Introduction to Rehabilitation in the Context of HIV for Family Physicians

1. Introduction: What is Rehabilitation?

The profile of HIV disease is changing: today, new drugs can slow disease progression and help people to live longer with improved quality of life[1]. However, while new drug therapies are helping people to live longer, treatments are often very complicated and can cause debilitating side effects.

Rehabilitation in the context of HIV can be broadly defined: optimizing choices for people with HIV by providing the tools and support to help people do what is meaningful to them. This includes physical, vocational, and psychological rehabilitation. One of the French translations for rehabilitation, *réinsertion sociale* or, literally translated, social re-insertion, captures a fundamental aspect of the rehabilitation process: return to active living and participation in society. Three primary goals of rehabilitation are[2]:

- To increase or maintain functional capacity
- To improve or maintain a person's quality of life, and
- To decrease hospitalizations and increase self care

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

- addressing impairments, activity limitations and participation restrictions (see definitions below) related to HIV or to the side effects of medications, including managing pain, weakness or fatigue and increasing mobility and independence
- managing treatment side effects, supporting the integration of often complex treatment regimens into daily activities, and tolerating treatments without increasing toxicity and thereby maintain complex treatment regimens, lower viral loads and reduced resistance
- staying at or returning to employment or volunteer work
- improving access to adequate income support programs to enable people to focus on improving their health and participation in society
- improving self-esteem, maintaining interpersonal relationships and support networks and reducing stress and isolation

[1] Barry Adam, Eleanor Maticka-Tyndale, Jeffrey J. Cohen, Living with Combination Therapies, University of Windsor and HIV Care Programme , Windsor Regional Hospital; August 2001, page 5.
[2] *Vocational Rehabilitation and Rehabilitation Services in the Context of HIV Infection: Issues and Guiding Principles*, British Columbia Persons with AIDS Society, 1998

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

- **Impairments:** Impairments are problems in body function or structure; they are at the level of the body part. E.g.: pain or tingling in feet (peripheral neuropathy).
- **Activity Limitations:** These are difficulties an individual may have executing activities; they are at the level of the person. E.g.: difficulties walking because of pain and sensitivity in feet.
- **Participation Restrictions:** These are problems an individual may experience in life situations or the social and environmental consequences of impairments and activity limitations; they are at the level of community or society. E.g.: difficulties working or taking care of their children because these activities may require walking

Rehabilitation interventions may be targeted at one or more level.

For more information about ICF, go to http://www3.who.int/icf/icftemplate.cfm.

While many health care providers have been working with people living with HIV on rehabilitation since the beginning of the epidemic, developments in the medical management of HIV have changed the role and scope of rehabilitation. Rehabilitation in this context now involves many players, including health care professionals who have not traditionally been involved in HIV issues, such as physiotherapists, occupational therapists, social workers, speech / language therapists and physiatrists.

Family physicians have an important role to play educating patients about rehabilitation services that are available, referring patients to appropriate service providers and making sure that these services are integrated into a patient's treatment plan. Family physicians also participate in rehabilitation by providing assessments and supporting documentation for insurance purposes.

Rehabilitation services, as with primary care, are centered on the needs of the patient and patients are active members of the rehabilitation team.[3]

An excellent overview of rehabilitation services is provided by Rehabilitation Services, Module 7 of A Comprehensive Guide for the Care of Persons with HIV Disease, by Wellesley Central Hospital and Health Canada, 1998. Module 7 is available on line at www.hivandrehab.ca and through the Canadian HIV/AIDS Information Centre 1-877-999-7740 or www.clearinghouse.cpha.ca.

[3] Module 7 was used as a source throughout this chapter.

2. Physical rehabilitation

> Amanda may have contracted HIV from previous injection drug use or sex trade work. Her HIV status was unknown when she was admitted comatose, hemiplegic and seizuring to hospital. She was found to have multiple toxoplasmic abscesses. Shortly after treatment had proven successful, she abruptly discharged herself from hospital. She has found it difficult to remember her antiretroviral, toxoplasma, anticonvulsant, and prophylactic medication. She has some residual hemiparesis, ataxia and dysarthria.
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> You refer her to physiotherapy, occupational therapy and a speech therapist. She is able to make considerable improvement. She says the regular interaction with rehabilitation professionals knowledgeable in HIV issues also helped her cope with psychosocial issues and medication adherence.

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

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

Referring clients to rehabilitation providers can sometimes be challenging given the range of issues that a person living with HIV may face. Service providers need to be sensitive to the impact of stigmatization and the need for confidentiality. As well, while some rehabilitation services may be covered through public or private insurance plans, or available free through a community-based organization, many rehabilitation services may be prohibitively expensive for a patient.

Contact your local HIV clinic for information on how to locate a rehabilitation professional with expertise treating people living with HIV.

> Tom has responded to his “last option salvage therapy.” It is probably contributing to exacerbation of peripheral neuropathy which is now causing excruciating shooting pains down his lower legs and burning dysesthesia in his feet. He also has protease inhibitor associated diabetes mellitus. He has been treated with tricyclics, anticonvulsants and potent analgesics with incomplete relief and dose-limiting drowsiness.
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> You suggest that acupuncture is worth exploring and are able to recommend an acupuncturist who has already worked with HIV patients.

