

HIV, Health and Rehabilitation Survey

Canada-UK HIV and Rehabilitation Research Collaborative

Profile of Disability and Rehabilitation Services Use Among People Living with HIV in Canada: Updates from the HIV, Health and Rehabilitation Survey (HHRIS)

*2nd International Forum on HIV and Rehabilitation Research
Chelsea and Westminster Hospital, London, United Kingdom*

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Kelly O'Brien, Department of Physical Therapy, University of Toronto

Background



- **People with HIV** live longer and encounter physical, social and psychological health-related challenges of HIV, the consequences of treatment, and comorbidities associated with aging.
- **Disability:** Any symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion and uncertainty or worrying about the future experienced by an individual.
- **Rehabilitation** can assist in managing the health challenges (or disability) associated with HIV, and complex comorbidities.
- **Rehabilitation:** Any service or provider that addresses or prevents impairments, activity limitations or participation restrictions experienced by an individual.
- **However,** nature and extent of disability, rehabilitation services use, and living strategies among adults with HIV is unknown

To establish a comprehensive profile of **disability** experienced by adults with HIV in Canada and determine how intrinsic and extrinsic contextual factors such as **comorbidities, related rehabilitation services use and living strategies** influence the disability experience

For today...



To provide preliminary descriptive highlights including **disability, comorbidities, rehabilitation services use and living strategies** experienced by adults living with HIV in Canada

Study Design

- Cross-sectional self-administered online survey using modified Dillman approach

Inclusion Criteria

- Adults (18 years of age or older), living in Canada, able to read and understand English who have access to internet and email.

Community-Engaged Approach

- Eight collaborator organizations and knowledge user organizations
- British Columbia, Manitoba, Ontario, Nova Scotia, Nfld and Labrador

HHRS team



RESEARCHERS

Kelly O'Brien

University of Toronto

Catherine Worthington

University of Victoria

Patty Solomon

McMaster University

Francisco Ibanez-Carrasco

Ontario HIV Treatment Network

Jacqueline Gahagan

Dalhousie University

Stephanie Nixon

University of Toronto

Steven Hanna

McMaster University

Brenda Merritt

Dalhousie University

KNOWLEDGE USERS

Steve Tattle / Tammy Yates / (Elisse Zack)

*Principal Knowledge User, CWGHR**

Will Chegwidden

*National Hospital for Neurology and
Neurosurgery, University College Hospitals*

Patriic Gayle

*CUHRRC** / Three Flying Piglets*

Larry Baxter

*CWGHR**

Greg Robinson

*CWGHR**

Tara Carnochan / Dawn James

Nine Circles Community Health Centre

Rosalind Baltzer-Turje / Patrick McDougall

Dr. Peter AIDS Foundation

RESEARCH COORDINATOR

Ayesha Nayar / Nkem Iku, University of Toronto



* Canadian Working Group on HIV and Rehabilitation

** Canada-UK HIV and Rehabilitation Research Collaborative



HHRS team collaborators



Positive Living Society of British Columbia
Wayne Campbell / Adam Reibin



Casey House
Soo Chan Carusone



CASEY HOUSE

Toronto People with AIDS Foundation
Murray Jose



AIDS Coalition of Nova Scotia
Laura Toole



HHRS survey instrument



1. Disability

- HIV Disability Questionnaire

2. Rehabilitation Services Use

- Traditional Rehabilitation Services - Occupational therapy (OT), physical therapy (PT), speech-language pathology (SLP), psychiatry
- Complementary and Alternative Therapies (CAM)
- AIDS Service Organizations (ASOs) and Community-Based Service Organizations (CBOs)

3. Comorbidities

- Any condition that coexists with HIV infection
- Currently living with and whether comorbidities existed prior to HIV diagnosis

4. Living Strategies

- Behaviours, attitudes and beliefs adopted to deal with HIV and resulting disability

5. Social Support and Stigma

6. Demographic and Disease Characteristics

- Age, gender, length of time since diagnosis, ARV use, geographical status, etc.

Methods – pilot #1



Pilot #1 Survey Implementation

- Collaborator and Knowledge User Organizations
- Emailed 7-15 clients inviting them to participate
- Modified Dillman Tailored Design Method (Dec 2011-Feb 2012)
- Initial invitation email with link to survey
- Thank you / reminder email (1 week later)

Follow-Up Telephone Interview

- Feedback on the survey process and instrument



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Original Paper

Considerations for Conducting Web-Based Survey Research With People Living With Human Immunodeficiency Virus Using a Community-Based Participatory Approach

Kelly K O'Brien^{1,2,3}, BSc(PT), PhD; Patricia Solomon², PhD; Catherine Worthington⁴, PhD; Francisco Ibáñez-Carrasco⁵, PhD; Larry Baxter³, BA; Stephanie A Nixon¹, PhD; Rosalind Baltzer-Turje⁶, BSN, RN, MA; Greg Robinson³, MD, MSc; Elisse Zack³, MMgt, MEd; The HIV, Health And Rehabilitation Survey Catalyst Team⁷

