclusive of other forms of rehabilitation-related activities.

Purpose and Objectives
The purpose of this descriptive study was to explore the knowledge, attitudes, and practices of selected health care provider groups concerning rehabilitation services for PHAs in order to provide baseline data to inform program and policy development. Specific objectives were to:

1. Describe the extent and nature of involvement of rehabilitation professionals (physical therapy, occupational therapy, physiatry, and speech-language pathology) in the provision of HIV services to PHAs in Canada; and
2. Describe the extent and nature of involvement of HIV specialists (physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), nurses, dieticians, pharmacists, social workers, and psychologists working in the HIV field) in rehabilitation in Canada. In particular, the following research questions were explored:

A) Current Practices in HIV Rehabilitation
   1. What are rehabilitation professionals’ experiences in the area of HIV/AIDS?
   2. What are HIV specialists’ experiences with rehabilitation in the context of HIV/AIDS?

B) Training, Knowledge and Workplace Awareness in Rehabilitation and HIV
   1. What are rehabilitation professionals’ levels of training in the area of HIV/AIDS?
   2. What are HIV specialists’ levels of training in rehabilitation?

C) Views on Professionals’ Roles in HIV Rehabilitation
   1. What are rehabilitation professionals’ views on their role in HIV rehabilitation?
   2. What are HIV specialists’ views on rehabilitation professionals’ role in HIV rehabilitation?

D) HIV Rehabilitation Service Delivery Issues
   1. What are the emerging professional and service delivery issues that may influence the current and future delivery of rehabilitation services for PHAs?

Research Design
Overview
A national, cross-sectional mail survey of two selected sets of health care provider groups (rehabilitation professionals and HIV specialists) was conducted. Survey data were collected using the Dillman Tailored Design Method. A random sample of rehabilitation professionals was drawn from lists obtained from health professional and regulatory organizations across Canada. The known population of selected HIV specialists was contacted using lists from professional organizations and supplemented using a snowball technique. The survey instrument was developed using the HIV/AIDS Conceptual Rehabilitation Framework in consultation with the national advisory committee, as described earlier.
Two versions of a survey instrument were created, one for rehabilitation professionals and one for HIV specialists. Each survey was available in English and in French.

**National Advisory Committee**
The national advisory committee that collaborated with investigators on the developmental study continued to provide guidance throughout the survey implementation study and was involved in the review of the results and interpretation and dissemination of findings. The committee consisted of six members. One original member left the committee and was supplemented by a new member for the survey implementation study. Committee members included people living with HIV/AIDS, health care providers knowledgeable in the area of rehabilitation in the context of HIV/AIDS, and representatives from regulatory bodies and HIV treatment organizations (Appendix A).

**Target Groups and Sample**
Surveying two sets of health care provider groups permitted examination of the practices, experiences, and attitudes from two different health care perspectives: rehabilitation professionals and HIV specialists. The rehabilitation professional group included occupational therapists, physical therapists, speech-language pathologists, and physiatrists who may or may not be practicing in the area of HIV/AIDS. The HIV specialist group included: dieticians, nurses, pharmacists, physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), psychologists and social workers working in the field of HIV/AIDS.

**Sampling Frame**
Professional organizations and/or regulatory bodies for each of the professional groups from the ten provinces, plus the Northwest Territories, Nunavut and the Yukon, were contacted to determine the level of endorsement and support for this research. Details of sampling frame creation, indicating professional association and regulatory body willingness to provide mailing lists and the resulting sample pools from which the samples for each provider group were drawn, are provided elsewhere.8 The sampling frames included provider groups from all provinces and territories grouped into seven Canadian regions: 1) British Columbia, 2) Alberta, 3) Prairies (Saskatchewan and Manitoba), 4) Ontario, 5) Quebec, 6) Atlantic Canada (New Brunswick, Newfoundland, Nova Scotia and Prince Edward Island), and 7) the Territories (Northwest Territories, Yukon, and Nunavut).

1) **Rehabilitation professionals**: Random samples of rehabilitation professionals who may or may not work in the field of HIV/AIDS were drawn from the sampling frames created for occupational therapists, physical therapists, and speech-language pathologists. These sampling frames included names from national voluntary organization lists, cross-checked with provincial regulatory body lists, where available. Cross-checking national professional organization lists with regulatory body lists increased the total rehabilitation pool from which to draw the random samples by 37% (occupational therapy), 24% (physical therapy), and 36% (speech-language pathology). For physiatrists, a random sample was drawn from a list compiled using physiatry regulatory body information.

2) **HIV specialists**: The known population of HIV specialists was identified through professional organizations and supplemented by asking survey respondents to provide the names of other professionals working in the HIV field (snowball technique). Snowball sampling contributed 6% of the total HIV specialist sample.

**Survey Instruments**
As noted previously, questionnaires for the two provider groups were developed in collaboration with the advisory committee and were comprised of six sections entitled: 1) Clinical (or Rehabilitation)
Practice, 2) Clients, 3) Training and HIV Knowledge, 4) Health Service Providers and HIV Rehabilitation, 5) Rehabilitation and HIV Service Delivery Issues and 6) Personal Information. The rehabilitation survey included a seventh section specifically for rehabilitation professionals who served clients living with HIV in the past year. Once the instruments were finalized they were translated into French by a translator knowledgeable in the HIV and rehabilitation field.

**Survey Implementation**

**Pretesting and Pilot Testing**
The preliminary survey instruments and survey protocol were finalized based on feedback from the national advisory committee and a small mailout to a sample of HIV specialists and rehabilitation professionals (n=10) respectively.

**Data Collection**
Survey data collection occurred between April and October 2004. Questionnaires were distributed in English to all provinces, and French versions were also included in packages mailed to Quebec and New Brunswick. The data collection strategy was based on the Dillman Tailored Design Method (TDM).7

a) An initial brief pre-notice letter was sent to the respondents a few days prior to the mailout of surveys. The letter indicated that the survey would arrive by mail in a few days and that a response would be appreciated;

b) A survey questionnaire was mailed, along with a cover letter identifying the aims and importance of the research and a promise of confidentiality; refusal card, and a self-addressed, prepaid return envelope;

c) A thank you postcard was sent one week after the survey that expressed appreciation to those who responded, and reminded those that had not yet mailed their survey to do so. The importance of responding was reiterated and a telephone number was provided to enable potential respondents to request an additional copy of the survey or further information about the research if necessary;

d) A fourth mail contact urging recipients to respond was sent 2-4 weeks after the first questionnaire mailout. It included a replacement cover letter, survey, refusal card, and return envelope.

**Data Management and Analysis**
An administrative database was developed to sample and track responses to the survey. SPSS was used for data entry, verification, cleaning, descriptive and bivariate statistics, and table generation. Thematic analysis was utilized for open-ended questions.

**Results**
Figure 1 displays data collection and response categories for rehabilitation professionals and HIV specialist groups, including ineligibles, refusals, and successful responses.

Survey results are presented according to the study objectives. For each of the two health care provider groups, after respondent characteristics are described, results are presented according to the four following areas: a) Current Practices in HIV Rehabilitation, b) Training, Knowledge and Workplace Awareness in Rehabilitation and HIV, c) Views on Professionals’ Roles in HIV Rehabilitation, and d) HIV Rehabilitation Service Delivery Issues.
Figure 1: Overview of Survey Responses for Rehabilitation Professionals and HIV Specialists

**LEGEND:**

Ineligible Responses = Providers (Rehabilitation professionals and HIV specialists) who did not meet the inclusion criteria. Those excluded were rehabilitation professionals who had not worked in a clinical setting or HIV specialists who had not worked in a clinical HIV setting in the previous 12 months. All surveys included preliminary screening questions on work in a clinical or clinical HIV setting in the previous year.

Success = Eligible providers who successfully completed and returned questionnaires.

Refused = Eligible providers who refused participation by returning a refusal card.

* Indicates response rate after returned to senders and ineligible respondents removed from denominator.
Rehabilitation Professional Results
Results for the rehabilitation professionals likely accurately represent Canadian rehabilitation professionals' knowledge, attitudes and practices with respect to rehabilitation in the context of HIV, given the detailed sampling frames constructed for each professional group and the response rates achieved.

Rehabilitation Professional Respondent Characteristics
Forty-seven percent of the 1058 survey respondents were PTs, 41% were OTs, 9% SLPs, and 3% physiatrists (these percentages are roughly proportionate to those surveyed in each profession). The majority of rehabilitation professional respondents were either between 25-35 years (42%) or 36-50 years of age (41%), 16% were over 50 years and 1% were less than 25 years of age. Eight-eight percent were female and 12% were male.

Rehabilitation professional respondents had practiced an average of 14 years. On average, PTs (mean 16 years) had practiced significantly longer than OTs (mean 13 years) or SLPs (mean 11 years). (Physiatrists in the sample had also practiced a mean of 16 years.) The largest percentage of respondents (43%) worked in metropolitan settings of 500,000 or more. Over half (53%) of rehabilitation professional respondents were from Ontario, 13% were from Alberta, 10% from British Columbia, 10% from the Prairies (Saskatchewan and Manitoba), 9% from Atlantic Canada, 3% from Quebec, and less than 1% from the Northwest Territories, Yukon and Nunavut. Respondents worked in a variety of clinical settings such as acute care hospitals [including inpatient settings (29%) and outpatient settings (21%)], home care (29%), individual private practice (22%), and group private practice (19%). Rehabilitation professional respondents interacted most with PTs, OTs, general physicians and nurses within their clinical practice. OTs, SLPs and PTs tended to interact mostly with those within their profession whereas physiatrists interacted mostly with pharmacists (87%), psychiatrists (62%) and psychologists (79%).

a) Current Practices in HIV Rehabilitation
Services to PHAs: Overall, 61% of rehabilitation professional respondents had never knowingly served a client who was HIV positive. Of those, 27% indicated this was a client group they would like to work with, 27% indicated they would not want to work with this client group and 46% were unsure.

Of the 39% of rehabilitation professional respondents who had served PHAs:
- On average, they served only 4 HIV positive clients (range: 1-240 clients) in the past year.
- 98% stated that less than 25% of their current rehabilitation caseload was HIV related.
- 75% indicated that less than 25% of the rehabilitation issues of their HIV clients were HIV-related.
- The majority of referrals to rehabilitation for PHAs were from physicians (81%) (general practitioners, neurologists, orthopaedic surgeons, general internists, infectious disease specialists, and psychiatrists), case managers (36%), other professionals who provide rehabilitation-related services (36%) (PTs, OTs, SLPs, social workers and nurses) and people living with HIV who self referred (12%).
- Activities related to their HIV clinical caseload ‘frequently’ or ‘always’ included assessment (53%), treatment (52%), consultation (48%), and health promotion (39%) in a typical week.
- Rehabilitation approaches used with their HIV clients within the past year included maintenance (63% of respondents), restorative (62%), supportive (61%), compensatory (56%), health promotion (46%), preventative (40%), and palliative (27%).
- 69% served adult PHAs 36-55 years of age, 54% served young adult PHAs between 18-35 years of age, 24% served older adult PHAs (56+ years) and 9% served PHAs under the age of 18.
HIV & Rehabilitation: The Canadian Providers’ Survey ~ Summary Report

- 61% served PHAs who were intravenous drug users, 59% served men who have sex with men, 51% served women, 47% served Aboriginals, 34% served people from endemic countries, 20% served youth and 18% served children.

- Rehabilitation services that were available to their HIV positive clients included: physiotherapy (reported by 83% of respondents), social work (82%), occupational therapy (81%), speech-language pathology (73%), physiatry (60%), rehabilitation assistants (PTA or OTA) (60%), recreation therapy (46%), kinesiology (33%), community-based HIV/AIDS service organizations (32%), exercise therapy (30%), complementary / alternative therapy (27%), and exercise physiology (16%).

Impairments, activity limitations and participation restrictions: HIV clients presented to rehabilitation professionals with a range of impairments, activity limitations, and participation restrictions during assessment. Table 1 displays the percentage of rehabilitation professionals who reported PHA clients presented with specific impairments, limitations and participation restrictions. Impairments, activity limitations and participation restrictions seen most often by rehabilitation providers for assessment included decreased activity tolerance, weakness, fatigue, musculoskeletal impairments, mobility issues, pain, difficulties with activities of daily living, and coping difficulties.

| Decreased activity tolerance / capacity | 82 |
| Weakness | 77 |
| Fatigue | 74 |
| Musculoskeletal impairments | 72 |
| Mobility issues | 69 |
| Pain | 67 |
| Difficulties with activities of daily living (e.g. bathing, dressing, eating) | 67 |
| Coping difficulties | 64 |
| Energy conservation | 60 |
| Psychosocial issues | 59 |
| Balance problems | 58 |
| Weight loss | 54 |
| Adaptive equipment prescription | 53 |
| Decreased coordination | 52 |
| Gait assessment | 49 |
| Instrumental activities of daily living (e.g. shopping, meal preparation) | 48 |
| Neurological dysfunction | 48 |
| Social service needs | 48 |
| Discharge planning issues | 46 |

| Shortness of breath | 39 |
| Cognitive impairment | 37 |
| Home safety assessment | 36 |
| Return to work / school issues | 36 |
| Poor lung ventilation | 32 |
| Income support | 31 |
| Difficulty / inability to manage finances | 30 |
| Peripheral neuropathy | 30 |
| Implications from prolonged bed rest | 30 |
| Housing needs | 29 |
| Difficulty / inability to make medical decisions | 29 |
| Disclosure issues pertaining to HIV status | 25 |
| Cardiac dysfunction | 23 |
| Secretion retention | 20 |
| Swallowing dysfunction | 17 |
| Speech dysfunction | 15 |
| Swallowing assessment | 14 |
| Vision loss | 13 |
| Vocational rehabilitation | 12 |

Treatment interventions used to address impairments, limitations and restrictions with PHA clients varied. Table 2 displays the percentage of rehabilitation professionals who used each type of treatment intervention to address impairments, limitations and participation restrictions of HIV clients. Treatment
interventions most often used by rehabilitation professional respondents included: strengthening exercises, energy conservation, adaptive equipment education, range of motion, activities of daily living training, and education.

**Table 2: Percentage of Rehabilitation Professionals Using Treatment Interventions to Address Impairments, Activity Limitations and Participation Restrictions of HIV Clients**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengthening exercises</td>
<td>64</td>
</tr>
<tr>
<td>Energy conservation</td>
<td>62</td>
</tr>
<tr>
<td>Adaptive equipment education</td>
<td>58</td>
</tr>
<tr>
<td>Range of motion</td>
<td>58</td>
</tr>
<tr>
<td>Activities of daily living training</td>
<td>56</td>
</tr>
<tr>
<td>Education</td>
<td>55</td>
</tr>
<tr>
<td>Positioning training and education</td>
<td>50</td>
</tr>
<tr>
<td>Gait / mobility training</td>
<td>50</td>
</tr>
<tr>
<td>Facilitate linkages to other professionals, services and resources</td>
<td>48</td>
</tr>
<tr>
<td>Pain control</td>
<td>46</td>
</tr>
<tr>
<td>Balance training</td>
<td>45</td>
</tr>
<tr>
<td>Postural retraining</td>
<td>43</td>
</tr>
<tr>
<td>Environmental assessment</td>
<td>43</td>
</tr>
<tr>
<td>Instrumental activities of daily living training</td>
<td>39</td>
</tr>
<tr>
<td>Aerobic exercise</td>
<td>35</td>
</tr>
<tr>
<td>Prevention</td>
<td>33</td>
</tr>
<tr>
<td>Advocacy</td>
<td>29</td>
</tr>
<tr>
<td>Cognitive interventions</td>
<td>28</td>
</tr>
<tr>
<td>Improve lung ventilation</td>
<td>25</td>
</tr>
<tr>
<td>Mobilization of secretions</td>
<td>23</td>
</tr>
<tr>
<td>Neurofacilitation techniques</td>
<td>22</td>
</tr>
<tr>
<td>Family interventions (counseling)</td>
<td>21</td>
</tr>
<tr>
<td>Electrotherapeutic modalities</td>
<td>20</td>
</tr>
<tr>
<td>Facilitate / assist with administrative duties (completion of forms, etc.)</td>
<td>18</td>
</tr>
<tr>
<td>Counseling</td>
<td>16</td>
</tr>
<tr>
<td>Feeding strategies / diet modification (for swallowing impairments)</td>
<td>12</td>
</tr>
<tr>
<td>Desensitization techniques</td>
<td>11</td>
</tr>
<tr>
<td>Psychological counseling</td>
<td>11</td>
</tr>
<tr>
<td>Nutrition</td>
<td>11</td>
</tr>
<tr>
<td>Swallowing therapy / exercises</td>
<td>8</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>6</td>
</tr>
<tr>
<td>Language / voice therapy / voice amplification</td>
<td>6</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>5</td>
</tr>
</tbody>
</table>

Links to Other HIV Service Providers: Only 14% of rehabilitation professional respondents who served PHAs within the past year stated that as part of their clinical practice they link with community-based AIDS service organizations (ASOs).

- **a.** Some ASOs they link with include: AIDS Committee of Toronto, Persons with AIDS Foundation (and other local ASOs), Casey House, Community Care Access Centres, CWGHR and the YMCA.

- **b.** ASO services accessed by rehabilitation professionals for their HIV clients include: meals on wheels, housing, peer counseling and group support, food bank, vocational counseling, legal and immigrant issues, medical treatment, home visits, rehabilitation services, palliative care, complementary therapies, and advocacy.

- **c.** ASO service providers that rehabilitation providers link with include: case coordinators, nurses, massage therapists, peer counselors and support group facilitators, medical personnel, personal support workers, social workers, OTs, and PTs.

Only 9% of rehabilitation professional respondents who served PHAs within the past year stated they link with service providers in the area of complementary and alternative therapies or medicine. These providers included yoga instructors, massage therapists, aromatherapists, chiropractors, acupuncturists, volunteers, and homeopaths.
b) Rehabilitation Professionals’ Training Knowledge and Workplace Awareness in HIV

Rehabilitation Professionals’ Training: Only 27% of rehabilitation professional respondents stated they received training in HIV/AIDS as part of their health degree education. In terms of professional groups, the least amount of training was reported among SLPs (90% did not receive any HIV training in their degree program). Of the 281 rehabilitation professional respondents who did receive training:

- the types of information or training received included: HIV lectures or guest speakers (68% of respondents who received training), HIV educational materials (e.g. literature, videos, manuals) (65%), case studies related to HIV (54%), HIV training opportunities (e.g. workshops, courses, conferences) (14%), clinical placements or internships in the area of HIV (12%) and mentorship or shadowing programs with health professionals in the area of HIV (9%).
- the mean total number of hours of education in the HIV/AIDS area was: 12 hours (range: 0-435 hours). The greatest average number of education hours was received by physiatrists (17 hours) and the least average was received by SLPs (7 hours).

In the past five years, only 11% of rehabilitation professional respondents participated in specialty training or continuing education in the area of rehabilitation related to HIV/AIDS beyond that received in their health degree education. Of the 116 who participated in specialty training or continuing education related to HIV/AIDS in the past five years:

- the types of training or continuing education included: HIV educational materials (e.g. literature, videos, manuals) (84%), HIV lectures or guest speakers (e.g. rounds, lectures) (68%), HIV training opportunities (e.g. workshops, courses) (34%), case studies related to HIV (29%), mentorship or shadowing programs with other professionals (10%), clinical placements or internships in the area of HIV (8%), and other types of training (40%) such as self reading, post-graduate studies, CWGHR forum, media, and current practice.

Rehabilitation Professionals’ Knowledge and Workplace Awareness of HIV: Rehabilitation professionals were asked a series of questions on their level of knowledge about various aspects of HIV. While the majority rated themselves as ‘somewhat’ or ‘very’ knowledgeable in many areas, there were also areas where a significant percentage rated themselves as ‘not at all knowledgeable’. Areas where a large percentage of rehabilitation professionals indicated they were ‘not at all knowledgeable’ included HIV related policies (79%), treatment medications for HIV (69%), the episodic course of HIV infection (68%), HIV pathogenesis (59%), HIV epidemiology (52%), psychosocial aspects of HIV (34%), HIV-associated disability (33%), and the diagnosis of HIV infection (32%). A very small percentage rated themselves as ‘not at all knowledgeable’ about HIV transmission (2%) and HIV prevention (3%).

Rehabilitation professionals were also asked about HIV rehabilitation awareness in their workplaces. Eighty-seven percent of rehabilitation professional respondents perceive that others in their workplace possess ‘little’ (41%) or ‘some’ (46%) levels of awareness of rehabilitation in the context of HIV/AIDS.

c) Views on Professionals’ Roles in HIV Rehabilitation

Forty-six percent of rehabilitation professional respondents felt their profession is ‘very important’ in the rehabilitation of PHAs. A significantly higher percentage of OTs considered their profession very important (63%) in HIV rehabilitation compared with PTs (37%), physiatrists (32%) and SLPs (17%).