Complementary or alternative therapies, therapies that are outside of conventional Western medicine, are also widely used by people living with HIV. Unfortunately, some health care

providers are unaware of the potential value of these therapies in a treatment repertoire, or they tend to diminish the value. All rehabilitation providers need to educate themselves on the wide range of complementary therapies.

Examples of more commonly used complementary therapies include: acupuncture, aromatherapy, chiropractic, dietary and other supplements, homeopathy, massage therapy, mind-body interaction (such as yoga, meditation, Tai Chi, etc.), Aboriginal traditional medicine, naturopathy, reflexology, shiatsu, therapeutic touch, traditional Chinese medicine and vitamins and minerals.

For more information or to find a naturopathic doctor in your area please contact the Canadian Association of Naturopathic Doctors (CAND), a not-for-profit professional association representing the interests of naturopathic doctors and promoting naturopathic medicine throughout Canada. Its membership consists of naturopathic doctors, naturopathic medical students, suppliers of natural remedies for professional use, and the provincial naturopathic associations.

Website: www.cand.ca
Tel. 416-496-8633, Toll-free 1-800-551-4381
Fax. 416-496-8634

3. Vocational rehabilitation

> Cynthia, a middle-aged university teacher, has been off work for 2 years with panic attacks and depression. This had been brought on by her unexpected diagnosis of advanced HIV with PCP (which had had a prolonged subacute course resulting in debilitating weight loss and anemia). She gradually responded to antiretroviral therapy, good nutrition and SSRI and psychotherapy. She would now like to return to work but is not sure how she'll manage. She is also concerned about the possible consequences of coming off her long term group and CPP disability programmes.
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> You are able to help her to arrange a graduated trial of return to work with her employer, her private insurance company and CPP without compromising future eligibility.

As a result of changes in the treatment of HIV, returning to or remaining in the work force, despite HIV-related disabilities, is a rapidly emerging issue. Individuals who have left work and are receiving benefits may be concerned about the risk of losing these benefits if they return to the workforce. Today, unfortunately, current income support programs in both the public and private sector present many barriers to effective, flexible work force participation, particularly for people with episodic disabilities such as HIV.

Many community-based AIDS organizations advocate on behalf of individuals with income support programs. Some organizations address the employment needs of individuals living with HIV (through, for example, information seminars, benefits information, psychosocial counseling, financial and career planning, and vocational rehabilitation).

When assisting a patient with issues related to work or insurance, see the College of Family Physicians of Canada's Primer on HIV, Chapter 5: Supporting Patients, for information on return to work counselling programs.

4. Psychological rehabilitation

> Dale recently tested HIV positive. He is currently unemployed and on provincial assistance. His repeat CD4 is again between 200-250 cell/mm^3 and viral load 150,000 RNA copies/ml. Apart from fatigue and some recent weight loss he has no symptoms of HIV. (After you discuss current guidelines and review factors that might prevent him achieving optimal adherence he decides to start antiretroviral therapy.) He has indicated that he is having difficulty adjusting to his new diagnosis and dealing with some of the relationships in his life.
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> You have advised Dale of the importance of a high protein high calorie well-balanced diet rich in vitamins and micronutrients in HIV. However, Dale lets you know that financing this is a problem. With Dale's permission you write to his social assistance worker advocating for supplementary dietary allowances and a gym pass. At your suggestion Dale obtains additional help from the PWA assistance fund and a community kitchen program. You are also able to refer Dale to a funded nutritionist interested in HIV. He is able to address primary prevention of HIV progression fully.

This scenario clearly illustrates the links between mental health and rehabilitation. Eating well, exercising, accessing social support through a community-based organization may play an important role in the rehabilitation process for a person living with HIV. Further, as people living with HIV experience high rates of depression, accessing psychological support may be critical to successful rehabilitation.

Primary prevention, in the form of exercise, adequate nutrition, and maximizing mental health, is a mainstay of HIV care and also falls within the scope of rehabilitation, though it may be less familiar to rehabilitation providers. Primary interventions tend to be based in the community rather than in medical facilities. Family physicians can help by hooking patients up to community-based agencies for support and rehabilitation services.

The HIV community has a rich tradition of health promotion activities. Excellent opportunities exist for partnerships between rehabilitation professionals and community-based organizations to address issues of preventive rehabilitation. Two components of preventive rehabilitation have been particularly well developed in the context of HIV disease – exercise and nutrition. Regular exercise is widely accepted as an integral component of optimal health. Optimal health for people living with HIV can only be achieved if nutrition is an integral part of preventive efforts.

The Canadian AIDS Society can help you identify an AIDS Service Organization (ASO) in your area. ASOs offer a range of support services, which may include services such as food banks or community kitchens, individual or group counselling, drop-in programs, and case management.

Canadian AIDS Society
1-800-884-1058
www.cdnaids.ca

5. Conclusion

Incorporating rehabilitation into the care, treatment and support of people living with HIV is critical to helping them achieve optimal health. For additional resources, information and links visit the Canadian Working Group on HIV and Rehabilitation (CWGHR) website at **www.hivandrehab.ca** This website also contains information on workshops that can be held in your organization or in your community to increase knowledge on rehabilitation in the context of HIV.