# Prevalence of Activity Limitation Among Persons Living with HIV/AIDS in British Columbia

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## ABSTRACT

**Background:** As antiretrovirals increase the life expectancy of persons living with HIV, quality of life issues become more important. Little research has examined the types and levels of activity limitations among HIV-positive populations. The objective of this report is to compare the levels of limitations among HIV-positive persons to the general population.

**Methods:** The BC Persons With AIDS (BCPWA) Society consists of approximately 3,500 HIV-positive members. A recent survey conducted among BCPWA members included a section assessing activity limitations. Prevalence of limitations in this group was compared to the general population of BC using the National Population Health Survey (NPHS) to calculate standardized prevalence ratios (SPR).

**Results:** Compared to the general BC population, BCPWA members were more likely to be male, aged over 30 years, not to have graduated from high school, unemployed, living alone and having a household income less than $10,000 per year. The SPR for activity limitations among male participants applying the rates of limitation among the general population of BC was 9.4 (8.4-10.6). The SPR for women was 9.9 (7.2-11.1). Using an NPHS rate restricted to individuals who reported a chronic condition, the SPR for males was 6.0 (5.9-6.5) and for females was 7.0 (5.8-8.2).

**Interpretation:** Limitations on activity are prevalent, even when comparing those with high CD4 counts and restricting the standard to those with chronic conditions. These findings suggest that implementation of programs offering support with everyday tasks would be of value in this population.

*La traduction du résumé se trouve à la fin de l'article.*

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In 2001, the WHO published the International Classification of Functioning, Disability and Health, a framework for categorizing the health-related consequences of disease.[1] This framework is based on three core concepts: physical and functional impairments involving the organ or body part (i.e., symptoms), activity limitations involving the whole body or person (i.e., daily tasks) and participation restrictions involving the person in his or her environment (i.e., challenges in normal social roles).

Research that has been done in the area of activity limitations has typically focussed on issues faced among select patient populations. Aside from the HIV Cost and Utilization Survey conducted in the US,[2] there are few population-based assessments of disability levels among persons living with HIV/AIDS. A palliative care study among patients with full-blown AIDS found an activity limitation prevalence of 71%.[3] It should be noted that even in late-stage disease, interventions focussing on pain and limitations were helpful in this study. Another study examining depression and other emotional and physical morbidities among an HIV-positive urban hospital population found approximately one third impaired in their ability to complete daily household chores.[4] Among HIV-positive women in the US, moderate levels of physical function were found on a scale combining self-care and household chores.[5]

Identifying physical and functional impairments arising from HIV/AIDS or side effects of the medications is increasingly important as medical improvements continue to extend the lives of those living with the disease.[6-8] Other quality of life issues, including activity limitations and participation restrictions, are often overshadowed. While these can be related to impairment, they arise also from other physical and psychological problems and are important in improving the lives of persons living with HIV.[9] The BCPWA Society survey, one of the largest population-based surveys of HIV-positive persons, afforded us with the opportunity to examine the prevalence of these life challenges.

Quality of life issues are important, not only for the individual, but also for broader healthcare issues. The morbidity and limitations imposed on an individual by

HIV infection are often accompanied by psychosocial effects, including depression, anxiety, and feelings of isolation. The interactions among these factors can augment physical pain, symptom burden and emotional well-being. There is also some evidence that suggests that emotional stress and depression can alter the effectiveness of the immune system and thereby the course of disease.[10] In the broader sense, helping patients with symptom management, activities of daily living and addressing quality of life issues not only can improve and perhaps prolong lives, but may also decrease the amount of primary health care visits required.

This brief report focusses on the prevalence of activity limitation among persons living with HIV/AIDS in BC and compares these findings with the general BC population.