Importance of Professional Groups in HIV Rehabilitation: Table 3 describes the level of importance rehabilitation professional respondents perceived health providers to have in HIV rehabilitation. Over 80% of respondents (highlighted) believed that dieticians, nurses, pharmacists, GPs, infectious disease specialists, social workers, and community based ASOS in areas of return to work, vocational rehabilitation, housing and coping support are ‘very important’ with respect to rehabilitation for PHAs.
Table 3: Rehabilitation Professionals’ Perceptions of the Importance of Health Provider Groups in HIV Rehabilitation

<table>
<thead>
<tr>
<th>Providers</th>
<th>Very important (%)</th>
<th>Somewhat important (%)</th>
<th>Not at all important (%)</th>
<th>Don’t know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncturists</td>
<td>21</td>
<td>42</td>
<td>9</td>
<td>29</td>
</tr>
<tr>
<td>Audiologists</td>
<td>6</td>
<td>29</td>
<td>22</td>
<td>42</td>
</tr>
<tr>
<td>Chiropodists</td>
<td>13</td>
<td>33</td>
<td>12</td>
<td>41</td>
</tr>
<tr>
<td>Chiropractors</td>
<td>8</td>
<td>34</td>
<td>24</td>
<td>34</td>
</tr>
<tr>
<td>Community-based ASOs – legal support</td>
<td>79</td>
<td>15</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Community-based ASOs – return to work</td>
<td>83</td>
<td>11</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Community-based ASOs – vocational rehabilitation</td>
<td>81</td>
<td>13</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Community-based ASOs – housing support</td>
<td>82</td>
<td>10</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Community-based ASOs – coping support</td>
<td>93</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Dental hygienists</td>
<td>38</td>
<td>36</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Dental technologists</td>
<td>22</td>
<td>33</td>
<td>8</td>
<td>38</td>
</tr>
<tr>
<td>Dentists</td>
<td>42</td>
<td>34</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Denturists</td>
<td>17</td>
<td>31</td>
<td>10</td>
<td>42</td>
</tr>
<tr>
<td>Dieticians</td>
<td>82</td>
<td>10</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Homeopaths</td>
<td>36</td>
<td>31</td>
<td>8</td>
<td>26</td>
</tr>
<tr>
<td>Massage therapists</td>
<td>29</td>
<td>46</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Medical laboratory technologists</td>
<td>74</td>
<td>14</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Medical radiation technologists</td>
<td>31</td>
<td>24</td>
<td>7</td>
<td>38</td>
</tr>
<tr>
<td>Naturopaths</td>
<td>31</td>
<td>34</td>
<td>9</td>
<td>26</td>
</tr>
<tr>
<td>Nurses</td>
<td>90</td>
<td>6</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>64</td>
<td>29</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Occupational therapy assistants</td>
<td>32</td>
<td>45</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>Opticians</td>
<td>18</td>
<td>40</td>
<td>6</td>
<td>36</td>
</tr>
<tr>
<td>Optometrists</td>
<td>26</td>
<td>37</td>
<td>5</td>
<td>32</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>93</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Physical therapists</td>
<td>53</td>
<td>38</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Physical therapy assistants</td>
<td>30</td>
<td>47</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>GPs</td>
<td>89</td>
<td>9</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Infectious disease specialists</td>
<td>94</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>65</td>
<td>26</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Other physicians such as: oncologists, neurologists, paediatricians, cardiologists</td>
<td>46</td>
<td>22</td>
<td>2</td>
<td>32</td>
</tr>
<tr>
<td>Psychologists</td>
<td>77</td>
<td>17</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Reflexologists</td>
<td>11</td>
<td>30</td>
<td>21</td>
<td>38</td>
</tr>
<tr>
<td>Respiratory therapists</td>
<td>59</td>
<td>25</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Recreation therapists</td>
<td>41</td>
<td>41</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Social workers</td>
<td>88</td>
<td>9</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Speech language pathologists</td>
<td>17</td>
<td>38</td>
<td>14</td>
<td>31</td>
</tr>
</tbody>
</table>

*Highlight indicates >80% of rehabilitation professionals who perceive providers as ‘very important’.
Personal Views on HIV and Rehabilitation: Rehabilitation professionals were asked their views on rehabilitation and HIV. Table 4 summarizes their views based on their level of agreement with a variety of statements pertaining to rehabilitation in the context of HIV/AIDS.

### Table 4: Rehabilitation Professionals’ Views on Rehabilitation in the Context of HIV/AIDS

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (%)</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
<th>Strongly Disagree (%)</th>
<th>Don’t Know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Rehabilitation professionals currently possess adequate knowledge and skills to assess and treat people living with HIV/AIDS.</td>
<td></td>
<td></td>
<td>56</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>b) Rehabilitation professionals who provide services for people living with HIV/AIDS need specialized training in the area of HIV/AIDS.</td>
<td>58</td>
<td>33</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>c) There are few people living with HIV/AIDS that live in my geographic area of practice.</td>
<td></td>
<td></td>
<td>23</td>
<td>15</td>
<td>42</td>
</tr>
<tr>
<td>d) Working with people living with HIV/AIDS is similar to working with individuals with other chronic illnesses.</td>
<td>9</td>
<td>43</td>
<td>28</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>e) Many rehabilitation professionals are uncomfortable with the idea of working with people living with HIV/AIDS.</td>
<td>8</td>
<td>42</td>
<td>23</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>f) Rehabilitation services are less available to people living with HIV/AIDS compared to people with other chronic illnesses or conditions.</td>
<td></td>
<td>5</td>
<td>23</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>g) Rehabilitation services are primarily needed for people living with HIV/AIDS at palliative stages of illness.</td>
<td>2</td>
<td>10</td>
<td>53</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>h) Serving people living with HIV is more demanding than serving clients with other chronic illnesses</td>
<td>3</td>
<td>11</td>
<td>48</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>i) Community-based agencies such as AIDS service organizations have a large role in rehabilitation in the context of HIV/AIDS.</td>
<td>26</td>
<td>42</td>
<td>2</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>j) Most rehabilitation services received by people living with HIV/AIDS are funded by government.</td>
<td>2</td>
<td>16</td>
<td>10</td>
<td>1</td>
<td>71</td>
</tr>
<tr>
<td>k) Currently, most people living with HIV/AIDS have to pay for their own rehabilitation services.</td>
<td>1</td>
<td>7</td>
<td>15</td>
<td>1</td>
<td>76</td>
</tr>
<tr>
<td>l) I personally feel that rehabilitation for people living with HIV/AIDS should be a larger priority.</td>
<td>7</td>
<td>39</td>
<td>14</td>
<td>1</td>
<td>39</td>
</tr>
</tbody>
</table>

*Highlight indicates category with the highest proportion for each statement.

### d) HIV Rehabilitation Service Delivery Issues
Rehabilitation professionals were asked about challenges in delivering rehabilitation services in general, and were also asked about barriers specific to HIV services.

Seventy-four percent of rehabilitation professional respondents indicated that in their area of practice in the last year, waiting lists was a challenge to access and delivery of rehabilitation services, while 72% indicated funding issues (e.g. high costs and under funding) were a challenge, 68% availability of rehabilitation services, and 64% clients’ lack of information about the availability of resources.

Forty-one percent of rehabilitation professional respondents felt that there are current barriers specific to HIV that might prevent PHAs from having their rehabilitation needs met. Reported barriers included...
stigma, fear, lack of available funding, lack of education of health care providers, and lack of available services in rural areas.

In a series of open-ended questions, rehabilitation professionals were asked how they perceive the role of rehabilitation in the context of HIV/AIDS has changed changing over the years, and how the needs of PHAs will change in the future. A large number (85) indicated that they “don’t know” or “cannot comment”. However, several distinct themes were evident from many other respondents’ answers. Respondents indicated that they felt there is an increased role for rehabilitation as PHAs are living longer. They also perceived that rehabilitation is now required earlier (shifting from the more traditional palliative focus of care), with an emphasis on optimizing physical function, participation and quality of life. Also, many respondents indicated that the needs of PHAs will shift, including an increased need for housing and flexible return to work programs. In turn, this will require increased community involvement, a multi-disciplinary approach to care, and the need for more education on the role for rehabilitation in HIV.

**HIV Specialist Results**

Results for HIV specialists should be considered exploratory, given the lack of a pre-existing sampling frame, use of snowball supplementation, and response rate. However, these results provide valuable complementary information to the rehabilitation professional results, and point to areas in need of further investigation and development.

**HIV Specialist Respondent Characteristics**

Forty-seven percent of the 214 survey respondents were nurses, 35% were physicians, 7% social workers, 6% pharmacists, 3% psychologists, and 2% dieticians (these percentages are roughly proportionate to those surveyed in each profession). The majority of HIV specialist respondents (54%) were between 36-50 years of age, with 14% between 25-35 years and 32% over 50 years of age. No respondents were under 25 years of age. Sixty-five percent were female.

HIV specialist respondents had practiced an average of 16 years, ranging from an average of 8 years for dieticians to 19 years for psychiatrists. The largest percentage of HIV specialist respondents (60%) worked in metropolitan settings of 500,000 or more. Only 8% reported they work in a northern region. Just over one-third (36%) of HIV specialist respondents were from Ontario, 20% were from Quebec, 18% were from British Columbia, 9% were from the Prairies (Saskatchewan and Manitoba), 8% from Alberta, 7% from Atlantic Canada, and 2% from the Northwest Territories, the Yukon, and Nunavut. Respondents worked in a variety of clinical settings such as acute care hospitals [including inpatient settings (42%), HIV clinics (46%) and outpatient settings (50%)], private practice (9%), home care (9%) and AIDS service organizations (9%).

In the context of their HIV clinical caseloads, the largest percentage of HIV specialists reported interacting with nurses (94%), general physicians (91%), pharmacists (90%), infectious disease specialists (89%), social workers (89%), dieticians (81%), and psychiatrists (78%). Some HIV specialists tended to interact more with two of the traditionally-defined rehabilitation professions (PT and OT) than other HIV specialist professions. While 40% of all HIV specialist respondents interacted with PTs in the context of their HIV caseload, a significantly higher percentage of social workers (53%) and nurses (49%) reported interacting with PTs. In terms of interaction with OTs in the HIV clinical caseload context, 39% of all HIV specialists reported interacting with OTs; however, 65% of social workers and 42% of general practitioners reported interacting with OTs. Thirteen percent of all HIV specialists reported interacting with SLPs. This percentage did not vary significantly across professions.
a) Current Practices in HIV Rehabilitation

Services to PHAs: On average, HIV specialist respondents served 126 clients in the past month, 54 of whom were HIV positive (43%). Although the number of HIV clients served did not differ significantly between professional groups, nurses (with an average of 70 HIV positive clients), pharmacists (with an average of 65 HIV positive clients) and GPs (with an average of 85 HIV positive clients) reported the highest number of HIV positive clients served in the past month. In a typical week, activities related to their HIV clinical caseload ‘frequently’ or ‘always’ included assessment (77%), treatment (72%), consultation (70%), and health promotion (65%).

Client groups:
- In the past year, 88% of HIV specialist respondents reported serving ‘some’ or ‘many’ young adults between 18-35 years, 92% served ‘some’ or ‘many’ adults between 36-55 years of age, and 47% served ‘some’ or ‘many’ older adults (56+ years).
- 91% never or rarely served children (< 18 years of age), 54% never or rarely served youth, 35% never or rarely served Aboriginal peoples, 26% never or rarely served people from HIV endemic countries, 13% never or rarely served women, 11% never or rarely served PHAs who were intravenous drug users, and 5% never or rarely served men who have sex with men.

HIV specialists were provided with the definition of rehabilitation adapted from the World Health Organization’s ICF (see page 3 of this document) and asked what proportion of their current HIV caseload they would consider to be rehabilitation-related. Overall, 63% of HIV specialist respondents indicated that less than half of their HIV clinical caseload was rehabilitation-related. However, this varied significantly by professional group. A substantial proportion of some professions indicated that 75-100% of their HIV caseload was rehabilitation-related, including 47% of social workers, 43% of psychologists, 40% of dieticians, and 32% of nurses.

Referral Practices and Rehabilitation Services Availability: Within the past year, 86% of HIV specialist respondents had referred their HIV positive clients to a social worker, 85% referred to a community-based HIV/AIDS service organization, 50% to a physiotherapist, 35% to an occupational therapist, 32% to a physiatrist, 30% to a complementary/alternative therapist, 10% to a speech-language pathologist, 8% to a recreation therapist, 8% to an exercise therapist, 4% to an exercise physiologist, and 1% to a kinesiologist.

- **Referrals to Physical Therapy (PT):** GPs (79%), nurses (57%), and infectious disease specialists (52%) referred significantly more to PT.
- **Referrals to Occupational Therapy (OT):** GPs (50%), social workers (47%) and psychologists (43%) tended to refer more to OT.
- **Referrals to Physiatry:** GPs (50%), social workers (47%) and nurses (35%) tended to refer more to Physiatry.
- **Referrals to Speech-Language Pathology (SLP):** GPs (15%), infectious disease specialists (14%) and nurses (11%) tended to refer more to SLP.

Rehabilitation services available to HIV specialists’ HIV clients included social work (95% of respondents reported they were available), community-based HIV/AIDS service organizations (90%), physiotherapy (86%), occupational therapy (83%), speech-language pathology (64%), physiatry (58%), complementary/alternative therapy (54%), rehabilitation assistants (PTA or OTA) (52%), recreation therapy (35%), exercise therapy (27%), exercise physiology (19%), and kinesiology (18%).
Reasons for Rehabilitation Referral: HIV specialists were asked the reasons they referred their HIV positive clients to health providers who provide rehabilitation-related services. The largest percentage of HIV specialists reported referrals to services that address *participation restrictions*, including social service assistance (85%), income support (80%), drug coverage assistance (79%), psychosocial issues (76%) and housing support (74%). Table 5 summarizes the percentage of HIV specialists referring to various rehabilitation-related services (in descending order).

**Table 5: HIV Specialists’ Reasons for Referrals to Rehabilitation Services / Providers**

<table>
<thead>
<tr>
<th>Reasons For Referral</th>
<th>Proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social service assistance</td>
<td>85</td>
</tr>
<tr>
<td>Income support</td>
<td>80</td>
</tr>
<tr>
<td>Drug coverage assistance</td>
<td>79</td>
</tr>
<tr>
<td>Psychosocial issues (e.g. coping strategies, motivation)</td>
<td>76</td>
</tr>
<tr>
<td>Housing support</td>
<td>74</td>
</tr>
<tr>
<td>Facilitate linkages to resources / services</td>
<td>65</td>
</tr>
<tr>
<td>Health promotion</td>
<td>59</td>
</tr>
<tr>
<td>Pain</td>
<td>56</td>
</tr>
<tr>
<td>Peripheral neuropathy</td>
<td>55</td>
</tr>
<tr>
<td>Advocacy</td>
<td>54</td>
</tr>
<tr>
<td>Education</td>
<td>53</td>
</tr>
<tr>
<td>Weight gain promotion</td>
<td>51</td>
</tr>
<tr>
<td>Cognitive assessment / rehabilitation</td>
<td>47</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>44</td>
</tr>
<tr>
<td>Vision assessment / treatment</td>
<td>43</td>
</tr>
<tr>
<td>Capacity / Competency Assessment</td>
<td>41</td>
</tr>
<tr>
<td>Instrumental activities of daily living (e.g. shopping, meal prep)</td>
<td>42</td>
</tr>
<tr>
<td>Activities of daily living training (e.g. bathing, dressing, eating)</td>
<td>39</td>
</tr>
<tr>
<td>Weight loss promotion</td>
<td>34</td>
</tr>
<tr>
<td>Home safety equipment</td>
<td>33</td>
</tr>
<tr>
<td>Adaptive equipment prescription</td>
<td>30</td>
</tr>
<tr>
<td>Musculoskeletal rehabilitation</td>
<td>27</td>
</tr>
<tr>
<td>Neurological rehabilitation</td>
<td>27</td>
</tr>
<tr>
<td>Vocational rehabilitation</td>
<td>23</td>
</tr>
<tr>
<td>Activity tolerance training</td>
<td>21</td>
</tr>
<tr>
<td>Mobility training</td>
<td>21</td>
</tr>
<tr>
<td>Prevention (e.g. from implications of prolonged bedrest such as contractures, deconditioning)</td>
<td>19</td>
</tr>
<tr>
<td>Cardiac rehabilitation</td>
<td>18</td>
</tr>
<tr>
<td>Cardiorespiratory Rehabilitation (e.g. improve lung ventilation, secretion clearance)</td>
<td>17</td>
</tr>
<tr>
<td>Swallowing assessment / treatment</td>
<td>17</td>
</tr>
<tr>
<td>Strength training</td>
<td>14</td>
</tr>
<tr>
<td>Energy conservation strategies</td>
<td>13</td>
</tr>
<tr>
<td>Speech assessment / treatment</td>
<td>12</td>
</tr>
<tr>
<td>Coordination training</td>
<td>11</td>
</tr>
<tr>
<td>Balance training</td>
<td>10</td>
</tr>
</tbody>
</table>
Links to Other HIV Service Providers: Eighty-five percent of HIV specialist respondents stated they link with community-based AIDS service organizations (ASOs) that serve PHAs as part of their clinical practice.

a. Some ASOs they link with include: AIDS Committee of Toronto, Persons with AIDS Foundation, 9 Circles, AIDS Committee London (and other local ASOs), Dr. Peter Centre, and Casey House.

b. ASO services accessed by HIV specialists include: advocacy, housing, peer counseling and group support, transport, needle exchange, meals / food bank, alternative therapists, financial assistance, assistance with application (i.e. Trillium), education, and legal advice.

c. ASO service providers that HIV specialists link with include: case coordinators, social workers, nurses, massage therapists, counselors and support group facilitators, medical personnel, addictions counselors, support workers and advocates.

Twenty-two percent of HIV specialist respondents stated they link with service providers in the area of complementary and alternative therapies or medicine. Some types of these providers included: yoga instructors, massage therapists, reflexologists, Reiki therapists, chiropractors, acupuncturists, naturopaths and homeopaths.

b) HIV Specialists’ Training, Knowledge and Workplace Awareness in Rehabilitation

HIV Specialists’ Training: Only 14% of HIV specialists stated they received training in rehabilitation as it relates to HIV/AIDS as part of their health degree education. Of the 29 HIV specialists who did receive training, (dieticians, nurses, pharmacists, GPs, infectious disease specialists and social workers):

- the types of information or training received included: rehabilitation and HIV lectures/guest speakers (89% of respondents who received training), rehabilitation and HIV training opportunities (e.g. workshops, courses, conferences) (78%), rehabilitation and HIV educational materials (e.g. literature, videos, manuals) (74%), case studies related to rehabilitation in the context of HIV (74%), mentorship/shadowing programs with health professionals in the area of HIV rehabilitation (59%), and clinical placements/internships in the area of rehabilitation in the context of HIV (52%).

- the mean total number of hours of education in the area of rehabilitation as it relates to HIV/AIDS was 65 hours. This ranged from a mean of 12 hours (dieticians) to 300 hours (social workers).

Fifty-nine percent of HIV specialist respondents participated in specialty training or continuing education in the area of rehabilitation related to HIV/AIDS beyond that received in their health degree education in the past 5 years. Of the 122 who participated in specialty training or continuing education in the area of rehabilitation as it related to HIV/AIDS in the past 5 years:

- the types of training or continuing education included: HIV lectures/guest speakers (e.g. rounds, lectures) (94%), HIV educational materials (e.g. literature, videos, manuals) (89%), HIV training opportunities (e.g. workshops, courses) (82%), case studies related to HIV (61%), mentorship/shadowing programs with other professionals (26%), and clinical placements/internships in the area of HIV (17%) and other types of training (26%) such as the CANAC conference, other conferences, and research.

HIV Specialists’ Knowledge and Awareness of HIV Rehabilitation: HIV specialist respondents rated themselves ‘very knowledgeable’ in areas of transmission of HIV (96%), HIV prevention (96%), diagnosis of HIV infection (88%), treatment medications for HIV (68%), HIV psychosocial aspects
(68%), episodic course of HIV infection (66%), HIV epidemiology (63%), HIV-associated disability (58%), HIV pathogenesis (55%), and HIV related policies (36%).

Forty percent of HIV specialist respondents perceived that others in their workplaces possess ‘high’ to ‘very high’ levels of awareness of rehabilitation in the context of HIV/AIDS. Another 42% perceived that others in their workplaces have ‘some’ awareness, while only 19% felt that others in their workplaces possessed no or little awareness of rehabilitation in the context of HIV.

c) Views on Professionals’ Roles in HIV Rehabilitation

Seventy-five percent of HIV specialist respondents felt their profession is ‘very important’ in the rehabilitation of PHAs. This varied across professions, with only 46% of responding pharmacists, 55% infectious disease specialists, and 65% general physicians rating their profession as ‘very important’ in the rehabilitation of PHAs.

Twenty-two percent of HIV specialist respondents indicated that “rehabilitation” as defined by the survey ‘very clearly describes’ their current practice (43% of psychologists, 41% of social workers, and 40% of dieticians placed their practice in this category), 47% said it ‘somewhat describes’ their current practice and 30% said it ‘does not describe’ their clinical practice (the majority of pharmacists (54%) and GPs (57%) placed their clinical practice in this category).

Importance of Professional Groups in HIV Rehabilitation: Table 5 describes the level of importance HIV specialist respondents perceived health providers to have in HIV rehabilitation. Over 80% of HIV specialist respondents (highlighted in yellow) believed that dieticians, nurses, pharmacists, GPs, infectious disease specialists, social workers, psychiatrists and community based ASOs in areas of legal support, return to work, housing and coping support are ‘very important’ with respect to rehabilitation for persons with HIV/AIDS. These importance ratings may be compared with Table 3, rehabilitation professionals’ views on the importance of various health provider groups in HIV rehabilitation.

<table>
<thead>
<tr>
<th>Providers</th>
<th>Very important (%)</th>
<th>Somewhat important (%)</th>
<th>Not at all important (%)</th>
<th>Don’t know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncturists</td>
<td>15</td>
<td>43</td>
<td>27</td>
<td>15</td>
</tr>
<tr>
<td>Audiologists</td>
<td>11</td>
<td>48</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td>Chiropodists</td>
<td>13</td>
<td>50</td>
<td>21</td>
<td>17</td>
</tr>
<tr>
<td>Chiropractors</td>
<td>16</td>
<td>42</td>
<td>28</td>
<td>15</td>
</tr>
<tr>
<td>Community-based ASOs – legal support</td>
<td>82</td>
<td>16</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Community-based ASOs – return to work</td>
<td>83</td>
<td>13</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Community-based ASOs – vocational rehab</td>
<td>73</td>
<td>24</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Community-based ASOs – housing support</td>
<td>90</td>
<td>7</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Community-based ASOs – coping support</td>
<td>93</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Dental hygienists</td>
<td>53</td>
<td>38</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Dental technologists</td>
<td>29</td>
<td>42</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>Dentists</td>
<td>63</td>
<td>32</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Denturists</td>
<td>31</td>
<td>43</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Dieticians</td>
<td>88</td>
<td>10</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Homeopaths</td>
<td>14</td>
<td>38</td>
<td>35</td>
<td>13</td>
</tr>
<tr>
<td>Massage therapists</td>
<td>33</td>
<td>45</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Medical laboratory technologists</td>
<td>54</td>
<td>26</td>
<td>14</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 5 continued…

<table>
<thead>
<tr>
<th>Providers</th>
<th>Very important (%)</th>
<th>Somewhat important (%)</th>
<th>Not at all important (%)</th>
<th>Don’t know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical radiation technologists</td>
<td>29</td>
<td>38</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Naturopaths</td>
<td>16</td>
<td>40</td>
<td>32</td>
<td>13</td>
</tr>
<tr>
<td><strong>Nurses</strong></td>
<td><strong>96</strong></td>
<td><strong>4</strong></td>
<td><strong>0</strong></td>
<td><strong>0</strong></td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>65</td>
<td>28</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Occupational therapy assistants</td>
<td>37</td>
<td>29</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>Opticians</td>
<td>33</td>
<td>45</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Optometrists</td>
<td>44</td>
<td>42</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>93</td>
<td>5</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Physical therapists</td>
<td>67</td>
<td>28</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Physical therapy assistants</td>
<td>35</td>
<td>34</td>
<td>12</td>
<td>19</td>
</tr>
<tr>
<td>GPs</td>
<td>91</td>
<td>8</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Infectious disease specialists</td>
<td>92</td>
<td>6</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>83</td>
<td>15</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other Physicians such as: oncologists, respirologists, dermatologists, neurologists, paediatricians, and cardiologists</td>
<td>54</td>
<td>37</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Psychologists</td>
<td>76</td>
<td>21</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Reflexologists</td>
<td>6</td>
<td>41</td>
<td>35</td>
<td>18</td>
</tr>
<tr>
<td>Respiratory therapists</td>
<td>32</td>
<td>44</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Recreation therapists</td>
<td>26</td>
<td>46</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Social workers</td>
<td>93</td>
<td>5</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Speech language pathologists</td>
<td>14</td>
<td>48</td>
<td>23</td>
<td>15</td>
</tr>
</tbody>
</table>

*Highlight indicates >80% of HIV specialists who perceive providers as ‘very important’.

