

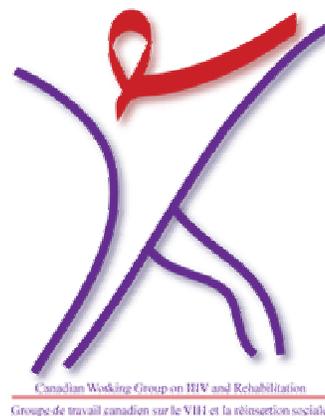


British Columbia
Centre *for* Excellence
in HIV/AIDS



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



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

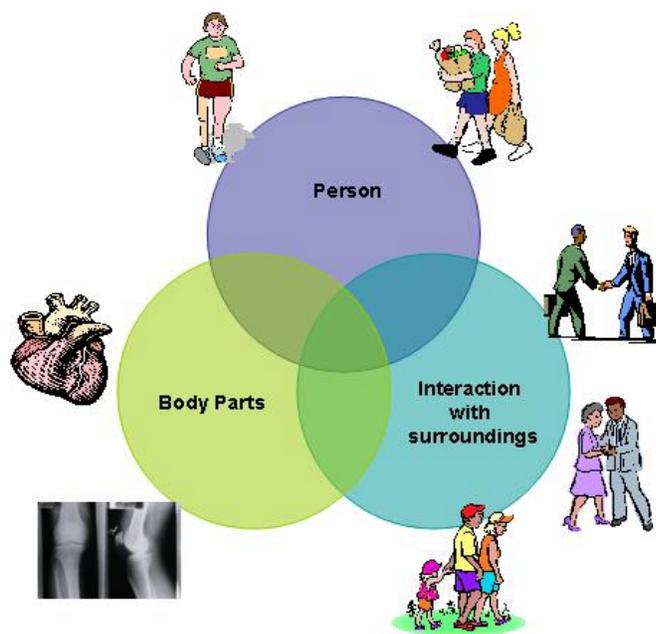
People living with HIV in British Columbia (BC) have been able to freely access antiretroviral therapy for the treatment of HIV infection via the provincial HIV/AIDS Drug Treatment Program since 1992. The introduction of highly active antiretroviral therapy (HAART) in the mid-1990's marked a turning 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

	Proportion of survey participants	Proportion of general population of BC*
Gender		
Male	90%	47%
Female	10%	53%
Ethnicity		
White	85%	83%
Other	15%	17%
Employment		
Employed	20%	52%
Unemployed	80%	48%
Household income		
Less than \$10,000	24%	5%
\$10,000–\$50,000	60%	52%
More than \$50,000	16%	43%

*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.

Prevalence of symptoms commonly experienced by people living with HIV in BC

Impairment	Proportion of participants reporting symptoms	Most commonly reported symptoms
Internal	81%	Diarrhea (57%),
Mental	78%	Reduced libido (56%)
Sensory	72%	General weakness (48%)
Nerve and muscle	50%	Headache (47%)
Pain	80%	Moderate or severe pain (40%)

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

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

	Proportion of survey participants reporting somewhat or very limited ability to perform the specified activity		Proportion of survey participants reporting somewhat or very limited ability to perform the specified activity
Undertake vigorous activity	72%	Get out of bed	21%
Undertake sexual activity	47%	Eat	20%
Undertake moderate activity	42%	Bank	16%
Perform household chores	40%	Walk one block	13%
Shop	33%	Shower	10%
Do the laundry	28%	Get dressed	10%
Use public transport	25%	Use the toilet	6%
Drive	22%		

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

Proportion of survey participants reporting somewhat or very limited ability to function in the specified roles		Proportion of survey participants reporting somewhat or very limited ability to function in the specified roles	
Sexual role	67%	Social role	63%
Hobby, sports and leisure roles	68%	Experience discrimination	60%
Student or employee role	58%	Volunteer role	56%
Experience financial independence	59%	Household role	59%
Community or family role	61%	Cultural or religious role	45%

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.