## METHODS

In 2002, the BCPWA Society and BC Center for Excellence in HIV/AIDS mailed out self-administered anonymous surveys, which included a section on activity limitations, to 1,508 members consenting to receive mail. The BCPWA is Western Canada's largest organization of people living with HIV, with over 3,500 HIV-positive members and a mission to empower persons living with HIV/AIDS through mutual support and collective action. Membership is open and free to anyone living with HIV/AIDS in British Columbia.

The 1999 National Population Health Survey (NPHS) was used to determine rates of activity limitation among BC residents. The NPHS is a probability sample of the Canadian population with oversampling of certain subgroups of the population.[11] To correct for this over-sampling, an NPHS weighting variable was used to correct the numbers of people.

Activity limitation from the NPHS was based on four questions, asking participants whether or not their limitations required them to seek help in each of the following areas: preparing their meals; shopping for groceries; looking after personal care such as washing, dressing and eating; and managing housework. Activity limitation was defined as needing help in any one of these areas. Activity limitation prevalence was determined from the BCPWA survey using parallel questions, asking participants if they were not able, able with effort or easily able to carry out each of the following activities: eating, dressing, showering and toileting, grocery shopping, and doing laundry and other household chores. Activity limitation was defined as unable to carry out any one of these tasks.

Activity limitations among the HIV-positive population and the general population living in BC were compared using standardized prevalence ratios (SPR). The prevalence of limitations derived from the NPHS data was applied to the BCPWA participants in order to compare the resulting expected prevalence to the actual prevalence. SPRs were calculated separately for men and women using the five-year age categories employed in the NPHS questionnaire and restricted to those between 20 and 64 years of age. Two comparison populations were used: a) all NPHS participants residing in BC, and b) NPHS participants who indicated presence of a chronic condition. The definition of chronic illnesses included conditions such as arthritis, diabetes, high blood pressure, heart disease, cancers and bowel disease. SPRs were also calculated for specific CD4 categories, in order to examine the relevance of immune status and clinical disease markers on levels of activity limitations. All analyses were carried out using STATA, version 7.0 (Statacorp, College Station, TX).

**TABLE I**

**General Characteristics of the BCPWA Population as Compared to the General Population of BC, Sampled by the National Population Health Survey**

| | BCPWA* N (%) | NPHS N (%) | p-value |
|---|---|---|---|
| Age | | | |
| <20 | 2 (0.3) | 418 (17.4) | <0.001 |
| 20-29 | 28 (3.9) | 214 (12.7) | |
| 30-49 | 494 (68.0) | 580 (34.4) | |
| 50-69 | 198 (27.3) | 330 (19.6) | |
| 70+ | 4 (0.6) | 142 (8.5) | |
| Gender | | | |
| Male | 672 (89.5) | 794 (47.1) | <0.001 |
| Female | 76 (10.1) | 891 (52.9) | |
| Ethnicity | | | |
| White | 651 (85.1) | 1397 (83.3) | 0.263 |
| Other | 114 (14.9) | 280 (16.7) | |
| Education | | | |
| High School | 559 (73.5) | 1192 (79.0) | 0.003 |
| Less than HS | 202 (26.5) | 317 (21.0) | |
| Employment | | | |
| Current | 150 (20.2) | 874 (51.9) | <0.001 |
| Non-current | 591 (79.8) | 811 (48.1) | |
| Living situation | | | |
| Alone | 366 (49.3) | 349 (20.7) | <0.001 |
| Partner | 183 (24.7) | 347 (20.6) | |
| Roommate | 132 (17.8) | 67 (4.0) | |
| Family | 61 (8.2) | 922 (54.7) | |
| Household income | | | |
| <$10K | 160 (23.9) | 72 (4.6) | <0.001 |
| $10-50K | 401 (59.9) | 822 (52.3) | |
| >$50K | 108 (16.1) | 679 (43.2) | |

* Categories do not always add up to total BCPWA population (N=761) due to missing values.

## RESULTS

Of 1,508 mailed surveys, 762 (50.5%) were returned. 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 population than among the subset of respondents (13.5% vs.10.2%; p=0.001).