Personal Views on HIV and Rehabilitation: HIV specialists were asked their views on rehabilitation and HIV. Table 6 summarizes their views based on their level of agreement with a variety of statements pertaining to rehabilitation in the context of HIV/AIDS. Statements with both dark and light highlighted boxes indicated differences in views among HIV specialist compared with rehabilitation professional respondents.

Table 6: HIV Specialists’ Views on Rehabilitation in the Context of HIV/AIDS

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (%)</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
<th>Strongly Disagree (%)</th>
<th>Don’t Know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Rehabilitation professionals currently possess adequate knowledge and skills to assess and treat people living with HIV/AIDS.</td>
<td>7</td>
<td>38</td>
<td>32</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>b) Rehabilitation professionals who provide services for people living with HIV/AIDS need specialized training in the area of HIV/AIDS.</td>
<td>55</td>
<td>39</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>c) There are few people living with HIV/AIDS that live in my geographic area of practice.</td>
<td>6</td>
<td>10</td>
<td>24</td>
<td>58</td>
<td>1</td>
</tr>
<tr>
<td>d) Working with people living with HIV/AIDS is similar to working with individuals with other chronic illnesses.</td>
<td>10</td>
<td>31</td>
<td>45</td>
<td>14</td>
<td>0</td>
</tr>
<tr>
<td>e) Many rehabilitation professionals are uncomfortable with the idea of working with people living with HIV/AIDS.</td>
<td>7</td>
<td>35</td>
<td>33</td>
<td>2</td>
<td>23</td>
</tr>
</tbody>
</table>
Table 6 continued…

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (%)</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
<th>Strongly Disagree (%)</th>
<th>Don’t Know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>f) Rehabilitation services are less available to people living with HIV/AIDS compared to people with other chronic illnesses.</td>
<td>12</td>
<td>28</td>
<td>33</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>g) Rehabilitation services are primarily needed for people living with HIV/AIDS at palliative stages of illness.</td>
<td>5</td>
<td>8</td>
<td>58</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>h) Serving people living with HIV is more demanding than serving clients with other chronic illnesses.</td>
<td>14</td>
<td>33</td>
<td>39</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>i) Community-based agencies such as AIDS service organizations have a large role in rehabilitation in the context of HIV/AIDS.</td>
<td>41</td>
<td>51</td>
<td>5</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>j) Most rehabilitation services received by people living with HIV/AIDS are funded by government.</td>
<td>12</td>
<td>42</td>
<td>19</td>
<td>3</td>
<td>25</td>
</tr>
<tr>
<td>k) Currently, most people living with HIV/AIDS have to pay for their own rehabilitation services.</td>
<td>3</td>
<td>14</td>
<td>48</td>
<td>6</td>
<td>29</td>
</tr>
<tr>
<td>l) I personally feel that rehabilitation for people living with HIV/AIDS should be a larger priority.</td>
<td>25</td>
<td>58</td>
<td>7</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

*Dark highlight (yellow) indicates category with the highest proportion for each statement for HIV specialists.*

*Light highlight (grey) indicates category with the highest proportion for each statement of the rehabilitation providers (if different from HIV specialists).*

### d) Rehabilitation and HIV Service Delivery Issues

HIV specialists were asked about challenges in delivering health and rehabilitation services in general, and were also asked about service barriers specific to HIV rehabilitation.

Sixty-eight percent of HIV specialist respondents indicated that in their area of practice in the last year, availability of rehabilitation services was an issue while 66% indicated client lack of information about resources was an issue, 61% indicated waiting lists, 59% indicated funding issues (e.g. high costs, under funding), 57% indicated restrictive service delivery policies (provincial, regional, or organizational), and 53% indicated stigmatization and discrimination associated with HIV were issues.

Seventy-four percent of HIV specialist respondents felt that there are current barriers specific to HIV that might prevent PHAs from having their rehabilitation needs met. Reported barriers include stigma, lack of education of health care providers, lack of knowledge about the episodic nature of HIV, waiting lists, and lack of services in rural settings.

HIV specialists were asked a series of open-ended questions about how they perceive the role of rehabilitation in the context of HIV/AIDS changing over the years, and how the needs of PHAs will change in the future. Themes generated from their responses on the changing role for rehabilitation included: increased focus on return to work; shift from palliation to chronic illness; increased awareness of HIV; shift to include broader determinants of health; people living longer; greater need and increased role for rehabilitation; increased need for vocational rehabilitation; more open-mindedness to alternative therapies; more focus on cardiac issues; increasing elderly HIV population; and, more emphasis on quality of life. Themes generated from responses to the question on how HIV specialists believe the rehabilitation needs of PHAs will change in the future included: increased focus on cardiac care; aging HIV population; increased complexity of needs; and, return to work issues.
Conclusions and Service Implications
Despite the role rehabilitation professionals have to play in the care and treatment of PHAs, only a minority currently serves PHAs. Of those who had served PHAs, they saw only a very small number of PHAs in the past year, and reasons for which they served their HIV clients were primarily for rehabilitation issues unrelated to their HIV status.

In general, HIV specialists currently provide limited rehabilitation-related services for PHAs; however, they refer to a range of services that do provide rehabilitation services for individuals with HIV. The largest percentages of the referrals made are to community-based ASOs and social workers for assistance with social participation restrictions. Fifty percent or under had referred to traditional rehabilitation professionals (occupational therapy, physical therapy, speech-language pathology or physiatry). Given the multiple body impairments, functional limitations, and social participation restrictions that may be experienced by PHAs, these referral patterns are unlikely to address the complexity of service needs related to disablement of individuals with HIV.

There is a need for increased information for, and education of, HIV specialists, rehabilitation professionals, people living with HIV, and other health and service providers who may refer to rehabilitation professionals on the role of rehabilitation in the context of HIV/AIDS. There is also a need for more collaborative practice among health care professionals to better meet the rehabilitative needs of PHAs.
References


Appendix A

List of Advisory Committee Members:

<table>
<thead>
<tr>
<th>Advisory Committee Member</th>
<th>Profession / Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evan Collins</td>
<td>Physician, University Health Network, Toronto, Ontario &amp; Person Living with HIV</td>
</tr>
<tr>
<td>Louis-Marie Gagnon</td>
<td>Maison Plein Coeur, Montreal, Quebec</td>
</tr>
<tr>
<td>Barney Hickey</td>
<td>Registered Nurse, Vancouver, British Columbia &amp; Person Living with HIV</td>
</tr>
<tr>
<td>Jim Marianchuk</td>
<td>Registered Nurse, Toronto, Ontario &amp; Person Living with HIV</td>
</tr>
<tr>
<td>Arlis McQuarrie</td>
<td>School of Physical Therapy, University of Saskatchewan, Saskatoon, Saskatchewan</td>
</tr>
<tr>
<td>Christopher Sulway</td>
<td>Physical Therapist, St. Michael’s Hospital, Toronto, Ontario</td>
</tr>
<tr>
<td>Elisse Zack</td>
<td>Executive Director, Canadian Working Group on HIV and Rehabilitation (CWGHR), Toronto, ON</td>
</tr>
<tr>
<td></td>
<td>*developmental study</td>
</tr>
<tr>
<td></td>
<td>*survey implementation study</td>
</tr>
</tbody>
</table>
Rehabilitation Professionals’ Perspectives

People living with HIV are living longer than at the onset of the HIV epidemic, but are living with significant levels of bodily impairments, functional limitations, and social participation restrictions. Rehabilitation - broadly defined as all services and activities that address or prevent impairments, activity limitations and participation restrictions experienced by an individual - can help address these issues of disablement.

To provide information for HIV services planning, a survey was conducted to explore the knowledge, attitudes and practices of Canadian rehabilitation professionals and HIV specialists concerning rehabilitation services for people living with HIV (PHAs).

This fact sheet summarizes findings from the rehabilitation professional survey.

Method

A sample of rehabilitation professionals (n=2006) [occupational therapists (OTs), physical therapists (PTs), speech-language pathologists (SLPs) and physiatrists] who may or may not work clinically in the HIV field in Canada was randomly surveyed by mail between April and October 2004. The overall response rate was 74% (n=1492) [of whom 53% successfully completed the questionnaire, 10% were ineligible and 12% refused to participate].

Respondent Characteristics

Forty-seven percent of the 1058 survey respondents were PTs, 41% were OTs, 9% SLPs, and 3% physiatrists (these percentages are roughly proportionate to those surveyed in each profession). Rehabilitation professional respondents had practiced an average of 14 years (range: <1 - 46 years). The largest percentage of respondents (43%) worked in metropolitan settings of 500,000 or more. Fifty-three percent of rehabilitation professional respondents worked in Ontario, 10% worked in the Prairies, 13% in Alberta, 11% in British Columbia, 9% in Atlantic Canada, 3% in Quebec, and less than 1% in the NWT, Yukon and Nunavut.

Respondents worked in a variety of clinical settings such as acute care hospitals [including inpatient (29%) and outpatient (21%) settings], home care (29%), individual (22%), and group private practice (19%).

Results

A) Current Practices in HIV Rehabilitation

Proportion of Rehabilitation Professionals who Served HIV Positive Clients within the past year

- Would LIKE to work with this client group (27%)
- Would NOT like to work with this client group (27%)
- Unsure (46%)

Of the 61% who did not serve HIV clients...

- Would LIKE to work with this client group (27%)
- Would NOT like to work with this client group (27%)
- Unsure (46%)

Of the 39% of rehabilitation professional respondents who had served PHAs:

- On average they served 4 HIV positive clients in the past year.
- 75% indicated that less than 25% of the rehabilitation issues of their HIV clients were HIV related.
- The majority of referrals to rehabilitation for PHAs were from physicians (81%) (general practitioners, psychiatrists, neurologists, ID specialists), case managers (36%), other rehabilitation professionals (36%) and PHAs who self referred (12%).
- Impairments, activity limitations and participation restrictions PHAs presented with to rehabilitation professionals who served PHAs in the past year varied. 82% of those who served PHAs indicated they had at least one HIV client who presented with decreased activity tolerance, 77% indicated they had at least one...
client who presented with weakness, 74% fatigue, 72% musculoskeletal impairments, and 69% mobility issues.

B) Rehabilitation Professionals’ HIV Training

Only 27% of rehabilitation professional respondents reported receipt of training in HIV/AIDS as part of their rehabilitation degree program. Only 11% of rehabilitation professional respondents participated in specialty training or continuing HIV education beyond their rehabilitation degree in the past 5 years.

C) Views on Professional Roles in HIV Rehabilitation

Despite few rehabilitation professionals working in HIV care, 46% feel their profession is ‘very important’ to the rehabilitation of PHAs. More OTs considered their profession was ‘very important’ (63%) compared with PTs (37%), physiatrists (32%) and SLPs (17%).

Did you know that...

- 66% of rehabilitation professional respondents disagree or strongly disagree that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat PHAs.
- 50% agree or strongly agree that many rehabilitation professionals are uncomfortable working with PHAs.
- 58% strongly agree (and 33% agree) that rehabilitation professionals who provide these services need specialized training in HIV.
- 70% feel that rehabilitation services are not just primarily needed by PHAs at palliative stages of illness.
- 46% agree or strongly agree that rehabilitation for PHAs should be a larger priority (39% don’t know).

However,

- 52% agree or strongly agree that working with PHAs is similar to working with individuals with other chronic illnesses.

D) HIV Rehabilitation Service Delivery Issues

Rehabilitation professionals were asked about challenges in delivering rehabilitation services in general, and were also asked about service barriers specific to HIV rehabilitation.

Seventy-four percent of respondents indicated that in their area of practice in the last year waiting lists was an issue, while 72% indicated funding issues, 68% availability of rehabilitation services, and 64% clients’ lack of information about the availability of resources.

Forty-one percent of respondents felt that there were barriers specific to HIV that might prevent PHAs from having their rehabilitation needs met. Reported barriers include: stigma, fear, lack of funding, lack of education of health providers and lack of services in rural settings.

Conclusions

Despite the role rehabilitation professionals have to play in the care and treatment of PHAs, only a minority currently serves PHAs. Of those who had served PHAs, they saw only a very small number of PHAs in the past year, and reasons for which they served their HIV clients were primarily for rehabilitation issues unrelated to their HIV status.

There is a need for increased information for, and education of, HIV specialists, rehabilitation professionals, PHAs, and other health and service providers who may refer to rehabilitation professionals on the role of rehabilitation in the context of HIV/AIDS. There is also a need for more collaborative practice among health care professionals to better meet PHAs’ rehabilitative needs.

For More Information: Consult the full Canadian Providers’ Survey report at: www.phs.utoronto.ca/hivstudiesunit. For more information on rehabilitation in the context of HIV, see the Canadian Working Group on HIV and Rehabilitation (CWGHR) website at www.hivandrehab.ca.

Study Investigators: Catherine Worthington, Ted Myers, Rhonda Cockerill and Stephanie Nixon. Research Staff: Kelly O’Brien and Tarik Bereket. Acknowledgements: This study was funded by the Canadian Institutes of Health Research (CIHR) and Canadian Working Group on HIV and Rehabilitation (CWGHR). The research team would like to acknowledge the national advisory committee (Evan Collins, Louis-Marie Gagnon, Barney Hickey, Jim Marianchuk, Arlis McQuarrie, Christopher Sulway & Elisse Zack) for their guidance.
HIV Specialists’ Perspectives

People living with HIV are living longer than at the onset of the HIV epidemic, but are living with significant levels of bodily impairments, functional limitations, and social participation restrictions. Rehabilitation - broadly defined as all services and activities that address or prevent impairments, activity limitations and participation restrictions experienced by an individual - can help address these issues of disablement.

To provide information for HIV services planning, a survey was conducted to explore the knowledge, attitudes and practices of Canadian rehabilitation professionals and HIV specialists concerning rehabilitation services for people living with HIV (PHAs).

This fact sheet summarizes findings from the HIV specialist survey.

Method

The known population of HIV specialists (n=731) [including dieticians, nurses, pharmacists, physicians (general practitioners (GPs), infectious disease (ID) specialists, psychiatrists), psychologists and social workers] working clinically in the HIV-related field in Canada was surveyed by mail between April and October 2004. The overall response rate was 63% (n=462) [of whom 47% successfully completed the questionnaire (n=214), 28% were ineligible (n=134) and 25% refused to participate (114)].

Respondent Characteristics

Forty-seven percent of the 214 survey respondents were nurses, 35% were physicians, 7% social workers, 6% pharmacists, 3% psychologists, and 2% dieticians (these percentages are roughly proportionate to those surveyed in each profession). HIV specialist respondents had practiced an average of 16 years (range: < 1 to 49 years). The largest percentage of respondents (60%) worked in metropolitan settings of 500,000 or more. Thirty-six percent of HIV respondents worked in Ontario, 20% worked in Quebec, 18% in British Columbia, 9% in the Prairies, 8% in Alberta, 7% in Atlantic Canada and 2% in the NWT, Yukon and Nunavut.

Results

A) Current Practices in HIV Rehabilitation

Overall, 62% of HIV specialist respondents indicated that less than half of their HIV clinical caseload was rehabilitation-related. However, a substantial proportion of some professions indicated that 75-100% of their HIV caseload was rehabilitation-related, including 47% of social workers, 43% of psychologists, 40% of dieticians, and 32% of nurses.

Referral Practices and Service Needs

The majority of reasons for referral to rehabilitation services were to address participation restrictions including: social service assistance (85%), income support (80%), drug coverage assistance (79%), psychosocial issues (76%), and housing support (74%).

B) HIV Specialists’ Training in Rehabilitation

Only 14% of HIV specialist respondents reported receipt of training in rehabilitation as it relates to HIV as part of their health degree program. 59% of HIV specialist respondents participated in specialty training or continuing education in the area of rehabilitation related to HIV beyond their health degree in the past 5 years.
C) Views on Professional Roles in HIV Rehabilitation

75% of HIV specialist respondents feel their profession is ‘very important’ to the rehabilitation of PHAs. This was consistent across professions.

Did you know that...

- 83% of HIV specialist respondents agree or strongly agree that rehabilitation for PHAs should be a larger priority.

However...

- Opinion was mixed about whether rehabilitation professionals currently possess adequate knowledge and skill to treat PHAs (44% agree or strongly agree, 35% disagree or strongly disagree).
- 42% agree or strongly agree that many rehabilitation professionals are uncomfortable working with PHAs.
- 59% disagree or strongly disagree that working with PHAs is similar to working with individuals with other chronic illnesses.
- 55% strongly agree (and 39% agree) that rehabilitation professionals who provide these services need specialized training in HIV.

D) HIV Rehabilitation Service Delivery Issues

HIV specialist respondents were asked about challenges in delivering health and rehabilitation services in general, and were also asked about service barriers specific to HIV rehabilitation.

Sixty-eight percent of respondents indicated that in their area of practice in the last year availability of rehabilitation services was an issue while 66% indicated client lack of information about resources was an issue, 61% indicated waiting lists, and 59% indicated funding issues (e.g., high costs, under-funding).

Seventy-four percent of HIV specialist respondents felt that there were barriers specific to HIV that might prevent PHAs from having their rehabilitation needs met. Reported barriers include: stigma, lack of awareness of resources, lack of knowledge about the episodic nature of HIV, waiting lists, and lack of services in rural settings.

Conclusions

The majority of study respondents currently provide limited rehabilitation-related services for PHAs; however, HIV specialists refer to a range of services that do provide rehabilitation services for individuals with HIV. The largest percentages of the referrals made are to community-based ASOs and social workers for assistance with social participation restrictions. Fifty percent or under had referred to traditional rehabilitation professionals (occupational therapy, physical therapy, speech-language pathology or physiatry).

Given the multiple body impairments, functional limitations, and social participation restrictions that may be experienced by PHAs, these referral patterns are unlikely to address the complexity of service needs related to disablement of individuals with HIV.

There is a need for increased information for, and education of, HIV specialists, rehabilitation professionals, people living with HIV, and other health and service providers who may refer to rehabilitation professionals on the role of rehabilitation in the context of HIV/AIDS. There is also a need for more collaborative practice among health care professionals to better meet the rehabilitative needs of PHAs.

For More Information: Consult the full Canadian Providers’ Survey report at: www.phs.utoronto.ca/hivstudiesunit. For more information on rehabilitation in the context of HIV, see the Canadian Working Group on HIV and Rehabilitation (CWGHR) website at www.hivandrehab.ca.

Study Investigators: Catherine Worthington, Ted Myers, Rhonda Cockerill and Stephanie Nixon. Research Staff: Kelly O’Brien and Tarik Bereket

Acknowledgements: This study was funded by the Canadian Institutes of Health Research (CIHR) and Canadian Working Group on HIV and Rehabilitation (CWGHR). The research team would like to acknowledge the national advisory committee (Evan Collins, Louis-Marie Gagnon, Barney Hickey, Jim Marianchuk, Arlis McQuarrie, Christopher Sulway & Elisse Zack) for their guidance.
Experiences of Contemplating Returning to Work for People Living With HIV/AIDS

Stephanie Nixon
Rebecca Renwick

In the mid-1990s, medical advances dramatically altered the experience of living with HIV/AIDS. The shifting medical climate spurred new social and financial questions, such as the possibility of returning to work. In this qualitative study, the authors examine how people living with HIV/AIDS perceive, attach meaning to, and approach the experience of returning to work. Findings demonstrate that the participants are influenced by, and wrestle with, both the dominant societal perspective that “people should return to work,” and the oppositional perspective that people living with HIV/AIDS “should not return to work.” Theoretical understanding of the results is enhanced using the concepts of the “sick role” and the “hierarchy of identities.” Findings have conceptual and methodological implications for literature in HIV/AIDS, return to work, and identity.

Keywords: HIV, AIDS, return to work, disability, employment, social theory, qualitative methods

Since the human immunodeficiency virus (HIV) was discovered two decades ago, advances in medical management have dramatically altered the experience of living with HIV/AIDS. In particular, the advent of protease inhibitors in 1996 and subsequent combination drug therapies have contributed considerably to slowing disease progression and improving survival for people who can access and tolerate the drugs (Carpenter et al., 1998; Palella et al., 1998). Although a known cure does not yet exist, HIV infection has come to be perceived as a chronic, cyclical illness in the developed world (Phillips, 1998). Many asymptomatic people have been staying healthier longer, and many people who were ill have regained health. However, despite the initially encouraging results, limitations of the new drugs, in the form of viral resistance and drug toxicities, are now being recognized. The long-term success of these drugs appears limited, and HIV/AIDS remains unpredictable.

These developments have raised new clinical and socioeconomic issues. Ironically, improvements in health have created a new assortment of stressors, as

AUTHORS’ NOTE: This study was completed as partial fulfillment of a master’s of science degree. The authors would like to acknowledge the valuable contributions of thesis cosupervisor, Dr. Jack Ivan Williams, and thesis committee member Dr. Joan Eakin to this study. Correspondence address: Stephanie Nixon, University of Toronto, Department of Physical Therapy, 500 University Avenue, Suite 860, Toronto, Ontario, Canada, M5G 1V7; e-mail stephanie.nixon@utoronto.ca; tel. +1-416-946-8560.
people who had accepted and engaged in the process of dying cautiously negotiate reengagement in living (Grubb & McClure, 1997). One such issue is the decision whether to return to the workforce.

The purpose of this study is to examine the experiences of people living with HIV/AIDS who are contemplating the difficult decision to return to work. The findings reported here are then located within two diverse social theoretical perspectives. First, Parsons’s (1951) “sick role” is used to provide a structural functionalist approach to understanding the dilemma of returning to work or not. Second, Charmaz’s (1987) “hierarchy of identities” is employed to understand the findings from a symbolic interactionist perspective.

THE HIV/AIDS COMMUNITY ADDRESSES THE RETURN-TO-WORK ISSUE

The emergence of returning to work as an issue was first identified and addressed in Canada by the network of community-based HIV/AIDS service organizations. A wealth of documentation was created in 1997 and 1998 in response to the needs of their constituents, ranging from information pamphlets (e.g., see HIV and AIDS Legal Clinic [Ontario], HALCO, 1998; Toronto Persons Living with AIDS Foundation, 1997) to comprehensive study reports (British Columbia Persons With AIDS Society, 1997; Canadian AIDS Society, 1998a, 1998b; Grubb & McClure, 1997; Jalbert & Masson, 1998).

Because they were created by HIV/AIDS service organizations, these documents have been designed to serve, educate, and protect people living with HIV/AIDS. Consequently, the following assumptions are interwoven throughout each document: that the quality of life of people living with HIV/AIDS is paramount, that returning to work can compromise the quality of life for people living with HIV/AIDS, and, therefore, that returning to work is a risky decision.

The comprehensive response of the HIV/AIDS community in Canada to the issue of returning to work for people living with HIV/AIDS resulted in a new discourse regarding returning to work from which one central theme emerged: Beware the risks. HIV/AIDS service organizations appear to conceptualize the decision whether to return to work as a scale, with the “pros” on one side and the “cons” on the other. Because these documents have been developed to protect people living with HIV/AIDS from the risks associated with returning to work, they strongly emphasize the weight of cons, or risks associated with returning to work.

Such risks include, but are not limited to, unpredictable durability of positive effects from new drugs, unpredictable onset of debilitating side effects, inability to return to disability insurance coverage if relapses occur, potential loss of job (and, therefore, benefits) after returning to work in this climate of “downsizing,” interference from symptoms such as diarrhea or profound fatigue, worsened health due to stress and long hours without rest, potentially unhealthy work environment due to immunocompromised condition, difficulty managing elaborate drug regimens (especially with food or refrigeration requirements), difficulty maintaining the schedule of medical appointments, risk of disclosure of HIV status (especially in trying to explain gaps in resumes), and risk of disclosure of sexual orientation (Canadian AIDS Society, 1998a; Grubb & McClure, 1997; HALCO, 1998). The
emphatic message communicated in these documents is that returning to work is a
dangerous decision that should not be undertaken unless the individual has care-
fully scrutinized the myriad possible pitfalls. In fact, the pro-con scale arguably
becomes so one-sided that the implicit message of “do not return to work”
predominates.

THE RETURN-TO-WORK ISSUE EMERGES
IN THE ACADEMIC LITERATURE

In the years following the response from the HIV/AIDS community, the academic
community has begun to address issues of returning to work for people living with
HIV/AIDS. In a large Australian survey of people living with HIV/AIDS, Ezzy, De
Visser, and Bartos (1999) found that of their respondents who were not working, 58%
were contemplating returning to work. Respondents gave various rationales
for wanting to return to work: 87% cited financial reasons, 73% cited “psychoemotional” reasons, and 46% reported improved health. There were no dif-
ferences with respect to number of years since HIV diagnosis, diagnosis with AIDS,
or most recent CD4+ or viral load counts (surrogate markers of disease progres-
sion). Thus, Ezzy and colleagues concluded that the decision to return to work for
people living with HIV/AIDS is affected by self-rated health and economic hard-
ship and not by markers of disease progression.

The issue of returning to work has emerged in several other studies exploring
the experience of living with HIV/AIDS since the advent of protease inhibitors.
Among other social and psychological concerns, individuals have described the
“identity dilemma” of feeling pressure to return to work while being concerned
“that their health would be adversely affected by the stress of working” (Brashers
positive results from the new combination therapies are now facing dramatic psy-
chological changes and have advocated an approach to policy and care that consid-
ers the needs of people living with HIV/AIDS within a chronic illness paradigm.

Crossley (1998) analyzed interviews with a group of people living long-term
with HIV/AIDS by locating their voices and opinions within the dominant dis-
courses available to them. Using this approach, Crossley highlighted implicit con-
tradictions within the increasingly popular ideology of empowerment, demon-
strating that the experience of people living long-term with HIV/AIDS actually lies
somewhere between the dependent sick role and the empowered individual. This
study builds on the findings of Brashers et al. (1998) and Sowell et al. (1998) in that it
highlights yet another aspect of the dilemma that people face when considering
returning to work.

Finally, Adams, Maticka-Tyndale, and Cohen (2001) conducted a qualitative
study on the significance of workplace issues in the lives of people taking combina-
tion drug therapies for HIV/AIDS. They found that returning to employment or
training represented overcoming poor health for some participants. Conversely, a
myriad of disincentives for returning to work emerged, including friends and sup-
port group members who challenged the decision, loss of government subsidies on
return to the paid labor force, and concern around discrimination and breaches of
confidentiality related to disclosure of serostatus. Adams et al. (2001) have also
described periods of existential reflection resulting from the process of survival and recovery, often resulting in a changed perspective on life and the place of paid employment in one’s life.

These studies are instructive in four ways. First, contemplating returning to work is consistently reported as an important issue for people living with HIV/AIDS who have experienced improvements in health from the new combination therapies and yet has received little focus in the literature to date. Second, the decision to return to work has been conceptualized as a dilemma, with pros and cons for both returning to work and not returning to work. Third, there appears to be a range of factors influencing the return to work process, including psychological, financial, and clinical issues. Finally, factors influencing returning to work have been framed within both psychological and sociological perspectives. In the current study, we have addressed a gap in the literature by seeking to understand and theorize how people living with HIV/AIDS perceive, attach meaning to, and approach the experience of returning to work.

THEORETICAL APPROACH

The theoretical orientation of this research lies within the interpretive tradition in sociology (Ritzer, 1983). The methodological approach associated with an interpretive perspective is generally qualitative, assuming that no single objective reality exists independently from human perception. Rather, human behavior is shaped by the meanings that individuals attach to phenomena. These meanings are socially constructed and interpretable only within the context in which they are created.

Grounded theory is a form of inquiry that is inductive rather than deductive. Rather than moving from the general to the specific using empirical data to test hypotheses deduced from existing theory, general concepts are inducted from specific empirical observations. Accordingly, data collection and analysis are not discrete phases but instead share a reciprocal relationship in which theory continues to be discovered, developed, and provisionally verified through constant comparative analysis (Strauss & Corbin, 1990). The goal of this methodology is to develop concepts and explanations that are grounded in the data, which, in this case, included the participants’ narratives and the researcher’s field notes.

These data were analyzed using Charmaz’s (1987) hierarchy of identities, a theory within the symbolic interactionist tradition. This kind of approach is concerned with subjective experiences and how individuals create, modify, and interpret the world in which they find themselves. A symbolic interactionist approach is concerned with what is unique to the individual as opposed to what is universal.

During the process of data collection and analysis, so many of the participants brought up the notion of the sick role in their interviews that the researcher felt compelled to consider the data in the context of this sociological frame as well. However, Parsons’s (1951) sick role is a conceptual framework that resides firmly within the structural functionalist paradigm. Like symbolic interactionism, a structural functionalist approach is concerned with individuals, but questions are cast from a different perspective. Structural functionalism considers society as an entity that exists and views the challenge for theorists as uncovering the universal laws that explain and govern the reality being observed.
Both structural functionalism and symbolic interactionism are concerned with order. However, symbolic interactionism comes from an interpretivist paradigm, whereas structural functionalism resides in positivism, which makes it an unusual perspective from which to consider these data. This kind of approach has been used effectively elsewhere (see, for example, Bellaby, 1990). This multifaceted approach to understanding the data is also consistent with Annandale’s (1998) call for theoretical eclecticism in the sociology of health and illness, recognizing that some of the best understandings come from multiple perspectives. First, we will discuss the contribution of the structural functionalist analysis to our understanding of the data. We will follow this with an examination drawing on the symbolic interactionist approach.

DATA COLLECTION

In this article, we draw on the results of a qualitative study about the experiences of thinking about returning to work for people living with HIV. We recruited 13 participants through advertisements and personal contacts at community-based organizations and healthcare centers. Responsibility rested with potential participants to contact the researcher to initiate dialogue if they were interested in more information about participation in the study.

We collected data using semistructured, in-depth interviews. Despite the fact that participants were free to choose the setting for the interviews, the primary investigator conducted the interviews in her office at the Wellesley Central Site of St. Michael’s Hospital in Toronto, Canada. The exception was one interview that was conducted by telephone for logistical reasons.

Inclusion criteria required participants to be HIV positive, to have left the workforce, and to self-identify as either considering returning to work or to have already returned to work. Using a theoretical sampling approach, we selected and interviewed a relatively homogeneous sample of individuals so that we could begin identifying and understanding patterns. Then, we selected a more heterogeneous sample to confirm or disconfirm the conditions under which our ideas held (Creswell, 1998). As such, during the second half of the study, we made an effort to enroll participants who were female and/or born outside Canada to increase the heterogeneity of the sample and to explore specific themes.

Interviews were 45 to 60 minutes in length and were guided by a series of open-ended questions and follow-up probes. The interviewer used questions to explore the experience of considering returning to work. Therefore, questions explored reasons both in favor of returning to work and for refraining from returning to work. Questions also focused on what it was like to be feeling better and thinking about returning to work. The interviewer made all efforts to present a neutral perspective regarding whether an individual “should” return to work. As potential themes emerged, we added questions in later interviews to explore these issues. For example, we explored returning to work as a mechanism for regaining “control” and the concept of taking care of one’s health as “a full-time job.” We tape-recorded all interviews and transcribed them verbatim. We analyzed data using a grounded theory approach (Charmaz, 1990; Strauss & Corbin, 1990).

Both the University of Toronto Research Ethics Board Standing Committee on HIV/AIDS, which included representation from people living with HIV/AIDS,
and the Research Ethics Board at the hospital where the interviews were conducted granted ethics approval for this study. We obtained informed, written consent from all participants. We made a special effort to ensure that participants understood that their decision to participate would in no way influence care or affect services they received, particularly as the primary investigator, who conducted the interviews, was also a health care provider for people living with HIV/AIDS.

RESULTS

Participant Characteristics

The 13 participants were HIV positive and had left work in the past. Eleven of these individuals self-identified as considering returning to work, and 2 had recently returned. We sought individuals who had already returned to work to capture relevant elements of the return-to-work experience beyond just considering the decision. The sample is made up largely of gay, white males. The two females were heterosexual. Participants were between 25 and 50 years old. Three were born outside Canada. Six participants were in a long-term relationship, and one participant was a parent. All participants except one had received services from and/or volunteered at an HIV/AIDS service organization.

Former employment ranged from part-time contract to permanent full-time and encompassed both labor and managerial jobs, including health care professional; secretary; counselor; repair person; flight attendant; broker; engineer; and, construction worker. Six of the participants were receiving private benefits. Time since HIV diagnosis ranged from 6 months to 17 years, and time since leaving work ranged from 6 months to 8 years. Approximately half of the sample originally left work because of ill heath. Several others reported leaving to prevent the onset of ill health.

In general, these 13 participants were heterogeneous with respect to many of the characteristics that could influence returning to work, such as former employment, private versus public income support, and time living with HIV/AIDS. Experiences not captured in this sample include those of other HIV/AIDS “risk groups,” such as Aboriginals, youths, and intravenous drug users.

Emerging Themes

The interviews resulted in 13 rich and diverse stories about the experience of considering returning to work. Within these stories, several major themes emerged. First, two dominant and oppositional perspectives regarding returning to work were represented in the participants’ narratives. The first perspective was that people living with HIV/AIDS “should not return to work.” This perspective was congruent with HIV/AIDS community dialogue and was predicated on the assumption that returning to work presents too great a risk to an individual’s physical, social, and financial well-being.

The second perspective was that “people should work,” that is, people have a social responsibility to work and to contribute to society. These social perspectives do not simply coexist in the narratives. Rather, the evidence demonstrated that
participants wrestle with these oppositional views, thus creating a catch-22 dilemma regarding their decision to return to work.

Alongside these perspectives related to social expectations concerning work, the theme of Identity Reconstruction emerged. The concept of identity was central to the participants’ discussions about returning to work. Furthermore, the transitory nature of the identities was highlighted as the participants reconstruct how they see themselves in light of their shifting health experiences.

In the following discussion, we ground these themes in the participants’ narratives and then draw on social theory to help account for the findings. We first explore the dilemma of returning to work using the structural functionalist perspective of Parsons’s (1951) sick role. We then employ Charmaz’s (1987) hierarchy of identities, which is based on symbolic interactionism, to account for the findings from a theoretical perspective that privileges agency.

In presenting these findings, we employ the convention “...” to denote words missing from the participant’s quote. We use square brackets to replace specific references with general terms to protect the anonymity of the participant or person identified in his or her quote. Finally, all names are pseudonyms.

“People Living With HIV/AIDS Should Not Return to Work”

Two dominant and oppositional perspectives regarding returning to work were represented in the participants’ narratives. The first perspective was that people living with HIV/AIDS “should not return to work.” The assumption underlying this perspective was that returning to work was an extremely risky decision that might compromise an individual’s physical, social, and financial well-being. One source of this perspective was HIV/AIDS service organizations. As discussed previously, the rapid and somewhat unified response of Canadian community-based HIV/AIDS service organizations resulted in the creation of a perspective opposed to returning to work for people living with HIV/AIDS. All but one participant in this study described direct personal links to HIV/AIDS service organizations and the broader HIV/AIDS community and, thus, were exposed to the “Do not return to work” message.

Health care professionals reinforce the message. These links with HIV/AIDS service organizations and the larger HIV/AIDS community demonstrated the ample opportunity for the Do not return to work perspective to be communicated and reinforced. The participants’ narratives revealed that health care professionals specializing in HIV/AIDS are another source of influence reinforcing this perspective. For instance, Zack’s decision to leave work in the first place was initiated by his physician. Bob discussed how he negotiates the decision to return to work: “There is a lot of factoring you have to discuss with your physician to see if your numbers, T-cells and viral load, are strong enough to support a job.” Later in the interview, when asked if anyone was telling him not to go back to work, Bob replied, “Yeah, my doctor, he was very, very apprehensive.”

Buoyed by the optimism concerning new drugs, Ed raised the prospect of returning to work with his physician. He commented on his doctor’s response: “Dr. [name] kept me very cautious. It was like, let’s wait and see . . . it’s better to leave
well enough alone... and he warned me about some issues, like don’t jump back in.”

Not all participants shared this experience. Greg reported, “I mentioned it [returning to work] to my doctor and she doesn’t think it’s a big deal.” Furthermore, Doug believed that some health care professionals “take a narrow perspective,” viewing their job as “to keep people working and paying taxes.” He further articulated his perception of physician attitudes: “We give you medicine, we get you well, you should be working.”

These contrasting comments pointed to the idea that it is health care professionals who specialize in HIV/AIDS who were advocates of the “Do not return to work” perspective. When asked about his decision to not return to the workforce, Zack replied,

Dr. [name], I think he’s the biggest support that makes me reluctant to go back to work. I can be all cheerful and I’ll see other doctors who say, “Oh I’ll support you whatever you choose,” but he always puts his foot down, you know?

Public perspective is articulated as private experience. Having established some of the sources of this dominant perspective, evidence will now be drawn from the narratives to demonstrate how this public “Do not return to work” view was adopted and articulated in terms of participants’ private experiences. For instance, the language used by participants was consistent with the HIV/AIDS service organization voice. Ian referred to “the barriers to return to work”; Kevin discussed “risk.” When asked about his concerns regarding returning to work, Andrew described a list of barriers that bear a striking resemblance to the HIV/AIDS service organization warnings:

Certainly one of the big things is not being able to do my job the way I used to. I used to work long hours, I was good at what I did... and uhh, if I go back now it’s going to be different because I get tired so easily. And there’s also the thing where this week I had five medical appointments, so I’d need time off for those... I’m also afraid of going back and getting sick again and of not being able to get back on long-term disability... and they [his colleagues] haven’t figured out that I’m HIV positive and I’m gay, uhh so there’s that aspect of it... but the rumours are already out there because of the symptoms I’ve had... and now I’ve accepted the fact that there’s going to be down days... people will ask me what’s wrong and I can’t really tell them, it’s just that I feel lousy and those things happen. I don’t know how it would be at work. The other big problem is that I have diarrhea from my nelfinavir [one of the protease inhibitors] and in the mornings I would have problems driving to work... and I know stress is a big factor, that is a concern for me.

Andrew later contradicted himself by revealing a perspective that differed from the HIV/AIDS service organization discourse that he so readily offered at the start of the interview. He “confessed” that his greatest concern is actually pride and fear of failure.

The impact of the HIV/AIDS community perspective is often implicit in the narratives. For instance, consider Zack’s responses:

Interviewer: Did the AIDS service organization literature influence your thinking?
Zack: No, it didn’t play any role at all. In fact, I saw the literature, I took it home, I thought, “Yawn, boring.”
Interviewer: It wasn’t for you?
Zack: Well, I mean, I have already thought out these things.

In denying that the literature influenced his perspective, Zack actually confirmed that he indeed sought and read the literature. Furthermore, his comment “Yawn, boring” suggests that it contains a rhetoric with which he is already familiar.

In other cases, the link between public and private perspectives was more explicit. For instance, Ian said, “I spoke with someone [the benefits counselor] at [HIV/AIDS service organization] and she said, ‘Oh be careful!’” Andrew commented,

I don’t trust the insurance companies, but I don’t know what they ever did to me… I know other guys in my support group have had problems with their insurance companies… a lot of it is rumours. There’s not a lot of trust there.

Another strategy for uncovering the public voice within private narratives involved focusing on each participant’s use of I versus you in describing his or her experience. Use of I suggested a private account, whereas a shift to you implied depersonalization of the issue, suggesting a more public or social nature (Mauthner & Doucet, 1998). In the instance of return to work, shifting to you represents articulation of a dominant social perspective. An example from Doug’s narrative illustrates how his personal fear of disclosure of his HIV serostatus in the workplace was framed in the social voice:

And the other thing that I really worry about too, and it’s a different stream, umm AIDS phobia, homophobia in the kind of workplace I left wasn’t the most educated about issues and the fear of going back, people with no respect, wanting to know why I was off or if they find out anything, and you have to be very closed and secretive about who you are, where you came from, why you were gone, those kinds of things, and if people find out you know you have AIDS, uh oh.

Finally, considering the assumption that HIV/AIDS service organizations are the source of the “Do not return to work” perspective, there was also value in exploring the narrative of the one participant who had no connection with the HIV/AIDS community. Investigating this respondent’s narrative reveals a conspicuous absence of evidence of the “Do not return to work” perspective relative to the other narratives.

“People Have a Social Responsibility to Work”

The Protestant work ethic is an ideology that values independence, individual responsibility, and hard work (Charmaz, 1983). In this perspective, people are viewed as having a social responsibility to work. As such, the legitimacy of not working is a contentious issue. Because of the predictable, progressive, terminal nature of HIV/AIDS until the mid-1990s, the legitimacy of not working for this population had gone completely unchallenged. Since the advent of combination drug therapies, however, HIV/AIDS has increasingly been viewed as a chronic illness because of the new possibility for increased longevity. Thus, the decision to remain out of the workforce is now being called into question; the idea that “people should work” now affects the private experiences of people living with HIV/AIDS.
External pressure: “You should work.” The “should be working” perspective appeared consistently in the narratives of all but one of the participants. Participants discussed perceptions of pressure to return to work from external sources, such as family members, insurance companies, and the government. For instance, Andrew commented, “There’s pressure from my wife, uhh, she doesn’t really understand, and there are little comments. She doesn’t say you should go back to work, but she’s implying that I should.” Greg echoed this perception of family pressure:

When I ask them [his family] why I don’t hear from them much, they say they are working. Okay, well, I’ve been hearing this for five years now and does this mean you’ve been working constantly for five years? I remember when I worked, I still saw my family . . . it seems hostility almost that I’m not working. The excuse they have for not staying in touch with me is that they are working. And I hear that as, “You’re not.”

Acquaintances served as another source of pressure to return to work. For instance, Zack remarked, “I just ran into an old friend a few weeks ago who really had it out with me about using taxpayers’ dollars.” Greg commented, “I’ve lost friends because I don’t work.”

Several participants believed the pressure was even stronger because they appeared to be well. Ed commented, “People would see me and think, ‘Well he looks perfectly fine. Why isn’t he at work?’ I was actually getting hassled.” Or Ian’s comment, “If you look healthy and you’re not working, you must be lazy.”

Finally, pressure to return to work was reported to come from institutional sources. For instance, Ed discussed “continued hassle and irritation from his insurance company.” Bob offered the following opinion regarding the government, “I think the most predominant and the most chilling one [external pressure] is the provincial government’s attitude toward people who collect disability, the rhetoric that you almost should be working.”

Internalized perceptions: “I should work.” The narratives also revealed internalized perceptions among the participants concerning their social responsibility to return to work. In all cases, participants’ reports of external influences to return to work were framed in a negative context: They described these comments as “inappropriate” and the people making them as “uninformed,” “out of line,” and “wrong.” Despite these statements, the participants also made comments throughout the narratives that represented the internalized perception of themselves that they should be working. For instance, almost half of the participants raised the concept of the Protestant work ethic. Bob explained, “For me, I’ve always been work ethic-oriented. I’ve always been driven in a family by work and so to be idle . . . the bottom line is I’m not being a productive human being.”

Greg expressed his unease regarding his current unemployed status, “Sitting at home not doing much, how productive do you feel to society? I grew up in a family with a very strong work ethic . . . I don’t want somebody giving me $700 a month to sit at home.”

Others described the perception that they should be working to fulfill a role for society. Doug remarked, “I think everyone has a role to play somewhere . . . you’re
giving back to society.” Zack noted, “You need to feel you’re doing something worthwhile . . . nothing replaces work.”

Others commented even more directly on the individual’s responsibility to work. In response to a question regarding good reasons for returning to work, Lara simply answered, “Because people should work.” Hank concurred: “I think the human body is designed to work and produce things with your hands and your mind. And I think if you have work, you are useful and can feel good.”

Wrestling With the Oppositional Perspectives: “Damned If You Do, Damned If You Don’t”

Evidence has now been presented to demonstrate that each of the two dominant perspectives on returning to work was represented in the narratives. Because of their oppositional nature, however, these perspectives did not simply coexist. Rather, participants wrestled with these powerful and conflicting influences. In this section, we will provide evidence of this struggle by drawing on quotes from the narratives to illustrate (a) perceptions of this wrestling, (b) emotions evoked by this struggle, (c) the shift between I and you, (d) contradictions, and (e) metaphors.

First, participants described wrestling with these oppositional perspectives in various ways. Bob perceived himself to “still be in the consider stage.” Chris perceived the return-to-work decision as “a constant struggle.” Chris outlined part of his dilemma as follows:

When I’m feeling well and looking well, I’d say I don’t have that dulling and I’m not too skinny and gaunt looking, umm, and people see you’re not working, they really think you should go back. And when you’re really ill, or you’re just recovering from being ill and you look gaunt, skinny, umm, and you say you want to go back to work, then they think you’re way too sick to be thinking about that sort of thing . . . so you don’t get any support either way.

Andrew epitomized the concept of wrestling with the two perspectives:

I’m sort of at a point now where I think I could work, but I’m not sure. There’s a lot of sort of barriers and I’ve heard lots of things where I shouldn’t go back, so it’s really, uh, I’m in a quandary about what I should do at this point.