Table I exhibits population characteristics of participants answering the BCPWA and the NPHS survey. The BCPWA population was comprised mainly of white males aged 30 to 49. Compared to the general population, BCPWA respondents were less likely to have completed high school (p=0.003) or be currently employed (p<0.001), and more likely to live alone (p<0.001) or have an income less than $10,000 CDN/yr (p<0.001).

Table II illustrates SPRs. Using the general NPHS population standard, the SPR for males was 9.4 (95% CI: 8.4-10.6) and for females was 9.9 (95% CI: 7.2-11.1).

**TABLE II**

**Standard Prevalence Ratios (95% Confidence Intervals) for Activity Limitations Experienced by BCPWA Participants As Compared to the General Population of BC or to Those Reporting the Presence of Other Chronic Illness**

| | BCPWA with NPHS | BCPWA with NPHS Chronic Conditions | BCPWA if CD4 >500 with NPHS | BCPWA if CD4 >500 with NPHS Chronic Conditions |
|---|---|---|---|---|
| Men | N=615 | | N=161 | |
| Observed | 305 | 305 | 65 | 65 |
| Expected | 32.41 | 50.99 | 7.82 | 12.72 |
| SPR | 9.41 | 5.98 | 8.31 | 5.12 |
| (95% CI) | (8.39-10.55) | (5.49-6.47) | (6.78-9.97) | (4.17-6.13) |
| Women | N=73 | | N=16 | |
| Observed | 47 | 47 | 7 | 7 |
| Expected | 4.77 | 6.72 | 0.9095 | 1.38 |
| SPR | 9.86 | 7.00 | 7.70 | 5.07 |
| (95% CI) | (7.19-11.05) | (5.80-8.19) | (3.30-12.09) | (2.17-7.97) |

Using an NPHS standard restricted to individuals who reported a chronic condition, the SPR for males was 6.0 (95% CI: 5.9-6.5) and for females was 7.0 (95% CI: 5.8-8.2).

Comparing BCPWA participants with CD4 counts higher than 500 cells/mm$^3$ to the general population, SPRs were 8.3 (95% CI: 6.8-10.0) and 7.7 (95% CI: 3.3-12.1) for men and women, respectively. Using those with chronic conditions for the standard, SPRs were 5.1 (95% CI: 4.2-6.1) and 5.1 (95% CI: 2.2-8.0) for men and women, respectively.

## DISCUSSION

Our study demonstrates much higher levels of activity limitation among people living with HIV/AIDS in BC than among the general population in BC. Furthermore, the prevalence of limitations is also higher among the BCPWA population when compared with a population experiencing other chronic illnesses. Even for participants who had relatively high CD4 cell counts, activity limitations were significantly higher than would be expected given the population rates. The prevalence of activity limitations reported among this population is comparable to other levels reported in HIV-positive populations. For example, 71% of late-stage AIDS patients were found to have any activity limitations, as compared to the 52% reported among all HIV-positive participants here.[3] Also, 31% of HIV-positive patients in a US urban hospital were found to have household chore limitations as compared to 39% in this population.[4]

As would be expected, there is a decline in the SPR when restricting to the HIV population with CD4 counts higher than 500 cells/mm$^3$. However, they are still experiencing significantly more limitations than the general population. This is not entirely surprising, since having more than 500 CD4 cells/mm$^3$ does not preclude the existence of symptoms or side effects from antiretroviral drugs. In addition, psychosocial co-morbidities may be influencing the perceptions of abilities to carry out these activities. For example, depression has been shown to have a high prevalence among persons living with HIV, including the population of study, and has also been linked to physical and social functioning[4,12,13] While not wholly unexpected, it remains important to underline the fact that among those who may be doing well with regard to clinical markers of disease, issues of quality of life and ability to carry out everyday tasks should not be dismissed.