Second, several participants described emotional responses evoked by wrestling with these dominant themes. Andrew, Hank, and Doug described the contemplation of returning to work as “scary.” Ian described his frustration: “It’s frustrating because I know I could make a contribution. I’m bright, I have a BSc degree, I have always been quick at learning, but I just don’t have the option [to return to work].” Despite this seemingly settled decision to not return to work, Ian made many references throughout the interview to how he “wants to work” and “should be working,” suggesting conflicted feelings around this issue. Zack echoed this conflict: “The possibility [of returning to work] excites me and then it depresses me.”

Third, evidence of wrestling was also revealed by the use of I/my versus you/your in describing personal perceptions in the narratives. For instance, Hank discussed reasons for going back to work:
Hank: To, uh, have better earnings, to use my time in better ways, even though I'm using my time for good things now.

Interviewer: What do you mean by “better ways”?

Hank: Better ways, like, when you have a job, you are working at a time, at the same time each day, just that commitment pushes you to get up earlier, to work hard, and to cover the day in a 100% way. Being like this where I am now, I have options. If I get tired, I cannot work because I don’t have any commitments, like someone pushing me.

Throughout this comment, Hank shifted between the dominant themes, also changing his use of pronoun that implied that he was wrestling between what he perceived to be a public standard and his own personal experience. Fourth, evidence of wrestling with the two perspectives was revealed in contradictions that occurred throughout the narratives. For instance, Andrew stated, “The fact is that I guess I have a feeling of guilt that I should be working.” Later in the interview, however, he again reflected on whether he felt he should be working: “If I was bored and woke up thinking I should be at work today, well I don’t.” There were even instances of contradictions within the same thought. Zack managed to weave arguments for both perspectives into his reply to a question about whether he felt content:

Yeah, I wouldn’t say I’m unhappy. Yeah, I’d love to do, umm, challenging work but I’ve had to work around it for years . . . I realize too that I’m alive. I’ve been positive for 17 years and I don’t say that too loud to some people because they think, ughh, you know? Some of their friends died in ’87, you know? So sometimes I do think, “Count your blessings.” I still think about it [returning to work], like I’m a human being, you know? I’d like to do well like everyone else does, but the hardest part is dealing with others that have succeeded. People that I have known as friends. People who are way ahead and I had every opportunity to do that and it didn’t happen. Even though in ways I have succeeded. I’ve been out [of work] for five years now. It wouldn’t be easy to go back.

Finally, metaphors were prevalent throughout the narratives. This use of metaphors might have represented the challenge of putting the struggle between perspectives into words. For instance, to describe the complexity of the issues involved in considering returning to work, Doug said, “Whether to stay on LTD or not, I’m trying to balance many risks, many different things and they’re complex decisions . . . it’s not like adding up a paper of numbers . . . you have to weigh the value of each piece qualitatively.” Zack described the issue as “a whole Pandora’s box.” Greg perceived that he was “caught in a catch-22.” Ed said, “You’re damned if you do, damned if you don’t.”

Bob viewed the uncertainties related to returning to work as an opportunity, stating, “It’s also the, the, the adventure of a new chapter, starting a new chapter.” Chris used metaphor first to describe his sense of not belonging because he does not work and then to characterize his acceptance of this situation:

It’s just that now I’m a square peg and I’m trying to fit into a round hole. That’s just a cross I have to bear. And I can be very Catholic about it and morose or I can be the atheist that I am about it and just think oh well there are worse things on the planet [than not being able to work].
In summary, participants articulated how they wrestled privately with the oppositional public perspectives of “people should work” and “do not return to work.” This struggle has been illustrated in many ways, including conflicting emotions evoked by wrestling, contradictions in the narratives, and the use of metaphors.

USING THE SICK-ROLE CONCEPT TO UNDERSTAND THE STRUGGLE

The narratives demonstrate that the participants were influenced by two conflicting perspectives: People should work, and People living with HIV/AIDS should not return to work. Although the participants themselves articulated this struggle, theory provides a framework for understanding the phenomenon. Parsons’s (1951) sick-role concept provides a structural-functionalist perspective from which to view the return to work process. This framework views being sick as a social role with a set of four normative expectations. These four features are considered behavioral prescriptions that serve to maintain social order.

Prior to the advent of protease inhibitors, one might argue, people living with HIV/AIDS assumed the sick role unproblematically: They were not expected to get better and, therefore, were exempt from normal social roles. Since the development of combination therapies and the associated improvements in health, the legitimacy of not working has been called into question. Taking on the sick role might be equated with not working. Conversely, returning to work might be viewed as abandoning the sick role. As such, the four features of the sick-role concept can be applied to the experience of the participants to further understand the struggle related to the decision of returning to work.

The individual must fulfill the normative expectations of the sick role to remain exempt from working and free of blame for being dependent on social support. The first three sick-role features dictate that the individual view the sick condition as undesirable to receive this exemption from responsibility for sickness and social roles such as working. He or she must want to get better and, thus, want to return to work. All participants adhered to this behavioral prescription, as evidenced by their many comments about “not liking not working” and “wishing that they could return to work.”

The fourth feature of the sick role, however, demands that people comply with the advice of physicians. Within this structural-functionalist framework, the physician is viewed as an agent of social control, a gatekeeper who functions to return well people to the workforce to restore social order. Health care professionals specializing in HIV/AIDS, however, advised the participants to remain out of the workforce, thus creating an expectation for the patient that contradicts the expectation of the first three sick-role features.

Therefore, although the normative expectations of the sick-role concept demand that individuals desire to return to work, the fourth feature of this framework demands that the sick person comply with medical advice. In the case of the participants, these sick-role expectations are contradictory and irreconcilable, thus
providing a theoretical way to account for the struggle or dilemma that exists in the participants’ return to work experience.

THE THEME OF IDENTITY RECONSTRUCTION: “WHAT ARE YOU AND WHO ARE YOU?”

The focus of the discussion will now shift to the recurring theme of Identity Reconstruction and how Charmaz’s (1983, 1990, 1994) symbolic interactionist approach might help to account for these findings. The conceptualization of identity in relation to the experience of chronic illness has received considerable attention. Identity can be understood as being formed through the lifelong processes of personal definition and social interaction (Yoshida, 1993). Charmaz (1987) has described self-identity as “an emergent structure or organization as it may shift or change as the person reflexively interprets the identifications and images that self and others confer on him or her” (p. 284). Identity is influenced by the various decisions that people face during their illnesses, such as returning to work, that affect who they are and who they become. Charmaz (1987) described the concept of identity as “encompass[ing] the person’s vision of future selves, reflecting his or her hopes, aspirations, objectives, and goals” (p. 284). It is within this conceptualization of identity that the voices of the participants will be located.

Identity and Work

Identity emerged as a prevalent theme in discussions about returning to work. Participants generally viewed work and identity as integrally linked. For instance, Lara stated that “work is an identity” and “[occupation] is my identity.” Kevin stated that “part of my self-identity was always linked to work.” In discussing his view of being gay, HIV positive, and unemployed, Hank stated, “Hey, that’s who I am.”

Bob described how work is related to his view of himself: “To feel like you’re contributing in some kind of way, to me, changes your self-esteem and your self-image.” In discussing the meaning of work, Ian stated, “It’s a lot of identity for a lot of people, me included, what you are and who you are, you know?” Andrew discussed the changes in his life since becoming ill and leaving work: “My brother told me I’m a completely different person than I used to be.”

Doug described how he thinks about the return to work decision, articulating a vision of hopes, needs, and motivations that mirrors Charmaz’s concept of identity:

Here’s my big picture, here’s how I look at the big picture. It’s how these decisions impact on your individual life and how we have to make optimal decisions, you know, for yourself, your need for financial income, your need for fulfillment, your need, your physical needs, uhh, your need to feel valuable, to contribute to society. And all those things have to be balanced.

Finally, Greg revealed the tension between his current status and his identity: “There are times when I think I’d like to be a little more productive to society. I don’t want someone giving me $700 a month to sit at home. That’s not who I am.”
conclusion, these quotes from the narratives illustrated the integrally linked nature of work and identity for the participants.

Identity Reconstruction and Returning to Work

Identity is influenced by the decisions and challenges that individuals face when living with illness (Charmaz, 1983). For the participants, the challenge of considering returning to work can be viewed as mirroring the process of identity reconstruction. In this section, we draw on the narratives to demonstrate the dynamic nature of these identities related to being HIV positive and thinking about returning to work.

First, Doug described the identity transformations that have occurred since he became HIV positive:

> What happened was from 1989 on, I slowly started to, uhh, kind of restructure my life. I went from thinking of long-term career plans and, to really preparing, preparing to get, to get very sick and ultimately die at a young age. ... Once I knew, umm, I myself was HIV, that experience really, it, it held a powerful grip on me. ... I really bought into that paradigm. So that shapes you, that powerfully shapes you. Your whole outlook changes and every, you know, every decision you make.

Greg echoed this sentiment: “When I tested positive six years ago, I thought I was going to die. That’s the main scenario. You cashed in your RRSPs [retirement savings] and went on holiday.” Andrew talks about his shifting identity since sickness forced him to leave the workforce a year ago: “Yeah, it’s been quite an amazing year. I guess it could have ruined me, but instead I’m a better person. Once I got through Christmas, that was pretty bad [healthwise], but I just sort of suddenly changed.”

In this quote, Ed struggled with describing his shifting identity and the implications for work:

> I [my health] started to improve, I guess. And even if it was just psychological, I mean I did, I don’t feel immensely better than I did before I took the drugs. I mean, I don’t feel like, I mean I do and I don’t. I feel, you know, there’s side effects of the drugs too. I mean, the way I, the way my, I hate the way, what it does to your face, lipodystrophy [a syndrome that involves hollowing of the cheeks]. That’s depressing. But I started to feel just better enough, and positive, I guess, enough that I started to think, well maybe I should try some things. Maybe I should consider trying it [returning to work].

Later, Ed described his shifting motivation with respect to returning to work in a discussion about “what kind of person” he is:

> I guess I just, I’m part content with being a little bit lazy, but I’m also part quite, how do I describe it, I’m a go-getter. I’m a doer. I’m the kind of person who thinks of doing something and doesn’t talk about it, just does it. I’m effective, I’m efficient, and I started to feel like, just kind of useless.

The concept of identity encompasses an individual’s vision of future selves based on goals, hopes, and expectations (Charmaz, 1987). Further examples
illustrate the transitory nature of identity by focusing on shifting expectations regarding returning to work. Lara recognized physical challenges yet still held high expectations of reentering the workforce: “I’m really considering going back to work, especially, I’m ready, mentally ready to go back, so it’s just my physical ability I’m working on.” Ed described his altered expectations and self-image, which led to his decision to consider returning to work: “All of the sudden, it was like four or six weeks after I started the drugs, I just woke up one morning and I felt like a whole new person.”

**DISCUSSION**

**Using Charmaz’s Hierarchy of Identities to Understand the Struggle**

Charmaz’s (1987) hierarchy of identities provides a conceptualization of identity reconstruction that illuminates the struggle faced by the participants in contemplating returning to work. The hierarchy of identities conceptualizes four “preferred identities” assumed by people who are chronically ill as they negotiate what it means to live with their illnesses. In descending order, these four preferred identities are the Supernormal Social Identity; the Restored Self; the Contingent Personal Identity; and the Salvaged Self. Individuals choose these identities based on reconsidered assumptions, hopes, and desires juxtaposed against the expectations and definitions of their specific conditions. Thus, these preferred identities reflect personal goals, including participation in the workforce.

Deciding to return to work represents ascent of the hierarchy, whereas deciding not to return to work represents the maintenance of a current preferred identity level. Examining the conditions for shifting identity levels provides insight into the struggle that people might experience in considering returning to work.

These preferred identity levels provide one way to conceptualize the link between identity and work that emerged from the interviews. There is evidence within the narratives to demonstrate that each of the participants could be considered to be assuming one of the three lower identities. Considering the link between identity level and work, individuals assuming a Salvaged Self are no longer working but are now attempting to maintain a positive and valued aspect of their former selves in the face of debilitating illness and growing physical dependence. Individuals assuming a Contingent Personal Identity view returning to the workforce as a goal that is hypothetically possible but unlikely, due to possible further illness. Individuals assuming a Restored Self anticipate, or have undertaken, a return to pre-illness identity that includes returning to the workforce.

Thus, although Charmaz (1987) primarily described descent down the identity hierarchy as health status worsens, ascent up the hierarchy parallels improving health and returning to work. Examining the conditions for shifting levels in the hierarchy with respect to the experiences of the participants provides further insight into their struggle over the decision to return to work. In particular, the examination of conditions for choosing identity levels highlights five issues that account theoretically for this struggle.
Conditions for Shifting Identity Levels

First, Charmaz (1987) stated that people aim for identity levels in an effort to lead “normal” lives and to avoid stigma. Both of these concepts are problematic for people living with HIV/AIDS. Many participants commented on the shifting expectation of what it means to live with HIV/AIDS, that is, what is “normal.” For instance, the optimism about new combination therapies is contrasted with their lack of durability and the potential to produce serious side effects. As such, “normal” responses to these drug therapies can range from restored health to death depending on each individual’s experience. Thus, a conceptual tension exists for participants in selecting an identity level that is congruent with the norm. This ambiguity, in turn, reflects a struggle between returning to work or not.

A second goal of choosing an identity level is to avoid stigma. Returning to work and, thus, ascending the hierarchy typically represent minimizing the stigma associated with being ill. The participants, however, described an increased potential for stigma associated with returning to work. In particular, participants feared the stigma associated with disclosure of HIV serostatus that will likely occur if they return to the workplace. This concern stems from the issue of how to respond to questions about the multiyear gap in their resumes, the multiple medications being consumed throughout the day, the regular medical appointments, and/or the change in physical appearance experienced by many people taking combination drug therapies. Furthermore, in many cases, the fear of stigma related to disclosure of HIV serostatus is compounded by the fear of disclosure of sexual orientation that might result as a consequence of the HIV disclosure. Thus, although Charmaz has described avoidance of stigma as a factor that motivates people to select a higher identity level, the participants are also influenced by stigma to resist choosing a higher level. Thus, another theoretical tension exists regarding the decision to return to work.

Degree of illness is another condition for choosing an identity level; that is, the more severe the illness, the more likely an individual is to descend the hierarchy. A third contradiction is revealed here. Charmaz (1987) presented the concept of degree of illness rather unproblematically. In discussing their illnesses, however, many participants described the experience of feeling well but receiving laboratory results that demonstrated immunological deteriorations, or vice versa. Participants described confusion and frustration about having CD4+ counts and viral loads that did not reflect their subjective experiences of wellness or illness. Thus, in the case of these people living with HIV/AIDS, the role of degree of illness in choosing an identity level presents a conceptual struggle. The confusion over this condition for changing identity levels directly reflects the confusion around the decision to return to work.

The incongruence between how well a person might look versus how well that person feels constitutes a fourth condition related to a shift in identity level. Participants described their frustration associated with expectations from other people regarding returning to work when these expectations were based on their appearance rather than subjective health status. Such judgments are particularly problematic because side effects from new combination therapies often lead to truncal weight gain rather than the preprotease image of wasted chest and abdominal regions. These side effects also cause the loss of a specific facial fat pad instead of the general facial thinning typically associated with HIV-related wasting. Furthermore,
these side effects often occur despite vast immunological improvements. Thus, incongruencies exist between the appearance of wellness and the subjective experience of wellness, presenting another way to understand the struggle in choosing an identity level.

Finally, Charmaz (1987) described one additional condition for selecting an identity level, namely, expectation of self. This condition considers typical expectations based on characteristics such as age and education. Several participants described the normative expectation that a person of their age and education level would typically be pursuing a career. At the same time, participants also viewed themselves as people who “should just be lucky to be alive” based on the length of their survival with HIV/AIDS relative to many of their peers. Thus, conflict is raised with respect to expectations of self, reflecting another theoretical explanation for the tug between returning to work and not.

In summary, returning to work can be equated with ascent of Charmaz’s (1987) hierarchy of preferred identities. Therefore, exploring the conditions for changing identity levels provides insight into the experience of considering returning to work. In particular, five conceptual conflicts have been identified by applying the conditions for shifting identity levels to the experiences of the participants. Thus, the hierarchy of identities framework provides a theoretical explanation for the participants’ struggle over the decision to return to work.

REFERENCES


HIV and AIDS Legal Clinic (Ontario). (1998). *Do you need income support because you have a disability or health problem?* [Brochure]. Toronto, Canada: Author.


Stephanie Nixon is a doctoral candidate in Public Health Sciences at the Joint Centre for Bioethics at the University of Toronto, Canada.

Rebecca Renwick is an associate professor in the Graduate Department of Rehabilitation Science and director of the Quality of Life Research Unit at the University of Toronto, Canada.
Rehabilitation Interventions

Session Outline

- Rehabilitation Opportunities
- Collaborative Practice
- Interventions and Strategies
- Advocacy

Rehabilitation Opportunities

- Across lifespan
  - Paediatrics → Elder care
- Across health care settings
  - Acute, long term, community, rehab, private practice
- Across specialty and generalist areas
Health Care Access

- Continuum of care
- Episodic nature of needs
- Health care reform
- Vulnerable populations

Barriers and Strategies for Accessing Rehabilitation

- Health systems barriers
  - Primary health care changes
  - Delisting physiotherapy services
- Referral source awareness
- Service provider awareness
- Client knowledge
  - Health priorities, risk of disclosure
- Other…

Collaborative Practice

- Client and family centred
- To improve client care
- Supported by interprofessional education
- Health Canada initiative
Interprofessional Education Model
Charles, Bainbridge & Gilbert 2004

Goal
Interprofessional Health Education for Patient/Client Centred Collaborative Practice to Improve Patient Care

Learning Process
Professional
Personal
Interprofessional

Interprofessional Education Development Stages
Exposure → Immersion → Mastery

Practice Implications
Rehabilitation Evaluation

- Baseline data
- Stage in illness process
- Psychosocial issues
- Cognitive/perceptual status
- Communication
- Sensorimotor status
- Activities of daily living

Considerations

- Relationship with the environment
- Perception of status and prognosis
- Predominant coping style
- Caregivers
- Social support system

Swallowing Disorders related to HIV

- Anorexia
- Dysguesia
- Mucositis & Odynophagia
- Oral-pharyngeal dysphagias
- Other GI Problems
Management of Swallowing Disorders

- Bedside Assessment
- Team Consultation
- Compensatory Techniques
- Rehabilitative Program(s)
- Patient & Family Education

Communication Disorders related to HIV

- Dysarthrias
- Dyphonias
- Hearing loss – conductive/sensorineural
- Language & Cognitive-Communication Disorders
- Tracheostomies & Ventilator-assisted
- Laryngectomees

Management of Communication Disorders

- Cognitive Communication & Language Ax
- Patient & Family Education
- Environmental Modification
- Supportive or Augmentative/Alternative Communication
- Rehabilitative Program(s)
Opportunities related to Physical Function

- Neurodevelopment
- Pain Management
- Range of Motion (ROM) & Strengthening Exercises
- Aerobic Fitness Training
- Work Hardening / Conditioning Programs
- Environmental Assessments
- Assistive Device Prescription
- Task/Job Modification Suggestions

Research Evidence

- Cochrane – Aerobic Exercise & HIV
- Cochrane – Resistance Exercise & HIV
  (O’Brien K, 2003)

Opportunities related to Occupation

- Cognitive strategies, sensory modifications
- ADL strategies
  - self care, medication management
- IADL
  - driving assessments, household upkeep
- Employment and Return to Work Issues
Research Evidence

• Barriers to RTW for Individuals with HIV
  (Braveman 2001)

• Symptoms of HIV as Barriers to RTW
  (Braveman 2001)

Symptoms of HIV as Barriers to RTW

• Fatigue
  - Decreased energy level

• Chronic Pain
  - Decreased ability to focus attention

• Peripheral Neuropathy
  - Decreased dexterity & increased risk of injury

• Muscle Weakness
  - Decreased ability to do heavy manual labour

• Decreased Endurance
  - Decreased tolerance for activity

Advocacy

• Role of rehabilitation professional

• Role of person living with HIV
Discussion

Summary

- Client focused and specific
- Collaborative
- Holistic
- Integrating advocacy and sensitive practice
Interprofessional Education for Collaborative Patient-centred Practice: An Evolving Framework

Interprofessional Education to Enhance Learner Outcomes

Collaborative Practice to Enhance Patient Care Outcomes

Interdependent

Educational System (eg. Accreditation, institutional structures)

Systemic Factors
(Systemic Factors: Macro)

Professional System (eg. Regulatory bodies, liability)

Health Professional Learner Outcomes

COMPETENCIES
+ Knowledge
+ Skills
+ Attitudes
+ Behavior

Patient/Provider Outcomes
+ Patient Clinical outcomes
Quality of care
Satisfaction
+ Professionals Satisfaction
Well-being
+ Organization Efficiency
Innovation
+ System Cost effectiveness
Responsiveness

Leadership/Resources

Administrative processes

Faculty development

Institutional Factors (Meso)

Teaching Factors (Micro)

Governance

Sharing goals/Vision

Organizational Factors (Meso)

Interactional Factors (Micro)

Structuring clinical care

Sense of belonging

Professionals

Task Complexity

Government Policies: Federal/Provincial/Regional/Territorial
(eg. education, health and social services)

Social & Cultural Values

Research to Inform & to Evaluate
• Understand the processes related to teaching & practicing collaboratively
• Measure outcomes/benchmarks with rigorous methodologies that are transparent
• Disseminate findings

Interprofessional Education for Collaborative Patient-Centred Practice

- Overview
- Collaborative patient-centred practice
- Interprofessional Education
- Accomplishments to Date
  - IECPCP Funded Projects
- Links and Resources
- Contact us

Overview

Changing the way we educate health providers is key to achieving system change and to ensuring that health providers have the necessary knowledge and training to work effectively in interprofessional teams within the evolving health care system.

This component of the proposed Pan-Canadian HHR Strategy will facilitate and support the implementation of a strategy on Interprofessional Education for Collaborative Patient-Centred Practice (IECPCP) across all health care sectors.

Collaborative patient-centred practice

Collaborative patient-centered practice is designed to promote the active participation of several health care disciplines and professions. It enhances patient-, family-, and community-centred goals and values, provides mechanisms for continuous communication among health care providers, optimizes staff participation in clinical decision making (within and across disciplines), and fosters respect for the contributions of all providers. There is growing consensus that interprofessional collaborative patient-centered practice - across all health sectors and along the continuum of care - will contribute to the following:

- improved population health / patient care;
- improved access to health care;
- improved recruitment and retention of health care providers;
- improved patient safety and communication among health care providers;
- more efficient and effective employment of health human resources; and
- improved satisfaction among patients and health care providers.

A closely related concept is that of collaborative care, which extends the collaboration to include patients, families, friends and informal caregivers. A key aspect of collaborative care and collaborative patient-centered practice is Supporting Self-Care, which has been the focus of an important initiative led by Health Canada from 1995 to 2002.

Interprofessional Education

Interprofessional education has been described as learning together to promote collaboration. It involves health care providers learning to work together, sharing in problem solving and decision making, to the benefit of patients, as follows:

- socializing health care providers in working together, in shared problem solving and decision making, towards enhancing the benefit for patients, and other recipients of services;
- developing mutual understanding of, and respect for, the contributions of various disciplines; and
- instilling the requisite competencies for collaborative practice.
Interprofessional education should occur before and after entry-to-practice, at the level of undergraduate, graduate, and continuing education, and across a continuum of care.

The specific objectives of the IECPCP initiative are as follows:

- promoting and demonstrating the benefits of interprofessional education for collaborative patient-centred practice;
- increasing the number of educators prepared to teach from an interprofessional collaborative patient-centred perspective;
- increasing the number of health professionals trained for collaborative patient-centred practice before, and after, entry-to-practice;
- stimulating networking and sharing of best educational approaches for collaborative patient-centred practice; and
- facilitating interprofessional collaborative care in both the education and practice settings.

Accomplishments to Date

Significant background work was conducted in the first year of the initiative, ensuring a solid foundation from which to build IECPCP. Promising practices in interprofessional education and collaborative patient-centred practice have been identified through a literature review and an environmental scan resulting in a 304-page IECPCP report. The Executive Summary and Chapter 10 of the report with the accompanying IECPCP Model (PDF Version) have been included below for your reference. In addition to the IECPCP report based on the literature review and environmental scan, a series of research papers exploring key concepts within the IECPCP have been commissioned. A synthesis of these papers by Dr. Vernon Curran is included below for your reference.

In-depth consultation of provincial and territorial governments has been conducted through the National Expert Committee (NEC) on Interprofessional Education for Collaborative Patient-Centred Practice. Consultations with experts representing professional and national stakeholders have occurred through a series of in-depth interviews, surveys, and bilateral meetings. Health Canada will continue to consult and collaborate with such stakeholders in the further development, implementation, and evaluation of the IECPCP initiative.

The Executive Summary
Chapter 10 of the report
Synthesis Report
IECPCP Model (PDF Version)

Links and Resources

Other Related Publications

Authored by Moira A. Stewart, Judith Belle Brown, W. Wayne Weston, Ian R. McWhinney, Carol L. McWilliam, Thomas R. Freeman (University of Western Ontario), this book describes and explains the patient-centered model of medicine; comprehensively covers the six interactive components of the clinical method, and learning and teaching the method; and examines and evaluates qualitative and quantitative research on the patient-centered clinical method, including reviews and recent studies. The first edition was published in Canada (Sage, 1995)

Organizations

College of Health Disciplines, University of British Columbia
(Vancouver, British Columbia, Canada)
CASE SCENARIO 1:

Gradually over the last twelve days Sonia, a 28 year old female, has noticed decreased energy levels and for the last four days she has had a persistent cough, fever and shortness of breath. She goes 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, she has no significant previous medical history except for a tonsillectomy at the age of seven. Until 6 months ago Sonia worked as a social services worker helping people get supportive housing, she is currently unemployed. She lives alone and has become too weak to care for herself. She reports use of marijuana and occasional injection drugs, mainly heroine, over the last year.

On physical examination Sonia has a fever of 39 degrees, is 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”

Objective: VS: RR 28, BP 105/70, HR 127
CRS: O$_2$ saturation 96% on 5L O$_2$ via NP
On auscultation: Poor air entry to lower lobes, decreased breath sounds throughout
Cough is voluntary, weak and non-productive, elicits pain
MSK: Complains of pain costal margins bilaterally, intercostals muscles tender on palpation on lower ribs
Poor mobility – assist of 1 for all transfers and ambulation
ADL: Assist of 1 for self-care
Cognition: Oriented x2 (person & place).
Appears confused and agitated at times
Lab results consistent with dehydration, HIV+ve (new diagnosis)

1. What are the impairments, activity limitations and participation restrictions that Sonia is experiencing? Potential rehabilitation goals and strategies for intervention?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Activity Limitation</th>
<th>Participation Restriction</th>
<th>Contextual Factors</th>
</tr>
</thead>
</table>

Canadian Working Group on HIV and Rehabilitation
Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists

<table>
<thead>
<tr>
<th>Goals:</th>
<th>Goals:</th>
<th>Goals:</th>
<th>Goals:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rx:</th>
<th>Rx:</th>
<th>Rx:</th>
<th>Rx:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evidence:</th>
<th>Evidence:</th>
<th>Evidence:</th>
<th>Evidence:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. What else would you want to assess with this patient? What might you expect to find?
Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists

3. Which members of a multidisciplinary team need to be involved with this case, and what would be their roles?

4. What things need to be considered regarding the patient's new HIV diagnosis?

5. What other information/questions would you like to know?
Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists

CASE SCENARIO 2:

James has been HIV positive for 6 years; it has been a year and a half since his last hospitalization related to medication toxicity. He is now on a stable anti-retroviral medication regimen. He has been on long-term disability for 5 years and is considering returning to work. Although James is looking forward to going back he has several concerns about his ability to keep up with the demands of work. He previously worked as a respiratory therapist in a community hospital. His energy levels still fluctuates, he can often have a full day with no need to rest, but 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.

As a result of the HIV and anti-retroviral therapy James has peripheral neuropathy leaving him with a mild decrease in sensation in both feet and hands. At times he finds that he stumbles while walking and has difficulty with some manual dexterity tasks. In addition the physical challenges that he faces, he has fears about work place phobias and how he will be accepted. At his last work place he experienced work place harassment and it was common to hear colleagues make comments under their breath in the staff room.

An insurance company has contracted you (a small independent multidisciplinary rehabilitation service provider) to assist James in his plan to return to work.

1. What are the impairments, activity limitations and participation restrictions that James is experiencing? Potential rehabilitation goals and strategies for intervention?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Activity Limitation</th>
<th>Participation Restriction</th>
<th>Contextual Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
</tr>
</tbody>
</table>

Canadian Working Group on HIV and Rehabilitation
2. What are the possible rehabilitation roles in this scenario?

3. What other information would you want to know?
4. What things need to be considered regarding the patient's longstanding HIV diagnosis?

5. Are there any other professionals that you would want involved in this case?
CASE SCENARIO 3:

Louis is an 83 year old male living alone in the community. 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 was diagnosed with bipolar disorder at the age of 55, and HIV infection approximately 2 years ago.

Louis lives in a 1 bedroom apartment, in the downtown area. As a community therapist, during your home visit, you noticed that his home is cluttered, disorganized and has not been recently cleaned. Louis has difficulty with ambulation and uses the furniture around his home to provide support for walking. Louis tells you he has a companion that 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.

Louis is currently not on any medication and you are the first health care provider to visit him at home.

1. What are the impairments, activity limitations and participation restrictions that Louis is experiencing? Potential rehabilitation goals and strategies for intervention?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Activity Limitation</th>
<th>Participation Restriction</th>
<th>Contextual Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
</tr>
</tbody>
</table>

Canadian Working Group on HIV and Rehabilitation
2. What else would you want to assess with this patient? What would you expect to find?

3. Which members of a multidisciplinary team need to be involved with this case, and what would be their roles?
4. What issues should be considered regarding the relatively new HIV diagnosis?

5. What other information/questions would you like to know?
CASE SCENARIO 4:

Natasha is a 16 year old living with cerebral palsy and HIV. She currently lives with her mother in a 2 bedroom apartment. 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 re-started highly active antiretroviral therapy (HAART), on a new combination of medications, and finds the side effects make her feel weak and nauseous. 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 it she has cancer. Natasha expresses that she does not want to be stigmatized or discriminated against, especially considering her family’s religious background.

The paediatric rehabilitation team is assessing Natasha’s needs to commence planning for transition to adult health and social care services. Natasha attends the rehab centre with her step-sister and mother; you note from the chart they have joint Power of Attorney in regard to Natasha’s care.

1. What are the impairments, activity limitations and participation restrictions that Natasha is experiencing? Potential rehabilitation goals and strategies for intervention?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Activity Limitation</th>
<th>Participation Restriction</th>
<th>Contextual Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
<td>Goals:</td>
</tr>
</tbody>
</table>

Canadian Working Group on HIV and Rehabilitation
2. How would you proceed with this assessment and rehabilitation care planning?

3. What things need to be considered regarding Natasha’s HIV diagnosis?
4. Which members of a multidisciplinary team should be involved with this case, and what would be their roles?

5. What other information/questions would you like to know?
Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building through Development of New Knowledge, Curriculum Resources and Partnerships

HIV and Rehabilitation: A Summary of Related References and Resources

Prepared by:
Kelly O’Brien (Phase 1), Natalie Gierman (Phase 2) and Gillian Bone

October 2006
ACKNOWLEDGEMENTS

HIV and Rehabilitation: A Summary of Related References and Resources forms part of A Compendium for Interprofessional Learning in Rehabilitation in the Context of HIV. The development of these resources has been made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

We would like to acknowledge the Project Advisory Committee for their contribution and guidance throughout this initiative.

<table>
<thead>
<tr>
<th>Advisory Committee Member</th>
<th>Organization represented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesley Bainbridge</td>
<td>University of British Columbia</td>
</tr>
<tr>
<td>Dr. Debra Cameron, Occupational Therapist</td>
<td>Canadian Association of Occupational Therapists (CAOT)</td>
</tr>
<tr>
<td>Geoff Lawrence and Michael Bailey</td>
<td>Canadian AIDS Treatment Information Exchange (CATIE)</td>
</tr>
<tr>
<td>Kelly O’Brien, Physical Therapist</td>
<td>Canadian Providers Survey Research Team, University of Toronto</td>
</tr>
<tr>
<td>Penny Parnes, Director</td>
<td>International Centre for Disability and Rehabilitation, University of Toronto</td>
</tr>
<tr>
<td>Dr. Greg Robinson, Family Physician</td>
<td>College of Family Physicians of Canada and Person Living with HIV</td>
</tr>
<tr>
<td>Lynne Sinclair, Director of Education,</td>
<td>Toronto Rehabilitation Institute</td>
</tr>
<tr>
<td>Dr. Patty Solomon, Professor, School of Rehabilitation</td>
<td>Canadian Physiotherapy Association (CPA)</td>
</tr>
<tr>
<td>Dr. Graham Smith, Family Physician</td>
<td>College of Family Physicians of Canada</td>
</tr>
<tr>
<td>Christopher Sulway, Physical Therapist</td>
<td>CWGHR’s Education / Practice Advisory Committee</td>
</tr>
<tr>
<td>Stephen Tattle, Registered Nurse</td>
<td>Canadian Association of Nurses in AIDS Care (CANAC)</td>
</tr>
<tr>
<td>Janet Wu, Speech-Language Pathologist, HIV Team</td>
<td>Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA)</td>
</tr>
</tbody>
</table>

The project team is completed by Janet London Project Administrative Assistant, San Patten Project Evaluator, Elisse Zack CWGHR Executive Director, Natalie Gierman Assistant Project Coordinator and Gillian Bone Project Coordinator.

Charitable registration number 85699 5535 RR0001
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Goals of the Compendium</td>
<td>2</td>
</tr>
<tr>
<td>Orientation to the Summary of Related References and Resources</td>
<td>3</td>
</tr>
<tr>
<td>Definitions of Key Terms</td>
<td>3</td>
</tr>
<tr>
<td>Section 1: Rehabilitation Needs of Persons Living with HIV and Current Knowledge of Rehabilitation Professionals</td>
<td>4</td>
</tr>
<tr>
<td>Section 2: Conceptual Frameworks on Rehabilitation in the Context of HIV</td>
<td>7</td>
</tr>
<tr>
<td>Section 3: Conceptual Frameworks on Interprofessional Education</td>
<td>10</td>
</tr>
<tr>
<td>Section 4: Curriculum Components on Rehabilitation in the Context of HIV</td>
<td>14</td>
</tr>
<tr>
<td>Section 5: Essential Topics for Comprehensive Capacity Building on HIV with Rehabilitation Professionals</td>
<td>19</td>
</tr>
<tr>
<td>Section 6: Additional Resources on HIV and Rehabilitation</td>
<td>24</td>
</tr>
<tr>
<td>Section 7: Electronic Resources and Websites related to HIV</td>
<td>27</td>
</tr>
<tr>
<td>References</td>
<td>28</td>
</tr>
</tbody>
</table>
Introduction

In developed countries, for those with access to antiretroviral therapy, persons living with HIV are living longer (Palella et al, 1998). As a result, these individuals may be living with the range of health-related sequelae associated with HIV disease and its associated treatments. A recent survey documented a remarkably high prevalence of disablement among persons living with HIV in British Columbia (Rusch et al, 2004). Types of disablement included a range of impairments (problems with body structure or function such as pain or weakness), activity limitations (difficulty carrying out day-to-day activities such as walking), and participation restrictions (difficulty engaging in life roles such as work or leisure activities) (World Health Organization, 2001). At least 80% of respondents experienced an impairment, activity limitation or participation restriction within the past month (Rusch et al, 2004). Results demonstrated the need for health care communities to respond to the changing needs of persons living with HIV, and specifically demonstrated the increased role for rehabilitation to address issues of disablement for these individuals.

In response to this need, a survey investigated rehabilitation in the context of HIV from a health provider perspective. A national survey was conducted to explore the knowledge, attitudes and practices of selected health care provider groups (rehabilitation professionals and HIV specialists) on rehabilitation services for persons living with HIV (Worthington et al, 2005). Rehabilitation professionals included: physical therapists, occupational therapists, physiatrists, and speech-language pathologists who may or may not have been working in the area of HIV/AIDS, and HIV specialists included: physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), nurses, dieticians, pharmacists, social workers, and psychologists working in the field of HIV/AIDS. Results from rehabilitation professional respondents demonstrated that 61% of rehabilitation professionals had reported never knowingly working with persons living with HIV. Of those who had worked with persons living with HIV, they only worked with four persons per year on average (O’Brien et al, 2005). While the majority of respondents indicated that rehabilitation is somewhat or very important for people living with HIV (86%), only 19% agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat people living with HIV. Only 27% had received training in HIV/AIDS as part of their rehabilitation degree education. Alternatively, results from HIV specialist survey respondents found that very few refer people living with HIV to rehabilitation professionals (Worthington et al, 2005). Furthermore, only 45% agreed or strongly agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat the rehabilitative needs of persons living with HIV.

Thus, despite the role that rehabilitation professionals have to play in the care and treatment of persons living with HIV, only a minority currently work with HIV clients. Additionally, HIV specialists (including physicians) currently provide limited rehabilitation-related services for persons living with HIV, and refer them to a range of rehabilitation services. As a result, the disablement needs of persons living with HIV are largely unmet. There is a need for further education and service development in this field. Overall, education of rehabilitation professionals and referring HIV specialist
health professionals is crucial in order to enhance access to rehabilitation services for persons living with HIV in Canada.

The Canadian Working Group on HIV and Rehabilitation (CWGHR) has responded to the critical need for development and delivery of high quality curriculum resources and educational initiatives through its capacity building project: Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building through Development of New Knowledge, Curriculum Resources and Partnerships. This project built on recent and current interprofessional education initiatives to enhance and increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS in Canada.

CWGHR is a national, multi-sector and multi-disciplinary organization that was established in 1998 to facilitate a national, coordinated response to emerging needs in rehabilitation in the context of HIV/AIDS. With persons living with HIV and rehabilitation professionals as key stakeholders, CWGHR’s primary goals are: 1) to improve the quality of life of people living with HIV through cross-sector research, education and advocacy on rehabilitation issues, and 2) to improve access to rehabilitation programs and services for people living with HIV.

Goals of the Compendium

Phase I: Compendium of Resources on HIV and Rehabilitation, developed at the beginning of the project, was to inform the project advisory committee and other members of the CWGHR Capacity Building Team of existing curriculum resources, educational initiatives, programs and tools in Canada and Internationally relevant to HIV and rehabilitation. This increased the capacity of the team to identify gaps in rehabilitation professional education and informed the project curriculum development.

Through the project activities new resources, programs and tools have been developed and additional initiatives identified; quantitatively and qualitatively enhancing Phase I. Phase II: A Compendium for Interprofessional Learning in Rehabilitation in the Context of HIV includes five components:

1. HIV and Rehabilitation: A Summary of Related References and Resources
   This document described on page 3
2. Rehabilitation in the Context of HIV: An Interprofessional Course for Occupational Therapists, Physiotherapists, Speech-Language Pathologists and Audiologists
   Course materials, including powerpoint presentations, references and resources
3. Project Final Report including Evaluation
4. An audiovisual record of the course presentations on DVD
5. Hard copies of all resources and reference articles described

This Compendium is designed to be a “living document” that will continually develop and expand. It will be of interest to educators, learners and others interested in learning about and/or educating health care professionals on rehabilitation in the context of HIV.
Orientation to the Summary of Related References and Resources

This summary provides an overview of the evidence and resources pertaining to education on rehabilitation in the context of HIV. Resources were identified through literature searches of databases including MEDLINE, CINAHL, EMBASE and AIDSEARCH and supplemented via consultation with advisory committee members, CWGHR members, and members of CWGHR’s Education and Practice Advisory Committee (EPAC). Project partners, environmental scan participants, course participants and facilitators also added valuable information and areas of focus to the compendium. This is in no way inclusive of all existing HIV and rehabilitation tools and will be continually expanded and updated through CWGHR’s future projects and activities.

CWGHR also recognizes the diversity of resources included in this compendium. Rather than attempt to appraise the quality of these resources, the goal of this compendium is to present existing resources and allow the user to determine their applicability based on a person’s learning needs and/or environment.

The compendium is organized into seven sections ranging from the need for capacity building among rehabilitation professionals to specific resources used in HIV education. Specific sections include:

1. Rehabilitation Needs of Persons Living with HIV and Current Knowledge of Rehabilitation Professionals
2. Conceptual Frameworks on Rehabilitation in the Context of HIV
3. Conceptual Frameworks on Interprofessional Education
4. Curriculum Components on Rehabilitation in the Context of HIV
5. Essential Topics for Comprehensive Capacity Building on HIV with Rehabilitation Professionals
6. Additional Resources on HIV and Rehabilitation
7. Electronic Resources and Websites related to HIV

Definitions of Key Terms

Definitions of key terms used in the context of this project are provided:

- **Acronyms to describe People living with HIV** vary from community to community, and may include PHA, PWA, and PLWHA.
- **Capacity**: The potential or ability to recognize and adequately respond to the rehabilitation needs of people living with HIV
- **Curriculum**: An integrated compilation of educational resources, timelines, and strategies to increase education, knowledge and skills among a group of individuals.
- **Disability**: in any life domain, any body impairment, activity limitation or participation restriction identified as an issue by a person living with HIV/AIDS
Canadian Working Group on HIV and Rehabilitation
Interprofessional Learning in Rehabilitation in the Context of HIV:
Stakeholder Capacity Building Through Development of New Knowledge, Curriculum Resources and Partnerships

(modified from the *International Classification of Functioning, Disability and Health* (ICF) Framework, WHO 2001).

- **Rehabilitation**: a dynamic process, including all prevention and/or treatment activities and/or services that address body impairments, activity limitations and participation restrictions for an individual (Worthington et al, 2005, based on the ICF Framework, WHO 2001)
- **Rehabilitation professionals**: in the context of this project, rehabilitation professionals include occupational therapists (OT), physical therapists (PT), speech-language pathologists (SLP) and audiologists.
- **Interprofessional Education (IPE)**: "members (or students) of two or more professions associated with health or social care, to be engaged in learning with, from and about each other" (Geissler, 2002). Related terms include **Interprofessional Collaboration (IPC)** and **Interprofessional Learning (IPL).**
- **Collaborative Patient-Centred Practice**: “is designed to promote the active participation of each discipline in patient care. It enhances patient and family centred goals and values, provides mechanisms for continuous communication among caregivers, optimizes staff participation in clinical decision making within and across disciplines and fosters respect for the disciplinary contributions of all professionals.” (Health Canada, 2003)

**Section 1:**
Rehabilitation Needs of Persons Living with HIV and Current Knowledge of Rehabilitation Professionals

**Overview:** This section provides evidence from past studies which identify the knowledge gaps and establish the need for capacity building among rehabilitation professionals to meet the needs of persons living with HIV.

### A) Rehabilitation Needs of Persons Living with HIV

<table>
<thead>
<tr>
<th>Title &amp; Citation</th>
<th>Brief Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) HIV &amp; Rehabilitation: The Canadian Providers’ Survey</td>
<td>Documents the knowledge, attitudes and practices of selected health care provider groups concerning rehabilitation service provision for persons living with HIV. Rehabilitation professionals included OTs, PTs, SLPs and physiatrists who may or may not have worked with HIV clients. HIV specialists included physicians, social workers, psychologists, dieticians, nurses, pharmacists who worked clinically in the field of HIV. Results identify the amount and types of HIV and rehabilitation education received, and identify learning needs and gaps in education.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>2) Factors Influencing Anxiety Concerning HIV/AIDS in Rehabilitation Workers</td>
<td>Examines factors that influenced anxiety of rehabilitation workers in a US public rehabilitation agency (professions not specified – job titles included administration, counselor, clerical, other) in providing services to persons living with HIV using an anxiety questionnaire. A two stage educational program of 2 hours, 45 minutes was provided. Factors included age and the amount of previous contact with persons living with HIV and homosexuals. Younger individuals and those who had previous contact with persons living with HIV were less anxious pre and post education. Although education did not significantly reduce anxiety, literature suggests that one time educational offerings may not be optimal in providing HIV education.</td>
</tr>
<tr>
<td>All AC, Fried JH. Factors Influencing Anxiety Concerning HIV/AIDS in Rehabilitation Workers. <em>Journal of Rehabilitation</em>. 1996; 17-21</td>
<td></td>
</tr>
<tr>
<td>3) Physiotherapists and HIV/AIDS: Knowledge and prevention: a study in Durban South Africa</td>
<td>Documents PTs knowledge about HIV in Durban South Africa using a questionnaire. Results demonstrated that 98% believed physical therapy was an integral component of HIV management. Only 38% were completely at ease when treating persons living with HIV, the other 62% reported minimal to moderate anxiety or fear, but were still willing to treat HIV clients. Only 24% attended educational workshops/seminars on HIV. In summary, there are many gaps in PTs knowledge about HIV demonstrating a need for development, implementation and evaluation of HIV educational programs.</td>
</tr>
<tr>
<td>4) The Effect of Professional Education on the Knowledge and Attitudes of Physical Therapist and Occupational Therapist Students About Acquired Immunodeficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Evaluates the effect of education of PT and OT students on their knowledge, attitudes and willingness to provide services to people living with HIV. Authors administered a questionnaire at the beginning of the program, after a 5 hour education session, and prior to graduation. Education session consisted of 1 hour lecture on ethical and legal issues in health care, 2 hour panel discussion on treatment options by various health providers, 1 hour small group interdisciplinary session of case study discussions, 1 hour case study session in each department. At graduation, students showed improvements in HIV knowledge (13.8% for PT students, 13.8% for OT students) and more positive attitudes towards people living with HIV, however their willingness to provide services for people living with HIV remained unchanged (could be attributed to ceiling effect of questionnaire).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5) HIV/AIDS Pandemic: Comparative knowledge and roles of physiotherapists in two African countries.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compares the knowledge, attitude and role of PTs in Nigeria and Zimbabwe. Results illustrated differences in level of knowledge between the two countries with PTs in Nigeria showing a lower level of knowledge compared to PTs in Zimbabwe. All PTs in Zimbabwe had served people living with HIV compared to only 43% in Nigeria. Roles of PTs were similar and included chest physiotherapy, aerobics, health education and counseling. In conclusion, a review of PT curriculum was recommended and enhancement of HIV education among rehabilitation professionals.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6) Physician Attitudes and Experience Regarding the Care of Patients with AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigates the attitudes and experience of physicians regarding care of persons living with HIV. Results demonstrated that both heterosexual and homosexual physicians indicated a lack of medical knowledge and experience working with persons living with HIV. Clinically based training opportunities were recommended to increase willingness to treat persons living with HIV.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7) The Effects of an AIDS Education Program on the Knowledge and Attitudes of a Physical Therapy Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Held SL. The Effects of an AIDS Education Program</td>
</tr>
<tr>
<td>Determines the effect of an education unit on PT students' knowledge, attitudes and willingness to treat persons living with HIV. PT students from one program were randomly assigned to HIV education unit or control (no)</td>
</tr>
</tbody>
</table>

Education was a 4 hour unit consisting of 2 areas: 1) HIV 101 and 2) feelings of being a person living with HIV, attitudes directed towards patients and the code of ethics. Students that participated in the education unit showed significant improvements in knowledge, attitudes and willingness to treat patients who have HIV as measured by a questionnaire. Education influencing knowledge, attitudes and willingness to treat persons living with HIV will ensure better access to appropriate health care services for persons living with HIV in need.