It is also relevant to note social and economic differences between the BCPWA population and the general population of BC, including the increased proportion of BCPWA members who reported living alone and/or decreased household income levels. This indicates that in addition to having increased limitations, the BCPWA population may be less equipped to deal with them.

While there are several studies that support the effectiveness of rehabilitation interventions and exercise programs on improving quality of life and perceived health status, there is a lack of literature examining interventions for activity limitations among persons living with HIV. Exercise programs have found improvements in depression, fatigue, BMI and other weight-related variables, among HIV-positive populations.[14,15] Symptom management, massage and stress management, and bereavement support groups are examples of interventions that have shown benefits on psychosocial factors, perceived health status and physical functioning.[16-18] Some of these types of interventions may help to improve limitations among those at early stages of disease; for advanced stage disease, assessment of the effectiveness of direct interventions on activity limitations is needed.

There are limitations in the generalizability of these results. The population who did not consent to receive mail was more likely to reside in the Greater Vancouver region. There is, therefore, a greater geographical representation of the province among those consenting to receive mail. However, non-consentors were more likely to be female (16% vs. 11%) and more likely to be First Nations, Inuit or Metis (27% vs. 8%). Females are especially under-represented, as they were also more likely to be non-respondents. This may be partly due to the co-morbidities of poverty, IDU and homelessness or highly transitional housing that are prevalent among HIV-positive women in BC (as of 2002, 49% of female HIV cases in BC were among IDUs and/or commercial sex workers), making these individuals more difficult to reach.[19]

Selection bias of respondents may artificially increase the levels of disability if those individuals responding to the survey are doing so because they are concerned about disability levels as they themselves have limitations. The survey itself had a much broader scope; therefore, this would not be the only factor in deciding whether or not to return the survey.

These findings suggest that implementation of programs offering support with everyday tasks, such as house cleaning and grocery shopping, may be of value in this population.

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## RÉSUMÉ

**Contexte :** Depuis que les antirétroviraux accroissent l'espérance de vie des personnes vivant avec le VIH, les questions de qualité de vie prennent de l'importance. Or, on a peu étudié le genre et le niveau des restrictions de l'activité chez les personnes séropositives pour le VIH. Nous avons voulu comparer ces restrictions chez les personnes séropositives aux niveaux qui prévalent dans la population générale.

**Méthode :** La BC Persons With AIDS Society (BCPWA) regroupe quelque 3 500 personnes séropositives pour le VIH. Une enquête menée récemment auprès des membres de cette société comprenait un volet sur les restrictions de l'activité. Nous avons comparé la prévalence des restrictions dans ce groupe à la population générale de la Colombie-Britannique, en utilisant l'Enquête nationale sur la santé de la population (ENSP) pour calculer des ratios de prévalence normalisés (RPN).

**Résultats :** Par rapport à la population générale de la Colombie-Britannique, les membres de la BCPWA étaient plus susceptibles d'être des hommes, d'avoir plus de 30 ans, de ne pas avoir terminé leurs études secondaires, d'être au chômage, de vivre seuls et d'avoir un revenu du ménage inférieur à 10 000 $ par année. Le RPN pour les restrictions de l'activité chez les participants de sexe masculin, selon les taux de restrictions de la population générale de la Colombie-Britannique, était de 9,4 (8,4-10,6). Ce RPN chez les femmes était de 9,9 (7,2-11,1). Selon le taux de l'ENSP se limitant aux personnes ayant déclaré un état chronique, le RPN chez les hommes était de 6,0 (5,9-6,5), et chez les femmes, de 7,0 (5,8-8,2).

**Interprétation :** Les restrictions de l'activité sont courantes, même lorsqu'on compare les personnes ayant de fortes concentrations de lymphocytes CD4 et qu'on se limite aux personnes ayant un état chronique, ce qui porte à croire que la mise en œuvre de programmes de soutien aux tâches quotidiennes serait utile dans cette population.