Section 2:
Conceptual Frameworks on Rehabilitation in the Context of HIV

Overview: This section provides an overview of conceptual frameworks or models that have been used in the rehabilitative context of HIV.

A) Conceptual Frameworks or Models

<table>
<thead>
<tr>
<th>Conceptual Framework</th>
<th>Brief Summary</th>
</tr>
</thead>
</table>
| **1) International Classification of Functioning, Disability and Health (ICF)**<br>World Health Organization, *International Classification of Functioning, Disability and Health (ICF)* Geneva. 2001 | This framework conceptualizes disablement using a biopsychosocial approach that includes components of impairments, activity limitations and participation restrictions experienced by individuals and influenced by personal and environmental contextual factors. This universal framework provides a useful way to approach thinking about rehabilitation assessment and interventions. Evidence has used this model (and past versions of this model such as the ICIDH) in the context of HIV including:
- Shifting Perspectives: Reconceptualizing HIV Disease in a Rehabilitation Framework. (Nixon S. *Physiotherapy Canada*. Summer 2000. 189-197)
- The International Classification of Functioning, Disability and Health (ICF) and Its Application to AIDS. (Hwang JL, Nochajski SM. *Journal of Rehabilitation*. 2003; 69(4): 4-12) |

Complete resources on ICF framework at [http://www3.who.int/icf/icftemplate.cfm](http://www3.who.int/icf/icftemplate.cfm)

| **2) Movement Continuum Theory**<br>Cott CA, Funch E, Gasner D, Yoshida K, Thomas SG, Verrier MC. The movement continuum of physical therapy. 1995. *Physiotherapy Canada*. 47(2): 87-95. | Conceptualizes rehabilitation along a continuum of care from the micro level at the cellular dimension to the macro level of the person in their environment. This theory was developed to conceptualize physical therapy practice encompassing the holistic view of movement including physical, social and psychological factors. Consists of |
three general principles: 1) movement is essential to human life, 2) movement occurs on a continuum from the microscopic level to the level of the individual in society and 3) movement levels on the continuum are influenced by physical, psychological, social and environmental factors. May be conceptualized in the rehabilitative context of HIV as disablement issues may impact persons living with HIV along all aspects of the continuum from the physiological level (CD4 count and viral loads) to the person in their environment (ability to work).

<table>
<thead>
<tr>
<th>3) Person-Environment-Occupation (PEO) Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>These articles conceptualize occupational therapy as focusing on complex dynamic relationships between people, occupations and environments. Using case studies, the authors provide ways in which occupational therapists may plan, communicate and evaluate occupational therapy interventions in varying environments.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4) Conceptual Model of Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>This model has been used to examine the relationships between clinical variables such as symptoms and quality of life for persons living with HIV. Model includes components that gradually progress from biological and physiological factors, symptom status, functional status, general health perceptions, to overall quality of life. Individual and environmental characteristics are included in the model and may impact all levels. Model demonstrates the shift from the cellular level to the person in society.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B) Conceptual frameworks specifically developed or adapted to Rehabilitation in the Context of HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Conceptual HIV/AIDS Rehabilitation Framework</td>
</tr>
<tr>
<td>This paper documents the development of an enhanced, multi-disciplinary conceptual framework of rehabilitation in the context of HIV, using the perceptions of persons living with HIV and rehabilitation professionals. The framework was developed through broad consultation and interviews with thirteen key informants. Themes that emerged related to concepts of rehabilitation in the context of HIV, rehabilitation professionals’ roles in the context of HIV, and barriers to access and delivery of rehabilitation services. The framework uses the perspective of the person living with HIV/AIDS, and includes individual life domains that</td>
</tr>
</tbody>
</table>
2) Cross-Disability Model


The purpose of CWGHR’s cross disability project was to collectively define common disability and rehabilitation issues among people living with lifelong and episodic illnesses, and to explore cross-disability partnerships between organizations across Canada. Methods involved interviews with non-HIV groups working with lifelong episodic illnesses, national consultation with key organizations to explore shared program and policy issues and face-to-face meeting with the Chair of the Subcommittee on the Status of Persons with Disabilities. The following themes were identified pertaining to episodic illness: need to develop new definitions of “disability” and “rehabilitation” applicable to persons with episodic illness, provision of care, treatment and support, workplace accommodation and employment, income security and support, legislation and policy, stigma and prejudice and the need for education.

Full report available at [www.hivandrehab.ca](http://www.hivandrehab.ca)

3) Model for rehabilitation in pediatric HIV Care.

Bone G. Perspectives of Models of Service Delivery in Rehabilitation for Children with Vertically Acquired HIV. Canadian Journal of Infectious Diseases. 2001, Volume 12, Supplement B: 98B

This qualitative study describes current models of service delivery of rehabilitation services for infants and children with HIV infection in selected pediatric HIV teams across Canada, the United States and the United Kingdom. Proposes that comprehensive rehabilitation services for infants and children are optimally provided through integration of the biopsychosocial and developmental models of service delivery.

4) An Innovative HIV/AIDS Health Care Delivery Model that Incorporates an Expanded Role for Physical Therapy


This paper proposes an interprofessional model of rehabilitation service delivery along the entire continuum of care for persons living with HIV, including preventative, acute, rehabilitative and palliative stages of illness.
Section 3:
Conceptual Frameworks on Interprofessional Education

Overview: This section provides an overview of conceptual frameworks or models of interprofessional education. Some of the most common attributes of IPE include:

- a holistic approach to patient care, places patient care at the centre of learning
- placing patient care at the centre of learning
- involving interactive learning between different professional groups
- developing knowledge and understanding of other professions involved in the delivery of health care
- accepting different sets of values about teaching and learning
- reflecting the needs of the health care team (Parsell and Bligh, 1998)

A) Conceptual Frameworks and Resources on Interprofessional Education

| 1) Interprofessional Education (IPE): New Knowledge in Need of Translation? |
| Toronto Rehabilitation Institute resources at www.torontorehab.on.ca |
| This article discusses the link between IPE and best practice in a rehabilitation hospital setting. Includes several definitions of IPE and links them to a professional practice portfolio. |

| 2) Interprofessionality as the field of interprofessional practice and interprofessional education: an emerging concept |
| This paper introduces the concept of “interprofessionality” which serves to bridge the gap between interprofessional education and interprofessional practice. A framework termed: Interprofessional Education for Collaborative Patient-Centred Practice is presented. This framework demonstrates the link between the learner, teacher and professionals, the link between teaching and health organizations, and links among political, socio-economic and cultural systems. |

<p>| 3) Key elements for interprofessional education. Part 1: The learner, the educator and the learning context. |
| This paper discusses the key components needed for the planning and implementation of IPE, starting with a historical review. This review reflects the work that has been initiated and implemented to advance IPE for health professional students. |</p>
<table>
<thead>
<tr>
<th>4) Key elements for interprofessional education. Part 2: Factors, processes and outcomes.</th>
<th>This paper discusses the factors that influence the success of an IPE initiative. A framework is proposed to facilitate the planning and implementation of an IPE program.</th>
</tr>
</thead>
<tbody>
<tr>
<td>5) A Blueprint for Interprofessional learning. <em>Journal of Interprofessional Care</em></td>
<td>This paper discusses ways to enable health professionals to work together in cooperative groups.</td>
</tr>
<tr>
<td>6) Learning together to teach together: Interprofessional education and faculty development.</td>
<td>This paper is aimed at educators in order to provide them with the tools to design and facilitate IPE. Areas discussed include: IPE and collaborative patient-centred practice, teaching and learning, and leadership and organizational change.</td>
</tr>
<tr>
<td>7) Academic administrators’ attitudes towards interprofessional education in Canadian schools of health professional education.</td>
<td>The purpose of this article was to examine the attitudes towards interprofessional teamwork and IPE amongst academic administrators of health professionals programs in Canada. Results showed positive perceptions of teamwork and IPE among administrators.</td>
</tr>
<tr>
<td>8) Interprofessional learning and higher education structural barriers.</td>
<td>This paper describes the structural barriers to interprofessional education within university environments.</td>
</tr>
<tr>
<td>9) Models of interprofessional learning in Canada</td>
<td>This paper provides an overview of the interprofessional learning models that have been implemented across Canada.</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Cook DA. Models of interprofessional learning in Canada.</td>
<td></td>
</tr>
<tr>
<td>10) Interdisciplinary Education and Teamwork: a long and winding road</td>
<td>This article describes the literature on IPE and teamwork. The two issues faced by health professionals including: the need to specialize, and the need to collaborate are discussed.</td>
</tr>
<tr>
<td>Hall P, Weaver L. Interdisciplinary education and Teamwork: a long winding road. Medical Education. 2001; 35:867-875</td>
<td></td>
</tr>
<tr>
<td>11) Interprofessional Education: Today, Yesterday and Tomorrow</td>
<td>This paper provides an overview of IPE, providing a historical perspective on the emergence of IPE and offers recommendations for future IPE research and development.</td>
</tr>
<tr>
<td>Barr H.</td>
<td></td>
</tr>
<tr>
<td>Full report available at:</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.health.ltsn.ac.uk/publications/occasionalpaper/occasionalpaper01.pdf">http://www.health.ltsn.ac.uk/publications/occasionalpaper/occasionalpaper01.pdf</a></td>
<td></td>
</tr>
<tr>
<td>12) Myths and Opportunities: An Examination of the Impact of Discipline-Specific Accreditation on Interprofessional Education</td>
<td>This project examined the impact of discipline-specific accreditation on IPE efforts. An overview of IPE including the history, models and challenges are discussed. Also examined are the linkages and differences between accreditation of professional education programs. Findings and recommendations to help sustain IPE are provided.</td>
</tr>
<tr>
<td>Preparing Human Service Workers for Interprofessional Practice. Collaborative project of the Council on Social Work Education, University of California School of Social Work, University of Southern California Department of Nursing, California State University, Fullerton Center for Collaboration for Children. 1999</td>
<td></td>
</tr>
<tr>
<td>Full report available at:</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.cswe.org/casey/noframes/cover-noframe.htm">http://www.cswe.org/casey/noframes/cover-noframe.htm</a></td>
<td></td>
</tr>
<tr>
<td>13) Center for Health Sciences Interprofessional Education. Working Together for Better Health. Courses on Interprofessional Competencies at the University of Washington, 2002</td>
<td>This course, offered at the University of Washington, assists health professionals in their ability to work together and with patients and clients. Five primary interprofessional competences are discussed.</td>
</tr>
<tr>
<td>Full course description available at:</td>
<td></td>
</tr>
<tr>
<td><a href="http://interprofessional.washington.edu/courses.asp">http://interprofessional.washington.edu/courses.asp</a></td>
<td></td>
</tr>
<tr>
<td><strong>14) Interprofessional Education and Collaboration: Theoretical Challenges, Practical Solutions</strong></td>
<td>Using the College of Health Disciplines, University of British Columbia as a model, this article proposes solutions to Interprofessional Education and collaboration through structural changes made at the university level.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>

**15) Student perspectives of Interprofessional Education**

This article represents the collaboration among nine students from seven disciplines who participated in a joint clinical placement. Students discuss both the rewards and challenges of working together in a collaborative team.


**16) Interprofessional Education for Collaborative Patient Centred Practice Research Synthesis Paper.**

This document provides a synthesis of research and policy outcomes from the Interprofessional Education for Collaborative Patient Centred Practice (IECPCP) Initiative.


**17) Canadian Academic IPE/C/L Websites**

Provide overview of Interprofessional education/Collaboration/Learning (IPCL) including importance of teamwork, bibliography of resources, journals, events locally, provincially, nationally and internationally, and course descriptions.

| University of British Columbia Interprofessional Continuing Education. [http://www.interprofessional.ubc.ca](http://www.interprofessional.ubc.ca) |  |
| University of Toronto Interprofessional Education (including the Interfaculty Pain Curriculum) [http://ipe.utoronto.ca](http://ipe.utoronto.ca) |  |
| Queen’s University, Inter-Professional Patient Centred Education Direction [http://meds.queensu.ca/quipped/home](http://meds.queensu.ca/quipped/home) |  |
| Memorial, University of Newfoundland: Centre for Collaborative Health Professional Education. [http://www.med.mun.ca/cchpe/default.htm](http://www.med.mun.ca/cchpe/default.htm) |  |
| University of Dalhousie, Interprofessional Learning (IPL) [http://ipl.dal.ca/index.html](http://ipl.dal.ca/index.html) |  |
Section 4:
Curriculum Components on Rehabilitation in the Context of HIV

Overview: This section provides an overview of existing curriculum models on HIV education. Ideally, we looked for models that consist of 1) interprofessional education for 2) rehabilitation professionals on 3) HIV/AIDS. Some of the curriculum found in the literature search was more broadly geared towards health care professionals (which may or may not have included rehabilitation professionals specifically). As a result, a fourth component was added to the model to reflect curriculum geared to this broader audience. Section A represents the ideal curriculum that possesses the three desired components of interprofessional education for rehabilitation professionals on HIV/AIDS. Section B represents HIV curriculum specific to rehabilitation professionals with no particular focus on IPE. Section C represents interprofessional HIV curriculum for health care professionals (including but not specific to rehabilitation professionals). Section D represents HIV curriculum more broadly to health care professionals who may or may not include rehabilitation professionals.

Model of Intersecting Components of Curricula in the Compendium of Resources
## Section A) Interprofessional HIV Curriculum Specific to Rehabilitation Professionals

<table>
<thead>
<tr>
<th>1) McMaster Project - An Interprofessional Problem-Based Learning Course on Rehabilitation Issues in HIV</th>
<th>Examines perceptions of rehabilitation professional students’ learning through participation in an interprofessional problem-based course on rehabilitation and HIV. Education included successful integration of persons living with HIV. Students from OT, PT, MD, nursing and social work participated in an 8 week interprofessional course consisting of 2 hour tutorial session weekly where students studied 4 health care problems. Qualitative analysis of student journals found the following themes: factual knowledge, benefits to interprofessional knowledge, rehabilitation insight, sense of confidence and enjoyment. Persons living with HIV as facilitators provided unique perspectives on HIV, acted as a resource, and challenged students assumptions. HIV and rehabilitation interprofessional learning is ideal in a problem-based environment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Report 1 and 2 are available at <a href="http://www.hivandrehab.ca">www.hivandrehab.ca</a></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2) HIV Problem-Based Interprofessional Learning Case</th>
<th>Students from medicine, physical therapy, and pharmacy participate in a six-hour module where they break into small interprofessional groups to work through an HIV-problem based learning case. This module has been implemented for the past 4-5 years.</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Saskatoon Contact: Peggy Procter, Department of Physical Therapy</td>
<td></td>
</tr>
</tbody>
</table>

## Section B) HIV Curriculum Specific to Rehabilitation Professionals (no IPE)

<table>
<thead>
<tr>
<th>1) HIV/AIDS Education: Systems Approach to Rehabilitation in the Context of HIV</th>
<th>Provides HIV/AIDS education to physical therapy students across systems units within the curriculum including cardiorespiratory (Unit 2), and neurological features (Unit 5) of HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Toronto, Department of Physical Therapy</td>
<td></td>
</tr>
</tbody>
</table>
**Contact:** Kelly O’Brien

and advanced rehabilitation issues for PHAs such as episodic disability, income support, and return to work issues in the form of lectures and small group complex case-based learning (Unit 8).

**2) HIV/AIDS and the Rehabilitation Professional – At Home Seminars Program**

A self-directed continuing education program offered in the US. Goal of the program is to familiarize students with the history of the AIDS epidemic, biology of HIV virus, modes of transmission, value of physical therapy and rehabilitation of persons living with HIV. This program counts towards contact hours in the US (Access to course objectives on website, booklet and test questions provided on registration approximately $85 US).

**3) A Comprehensive Guide for the Care of Persons with HIV Disease. Module 7 Rehabilitation Services.**

This resource was developed to respond to the growing role for rehabilitation professionals in HIV care. The project developed out of an extensive consulting process that was inclusive of both rehabilitation professionals and people living with HIV.

**Section C) Interprofessional HIV Curriculum for Health Care Professionals (may or may not include Rehabilitation Professionals)**

**1) Guide to Multi-Sector Workshops on Rehabilitation in the Context of HIV**

This curriculum was developed to promote education on rehabilitation in the context of HIV. Multiple workshops across Canada were conducted by CWGHR. Participants included multiple stakeholders such as persons living with HIV, rehabilitation professionals, representatives from the private and public sector, insurance, government, etc. Topics covered include profile of CWGHR, definitions of rehabilitation, overview of BC Prevalence Study, rehabilitation in the hospital setting, complementary therapy, aboriginal health, Canada pension plan and benefits.

**2) Interprofessional Learning Modules at Dalhousie University (HIV/AIDS)**

This article describes the first two years of an interprofessional learning module implemented with students from nursing, medicine, social work, physical therapy, occupational therapy, pharmacy, speech-language pathology, audiology, dental hygiene, dentistry, leisure studies, health education and kinesiology at
Canadian Working Group on HIV and Rehabilitation  
Interprofessional Learning in Rehabilitation in the Context of HIV: 
Stakeholder Capacity Building Through Development of New Knowledge, Curriculum Resources and Partnerships

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Dental Consultant Course</td>
<td>The purpose of this article was to describe the training needs, delivery and evaluation of a two day course for senior dental health care workers on oral HIV awareness held by a multidisciplinary training group. Course comprised an information update, practical experience in the diagnosis of oral conditions, 'hands on' experience in infection control, and communication skills training via role play with actors and video feedback. Participants found the training valuable and results showed increased confidence in knowledge and ability to communicate with HIV clients and talking with staff unwilling to provide treatment.</td>
</tr>
<tr>
<td>2) AIDS Related Training in US Schools of Social Work</td>
<td>The purpose of this article was to assess, via a survey, the degree and way in which social work schools in the US train students in the area of HIV. Results demonstrated 8 (n=5) to 15%</td>
</tr>
<tr>
<td>3) Improving Care Through Interprofessional Education</td>
<td>Interprofessional course for senior students in health professions (currently does not include rehabilitation disciplines) to respond effectively as members of a health care team to the HIV episodic and biological and social consequences associated with HIV. Skills for working in partnership with clients, families and community agencies are addressed to meet the complex issues of HIV. Components include problem-based learning scenarios, presentations and workshops. Clinical experiences also occur in clinical and community settings with health care professionals with knowledge in HIV.</td>
</tr>
<tr>
<td>4) Interprofessional HIV/AIDS Education Program on Role Perception, Attitudes and Teamwork Skills of Undergraduate Health Sciences Students</td>
<td>This study evaluated an undergraduate HIV/AIDS interprofessional education program for medical, nursing and pharmacy students at Memorial University, Newfoundland. Changes in role perception, attitudes towards collaboration, teamwork skills and satisfaction with shared learning experience were assessed.</td>
</tr>
<tr>
<td>Section D) HIV Curriculum for Health Care Professionals (no IPE; may or may not include Rehabilitation Professionals)</td>
<td>Dalhousie University. Five interprofessional learning modules (3 hours each) were targeted in areas of: professional roles and values, integrity in scholarly activity, disability, interpersonal violence and HIV/AIDS.</td>
</tr>
</tbody>
</table>

<p>| 2) AIDS Related Training in US Schools of Social Work | Diaz YE, Kelly JA, AIDS-Related Training in |</p>
<table>
<thead>
<tr>
<th><strong>US Schools of Social Work. Social Work. 1991; 36(1): 38-42.</strong></th>
<th><strong>(n=10) programs offered full courses on AIDS-specific topics (such as HIV infection, risk behaviours), just over one third incorporate some HIV content into their courses and 58% (n=41) offered HIV training by encouraging students to obtain education through workshops offered by other organizations. Graduate schools of social work provide training and course work in the area of HIV, many lack training in human sexuality, which may have implications for persons living with HIV.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>3) HIV/AIDS and Human Rights in a Nutshell. A quick and useful guide for action as well as a framework to carry HIV/AIDS and human rights actions forward</strong></td>
<td><strong>This tool offers insights into the relationship between human rights and HIV in three main ways: accountability, advocacy and approaches to programming and services. The centre has also developed and implemented other courses linking health and human rights offered through HSPH and internationally.</strong></td>
</tr>
<tr>
<td></td>
<td>Full guide available at: <a href="http://www.hsph.harvard.edu/fxbcenter/">www.hsph.harvard.edu/fxbcenter/</a></td>
</tr>
<tr>
<td><strong>4) Prevention of Mother-to-Child Transmission of HIV in Resource-Limited Settings: A Training Course.</strong></td>
<td><strong>This course provides resources on the prevention and treatment of HIV infection in women and children targeted at health workers, program managers, and policy makers in resource-poor settings. Information is geared towards health care providers with basic knowledge and familiarity with HIV care and treatment. The training course consists of 5 modules, and also provides links to key resources that were used in the development of this course.</strong></td>
</tr>
<tr>
<td></td>
<td>Full course modules are from: <a href="http://www.womenchildrenhiv.org/">http://www.womenchildrenhiv.org/</a></td>
</tr>
<tr>
<td><strong>5) Designing and Delivering HIV/AIDS Training: A Facilitator’s Guide. Canadian Public Health Association. 2003</strong></td>
<td><strong>This manual can assist frontline workers to incorporate HIV/AIDS education into their work with the public. It also includes resources for additional information.</strong></td>
</tr>
<tr>
<td></td>
<td>Reference copy available through CWGHR office. Full content available through <a href="http://www.aidssida.cpha.ca">www.aidssida.cpha.ca</a></td>
</tr>
</tbody>
</table>
Section 5:  
Essential Topics for Comprehensive Capacity Building on HIV with Rehabilitation Professionals

Overview: This section provides topics or content areas that should be included in HIV curriculum for rehabilitation professionals. An example from the literature pertaining to each topic is provided in no particular order. Some of these articles may also fit into several categories. Some of these topics may be specific to HIV/AIDS, whereas others may include knowledge and skills required broadly across general practice. HIV/AIDS is often an ideal medium in which to introduce and address these often complex, yet critical components of rehabilitation practice.

1) Introduction to HIV

<table>
<thead>
<tr>
<th>Example Resource / Article</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. HIV and Its Transmission.</td>
<td>This fact sheet specifically addresses some known myths and misperceptions regarding the transmission of HIV.</td>
</tr>
<tr>
<td>Centres for Disease Control. 1999</td>
<td></td>
</tr>
<tr>
<td>Full content available at: <a href="http://www.cdc.gov/hiv/resources/factsheets/transmission.htm">http://www.cdc.gov/hiv/resources/factsheets/transmission.htm</a></td>
<td></td>
</tr>
<tr>
<td>b. Guide to Primary Care of People with HIV/AIDS</td>
<td>This guide addresses important aspects of HIV/AIDS care, and provides practical information to commonly asked questions.</td>
</tr>
<tr>
<td>Also see Section 7: Electronic resources for more information on HIV/AIDS</td>
<td></td>
</tr>
</tbody>
</table>

2) Living with HIV

<table>
<thead>
<tr>
<th>Example Resource / Article</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Managing Your Health: A Guide for People Living with HIV or AIDS (Module 5). CATIE. 1999 Edition.</td>
<td>The Canadian AIDS Treatment Information Exchange (CATIE) offers a variety of resources which are client-centered, and consists of concise overviews of HIV/AIDS treatment issues and wellness issues. These include information on both biomedical approaches to treatment as well as complementary therapy, nutrition and mental health.</td>
</tr>
<tr>
<td>Full content resource available at: <a href="http://www.catie.ca">www.catie.ca</a></td>
<td></td>
</tr>
</tbody>
</table>
| **b. Positive Living Manual (3rd Edition).**  
British Columbia Persons with AIDS Society. 2004 | This manual was created to assist those living with HIV to live well. Each section is designed as a step by step guide to information ranging from nutrition to finances.  
Full manual available at [www.bcpwa.org](http://www.bcpwa.org) |
| **c. The Medical Personal and Social Causes of Uncertainty in HIV Illness.**  
Brashers, D et al, Issues in Mental Health Nursing. 2003, 24: 497-522. | This qualitative study examines the nature of uncertainty experienced by individuals living with HIV/AIDS. The authors suggest that uncertainty can have serious implications for mental health and quality of life. |
| **d. Impact of Antiretroviral Therapy on Quality of Life.**  
Park-Wyllie L et al. Poster Presentation, Ontario HIV Treatment Network Research Conference, 2005. | This project worked to identify the impact of antiretroviral therapy on quality of life for those living with HIV infection. The authors contend that commonly used instruments for measuring quality of life may be missing important and negative consequences of HAART. |

**3) Disability in the Context of HIV**

| **a. Phase II – Episodic Disability Project – Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study**  
Full report available at [www.hivandrehab.ca](http://www.hivandrehab.ca) | This study examined the uncertain, unpredictable, episodic and fluctuating nature of HIV and to articulate this experience in order to provide recommendations for rehabilitation programs and policies. |
| **b. Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia.**  
2004; 2:46.  
Full report available at [www.hivandrehab.ca](http://www.hivandrehab.ca) and [http://www.hqlo.com/content/2/1/46](http://www.hqlo.com/content/2/1/46) | Demonstrated remarkably high prevalence of disablement among persons living with HIV in British Columbia. At least 80% experienced at least one impairment, activity limitation or participation restriction in the previous month including a high prevalence of mental health issues. This study demonstrates the need for rehabilitation among persons living with HIV. |

**4) Stigma & Discrimination**

Duffy L. JANAC. 2005; 16(1): 13-20. | This article examines the meaning of stigma and experiences of people living with HIV in Zimbabwe. The authors emphasize the role of nurses and other health care professionals in helping to create healthy public policy. |
b. Stigma: A Health Barrier for Women With HIV/AIDS.

This article describes the multidimensional effect of stigma on women's health. The authors argue for interventions that promote wellness and increase quality of life for women living with HIV.

5) Patient-Centred Care / Sensitive Practice

a. Handbook on Sensitive Practice for Health Professionals: Lessons from Women Survivors of Childhood Sexual Abuse

While the focus of this handbook is to provide strategies of ways to practice that are sensitive to the needs of survivors of sexual abuse, its underlying principles are also applicable to the context of HIV. These include respecting boundaries, sharing control, and fostering a mutual learning process among many others.


This guide defines patient-centred practice and provides a model that consists of seven overlapping elements that include: respect for individuality, partnership, contextual congruence, respect for diversity, accessibility and flexibility, communication and education, and continuity and transition.

6) Aboriginal Communities

a. Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support issues.
Jackson, R., Reimer, G. Canadian Aboriginal AIDS Network (CAAN). 2005

This document reports the findings of a nation wide survey of Aboriginal people living with HIV/AIDS (APHAs) documenting the service needs and barriers encountered by Aboriginal people living with HIV/AIDS.

7) Social Determinants of Health

a. The Social Determinants of Health: An Overview of the Implications for Policy and the Role of the Health Sector.


This document provides an overview of 9 social determinants of health which include: income inequality, social inclusion and exclusion, employment and job security, working conditions, contribution of the social economy, early childhood care, education, food security, and housing.
|---|---|

8) Return to Work in the Context of HIV/AIDS

a. Experiences of Contemplating Returning to Work for People Living with HIV/AIDS

This article explores how PHAs perceive, attach meaning to, and approach the experience of returning to work. PHAs wrestle with the dominant societal perspective that people should return to work and the alternate perspective that PHAs should not return to work.


This article provides a model of return to work that could apply to chronic illnesses with an uncertain or fluctuating disease course.

c. HIV and Disability Insurance in Canada: An Environmental Scan.
Anderson, J., Brown, G. Canadian Working Group on HIV and Rehabilitation. March 2005

This project was developed to determine current policies and practices for the Canada Pension Plan Disability Program and the private insurance industry relevant to people living with HIV.

9) Sexuality and Gender

a. Understanding the experience of HIV/AIDS for women: Implications for occupational therapists.

This qualitative study examines the experiences of women living with HIV, and explores the potential roles and implications for occupational therapy within this context.

b. Integrating Gender into HIV/AIDS Programs.
WHO 2003

Suggests a framework for considering the issues and challenges of integrating gender into programs and policies. Provides examples of successful HIV interventions that have addressed gender issues. Recommends that HIV programs and policies are greatly enhanced when gender differences are acknowledged, the gender-specific concerns and needs of women and men are addressed, and gender inequalities are reduced.

Full report available at [http://www.who.int/gender/hiv_aids/en:Integrating%5b258KB%5d.pdf](http://www.who.int/gender/hiv_aids/en:Integrating%5b258KB%5d.pdf)
10) Harm Reduction

| a. Youth & Drugs and Mental Health: A Resource for Professionals. | This resource provides information about addressing substance use among young people - including the context of other mental health problems. |
| Centre for Addiction and Mental Health |  |
| http://www.camh.net/Care_Treatment/Resources_for_Professionals/YDMH/index.html |  |

11) Nutrition

| a. For the Pleasure of Eating: Information, Tips and Recipes for People Living with HIV. | The authors concede that a healthy diet can boost your immune system, help you fight diseases and increase quality of life through proper diet and nutrition. This book includes quick information on which foods to choose from and how to prepare them to achieve optimum health. |
| Cossette, M. Delaney, M., Legault, H., La Maison du Parc. |  |
| Text can be ordered through www.maisonduparc.org |  |

12) HIV Policy and Research Directives in Canada

| a. Leading Together: Canada Takes Action on HIV/AIDS (2005-2010). | This document was creating by stakeholders from across Canada. It lays out the ideal response to HIV/AIDS and represents a collective view of what is needed in the future. |
| Full content available at http://www.leadingtogether.ca |  |

| Government of Canada. 2005 |  |
| Full content available at: www.aidssida.cpha.ca |  |

13) Care for Infants, Children and Youth living with HIV/AIDS

| a. A comprehensive Guide for the Care of Persons with HIV Diseases. Module 2: Infants, Children and Youth. | This resource was designed for both health care professionals and community caregivers. The focus of the document is on clinical management, but also includes community resources and references. While it contains outdated information about drug therapies, it still contains concise general information about HIV/AIDS. |
| Full content available at: http://www.phac-aspc.gc.ca/aids-sida/info/guide_e.html |  |

| b. Baylor International Paediatric AIDS Initiative – HIV Curriculum for the Health Care Professional | This HIV training curriculum was developed to build capacity among health care professionals. It includes a range of modules from epidemiology to the legal and ethical issues in HIV. Learning modules includes key points, objectives, case studies, review questions and references |
| Full Modules (3rd edition-2006) are available at: http://bayloraids.org/curriculum/ |  |
Section 6:
Additional Resources on HIV and Rehabilitation

Overview: This section provides an overview of additional resources on rehabilitation in the context of HIV not already covered in Section 5.

<table>
<thead>
<tr>
<th>1) Background Reading (Published before 1996)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Physiotherapy for People with HIV/AIDS&lt;br&gt;Lang C. <em>Physiotherapy</em>. 1993; 79(3): 163-167.</td>
</tr>
<tr>
<td>The Role of Physiotherapy in HIV and AIDS&lt;br&gt;McClure J. The role of physiotherapy in HIV and AIDS. <em>Physiotherapy</em>. 1993; 79(6). 388-393.</td>
</tr>
<tr>
<td>Rehabilitation in Adults with Human Immunodeficiency Virus-Related Diseases.&lt;br&gt;O’Dell MW &amp; Dillon ME. <em>American Journal of Physical Medicine and Rehabilitation</em>. 1992; 71:183-190.</td>
</tr>
<tr>
<td>HIV Infection: Neurological Implications for Rehabilitation.&lt;br&gt;Galantino ML &amp; Levy JK. <em>Clinical Management in Physical Therapy</em>. 1988; 8:1-12.</td>
</tr>
<tr>
<td>HIV-Related Disability: Assessment and Management&lt;br&gt;Michael W. O’Dell, Editor <em>Physical Medicine and Rehabilitation</em>: State of the Art Reviews. 1993. Volume 7, Special Issue.</td>
</tr>
<tr>
<td>Rehabilitation Dimensions of AIDS: A Review.&lt;br&gt;Levinson SF, O’Connell PG. <em>Archives of Physical Medicine and Rehabilitation</em>. 1991; 72(9):690-696.</td>
</tr>
</tbody>
</table>
2) Review Articles on Rehabilitation in the Context of HIV

<table>
<thead>
<tr>
<th>Title</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contemporary issues in rehabilitation of patients with HIV disease: Part I: The team approach to rehabilitation of patients with HIV disease. Part II: Complications of HIV disease Kietrys D, Gillardon P, Galantino ML. <em>Rehabilitation Oncology</em>. 2002; 20(1):21-26.</td>
<td>This article reviews some of the more common symptoms related to HIV, and explains the role that rehabilitation professionals can play in managing them.</td>
</tr>
<tr>
<td>Contemporary issues in rehabilitation of patients with HIV disease: Part III: The effects of exercise on individuals with HIV disease. Kietrys D, Gillardon P, Galantino ML. <em>Rehabilitation Oncology</em>. 2002; 20(2):10-14.</td>
<td>This article summarizes research that has explored the effects of therapeutic exercise on individuals living with HIV/AIDS. They argue that the stage of HIV disease greatly influences both the exercise prescription and the ability of the individual to comply.</td>
</tr>
<tr>
<td>3) HIV and Therapeutic Exercise</td>
<td></td>
</tr>
<tr>
<td><strong>Aerobic Exercise Interventions for Adults Living with HIV/AIDS</strong> Nixon S, O'Brien K, Glazier RH, Tynan AM. <em>The Cochrane Database of Systematic Reviews</em>. 2005, Issue 2. Art. No.: CD001796.pub2. DOI: 10.1002/14651858.CD001796.pub2.</td>
<td>Performing constant or interval aerobic exercise, or a combination of constant aerobic exercise and progressive resistive exercise, for at least 20 minutes 3 times a week for at least 4 weeks appears to be safe and may be able to improve cardiopulmonary fitness and psychological wellbeing for adults living with HIV.</td>
</tr>
<tr>
<td><strong>Progressive Resistive Exercise Interventions for Adults Living with HIV/AIDS</strong> O’Brien K, Nixon S, Glazier RH, Tynan AM. <em>The Cochrane Database of Systematic Reviews</em>. 2004, Issue 4. Art. No.: CD004248.pub2. DOI: 10.1002/14651858.CD004248.pub2</td>
<td>Examines the safety and effectiveness of progressive resistive exercise for adults living with HIV. Progressive resistive exercise or a combination of progressive resistive and aerobic exercise at least 3 times a week for at least 4 weeks appears to be safe and may lead to statistically and possibly clinically important increase in body weight and composition and improvements in cardiopulmonary fitness.</td>
</tr>
<tr>
<td><strong>Physiological and Psychological Effects of Exercise Interventions in HIV Disease</strong> Dudgeon W, Phillips K, Bopp C, Hand G. <em>AIDS Patient Care</em> 2004, 18: 81 -98. Full content available at <a href="http://www.hivandrehab.ca">www.hivandrehab.ca</a></td>
<td>The focus of this paper is to review the research that has been performed using exercise as an intervention for HIV-infected persons and to determine how the HIV-infected body and mind respond to exercise training.</td>
</tr>
</tbody>
</table>
### 4) Speech Language Pathology and/or Audiology Practice in the Context of HIV

<table>
<thead>
<tr>
<th>Training, current practices and resources of a group of South African Hospital-Based Speech Language Therapists and Audiologists working with patients living with HIV/AIDS</th>
<th>This article reports on a cross sectional survey research design carried out at to examine the training of SLPs and Audiologists at a South African Hospital. Surveyed professionals did not perceive themselves as being equipped to deal with patients living with HIV and AIDS.</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV and Communication</td>
<td>HIV can affect the hearing, speech, language, and swallowing of both pediatric and adult patients. This article outlines some of the interventions that SLPs and Audiologists may follow with their clients to enhance quality of life.</td>
</tr>
<tr>
<td>McNeilly, GL. <em>Journal Of Communication Disorders</em>. 2005, 38: 303-310</td>
<td></td>
</tr>
<tr>
<td>Videofluoroscopic evaluation of HIV/AIDS patients with swallowing dysfunction. Halvorsen RA, Moellen SMC, Kearney AT. <em>Abdominal Imaging</em> 2003, 28:244-247</td>
<td>In this study, speech language pathologists examine swallowing abnormalities associated with HIV. Detection and therapy can prevent patients being affected by aspiration.</td>
</tr>
<tr>
<td>What do speech pathologists know about HIV? McCabe P, Sheard C, Code C. <em>Advances in Speech Language Pathology</em>. 1999, 1: 9-18</td>
<td>While many SLP are seeing patients living with HIV for a variety of reasons, there has not yet been an epidemiological study that captures the range or number of these encounters.</td>
</tr>
</tbody>
</table>

### 5) HIV and Rehabilitation within a Global Context

<table>
<thead>
<tr>
<th>Rehabilitation and HIV: Exploring Intersections at the Global Level</th>
<th>The authors examine how community-based rehabilitation has affected HIV policy and practice in developing contexts. They argue that full global access to HIV care, treatment and support is a mandatory goal.</th>
</tr>
</thead>
</table>
## Section 7:  
**Electronic resources and informative websites**

<table>
<thead>
<tr>
<th>Resource</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Legal Resource Centre for Persons with Disabilities</td>
<td><a href="http://www.archdisabilitylaw.ca">www.archdisabilitylaw.ca</a></td>
</tr>
<tr>
<td>Canadian Aboriginal AIDS Network</td>
<td><a href="http://www.caan.ca">www.caan.ca</a></td>
</tr>
<tr>
<td>Canadian AIDS Society</td>
<td><a href="http://www.cdnaids.ca">www.cdnaids.ca</a></td>
</tr>
<tr>
<td>Canadian AIDS Treatment Information Exchange</td>
<td><a href="http://www.catie.ca">www.catie.ca</a></td>
</tr>
<tr>
<td>Canadian Association for HIV Research</td>
<td><a href="http://www.cahr-acrv.ca">www.cahr-acrv.ca</a></td>
</tr>
<tr>
<td>Canadian Association of Nurses in AIDS Care</td>
<td><a href="http://www.canac.org">www.canac.org</a></td>
</tr>
<tr>
<td>Canadian Association of Occupational Therapists</td>
<td><a href="http://www.caot.ca">www.caot.ca</a></td>
</tr>
<tr>
<td>Canadian Association of Speech-Language Pathologists and Audiologists</td>
<td><a href="http://www.caslpa.ca">www.caslpa.ca</a></td>
</tr>
<tr>
<td>Canadian Council on Rehabilitation and Work</td>
<td><a href="http://www.ccrw.org/en">www.ccrw.org/en</a></td>
</tr>
<tr>
<td>Canadian Federation for Sexual Health</td>
<td><a href="http://www.cfsf.ca">www.cfsf.ca</a></td>
</tr>
<tr>
<td>Canadian Harm Reduction Network</td>
<td><a href="http://www.canadianharmreduction.com">www.canadianharmreduction.com</a></td>
</tr>
<tr>
<td>Canadian HIV/AIDS Information Centre</td>
<td><a href="http://www.aidsssida.cpha.ca">www.aidsssida.cpha.ca</a></td>
</tr>
<tr>
<td>Canadian HIV/AIDS Legal Network</td>
<td><a href="http://www.aidslaw.ca">www.aidslaw.ca</a></td>
</tr>
<tr>
<td>Canadian HIV Trials Network</td>
<td><a href="http://www.hivnet.ubc.ca">www.hivnet.ubc.ca</a></td>
</tr>
<tr>
<td>Canadian Physiotherapy Association</td>
<td><a href="http://www.physiotherapy.ca">www.physiotherapy.ca</a></td>
</tr>
<tr>
<td>Canadian Rainbow Health Coalition</td>
<td><a href="http://www.rainbowhealth.ca">www.rainbowhealth.ca</a></td>
</tr>
<tr>
<td>Canadian Treatment Action Council</td>
<td><a href="http://www.ctac.ca">www.ctac.ca</a></td>
</tr>
<tr>
<td>Canadian Working Group on HIV and Rehabilitation</td>
<td><a href="http://www.hivandrehab.ca">www.hivandrehab.ca</a></td>
</tr>
<tr>
<td>Hepatitis C Society of Canada</td>
<td><a href="http://www.hepatitissociety.com">www.hepatitissociety.com</a></td>
</tr>
<tr>
<td>Institute for Work and Health</td>
<td><a href="http://www.iwh.on.ca">www.iwh.on.ca</a></td>
</tr>
<tr>
<td>Interagency Coalition on AIDS and Development</td>
<td><a href="http://www.icad-cisd.com">www.icad-cisd.com</a></td>
</tr>
<tr>
<td>Joint United Nations Program on HIV/AIDS</td>
<td><a href="http://www.unaids.org">www.unaids.org</a></td>
</tr>
<tr>
<td>NAM (UK based HIV/AIDS resources)</td>
<td><a href="http://www.aidsmap.com">www.aidsmap.com</a></td>
</tr>
<tr>
<td>Public Health Agency of Canada</td>
<td><a href="http://www.phac-aspc.gc.ca">www.phac-aspc.gc.ca</a></td>
</tr>
<tr>
<td>Sexuality and You (for health professionals)</td>
<td><a href="http://www.sexualityandu.ca/professionals">www.sexualityandu.ca/professionals</a></td>
</tr>
<tr>
<td>The Body: Information about HIV/AIDS and Sexuality</td>
<td><a href="http://www.thebody.com">www.thebody.com</a></td>
</tr>
<tr>
<td>Voices of Positive Women</td>
<td><a href="http://www.vopw.org">www.vopw.org</a></td>
</tr>
</tbody>
</table>

Compendium of Resources on HIV and Rehabilitation 27
References

All AC, Fried JH. Factors Influencing Anxiety Concerning HIV/AIDS in Rehabilitation Workers. *Journal of Rehabilitation*. 1996; 17-21


At Home Seminars Program. HIV/AIDS and the Rehabilitation Professional. [http://www.athomeseminars.com](http://www.athomeseminars.com)

Balogun JA, Kaplan MT, Miller TM. The Effect of Professional Education on the Knowledge and Attitudes of Physical Therapist and Occupational Therapist Students About Acquired Immunodeficiency Syndrome *Physical Therapy*. 1998; 78 (10): 1073-1082


Bone G. Perspectives of Models of Service Delivery in Rehabilitation for Children with Vertically Acquired HIV. *Canadian Journal of Infectious Diseases*. 2001, Volume 12, Supplement B: 98B

Bromm M. Private Long-Term Disability Insurers and the Canada Pension Plan Available on CWGHR website: www.hivandrehab.ca


Cossette M, Delaney M, Legault H. La Maison du Parc. For the Pleasure of Eating: Information, Tips and Recipes for People Living with HIV. Maison du Parc, 2004


Druck E, Ross E. Training, current practices and resources of a group of South African Hospital-Based Speech Language Therapists and Audiologists working with patients living with HIV/AIDS Die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings . 2002, 49: 3-13


Halvorsen RA, Moelleken SMC, Kearney AT. Video fluoroscopic evaluation of HIV/AIDS patients with swallowing dysfunction. *Abdominal Imaging* 2003, 28:244-247


Hsu L, Konjarski G, O’Brien K, Quant S, Salvati L, Sim LM. 1998; University of Toronto, Module 10 Course Requirement.


http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/interprof/summ-somm_e.html

Hwang JL, Nochajski SM. The International Classification of Functioning, Disability and Health (ICF) and Its Application to AIDS. *Journal of Rehabilitation*. 2003; 69(4): 4-12

Jackson R, Reimer G. Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support issues. *Canadian Aboriginal AIDS Network (CAAN)*. 2005


Nixon S, Renwick R. Experiences of contemplating returning to work for people living with HIV/AIDS. *Qualitative Health Research*. 2003. 13(9): 1272-1290