<http://www.jmir.org/2014/3/e81>

Methods – pilot #2



Pilot #2 Survey Implementation

- Collaborator and Knowledge User Organizations
- Modified Dillman Tailored Design Method (Jan – March 2013)
 - Initial invitation email with link to survey
 - Thank you / reminder email (1 week later)
 - Final thank you / reminder (2-4weeks later)
- \$25 e-gift card
 - Amazon, Cineplex, Best Buy, Starbucks, Bath and Body Works
- 1-855 number if any questions or feedback
- ~ 30 people with HIV were invited to participate;
 - 23 accessed the survey link (%) and 17 (%) completed the survey



Methods – recruitment



HHRS Launched October 2013 – August 2014

- 7 Collaborator and Knowledge User
plus 21 Recruitment Network Organizations across Canada
 - Email / e-blast to organization client list
 - Initial email invitation
 - Thank you / reminder
 - Second thank you / reminder
 - Final (last chance) thank you / reminder
- Supplemented by posters, recruitment cards, word of mouth
- 'Penguin Video' www.youtube.com/watch?v=fpkPKSS5bAY
- Token of Appreciation - \$25 gift card (Starbucks)

Electronic questionnaire administered via Lime Survey

- Estimated ~40 minutes to complete

Sample Size Estimation

- Targeted sample size ~1300 complete responses

REB Amendments (n=4) *multiple responses, tokens, enhancing recruitment strategy*



It's amazing what you can do in 30 minutes

Promotional 'Penguin' Video

Recruitment results



1850 Accessed the Survey Link
*View Rate: 38% (1850/4892)**

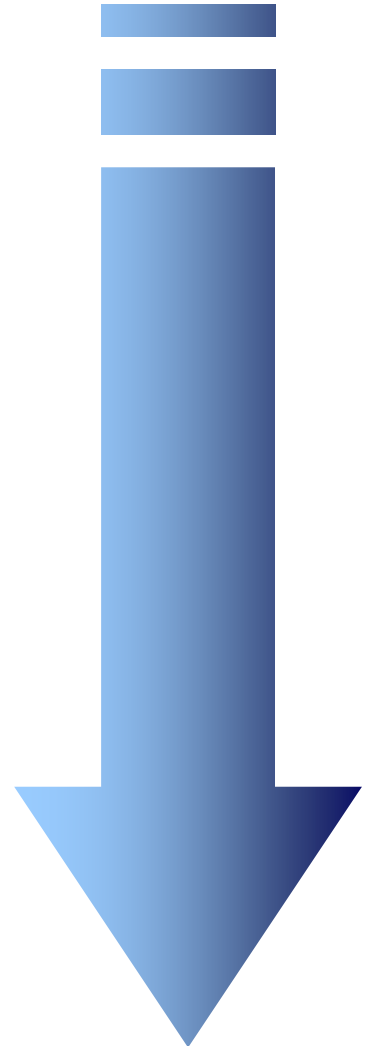
1540 were Eligible and Agreed to Participate
Participation Rate (Eligibility): 83% (1540/1850)

1477 Initiated the Survey Questionnaire
Participation Rate: 80% (1477/1850)

1171 Completed the HHRS
Completion Rate: 79% (1171/1477)

**230 Responses Removed for Missingness,
Suspected Multiple Responses, Nonsensical Responses**
Removed: 19% (230/1171)

941 "Valid" Complete HHRS Responses



941/4892
(19% overall response rate*)

**Overestimation in rates given true denominator is unknown (snowballing)*

Characteristics of participants




n=941 Participants	N (%)
Geographical Location	
Ontario	671 (71%)
British Columbia	139 (15%)
Quebec and Nunavut	57 (6%)
Atlantic Canada (Nfld and Labrador, PEI, Nova Scotia, New Brunswick)	46 (5%)
Prairies (Alberta, Saskatchewan, Manitoba)	25 (3%)
Living in a Metropolitan Geographical Area (>500,000 people)	636 (68%)
Median Age (years, IQR)	48 (39, 54)
≥50 years	405 (43%)
Gender	
Men	740 (79%)
Women	159 (17%)
Other	34 (4%)
Number who live alone	511 (61%)
Median Year of Diagnosis (IQR)	2000 (1992, 2007)
Currently Taking Antiretrovirals	851 (90%)
Currently Working for Pay Full-Time or Part-Time	350 (37%)
Average Gross Personal Yearly Income <\$20,000	449 (48%)
Medical Insurance Benefits	
None (other than provincial healthcare)	366 (39%)
Benefits through social assistance program	266 (28%)

Comorbidities



n=941 Participants	N (%)
Living with ≥ 2 comorbidities	518 (72%)
Common Comorbidities (>10%)	
Mental Health Condition (e.g. depression, anxiety)*	395 (42%)
Muscle pain	308 (33%)
Joint Pain (arthritis)	282 (30%)
High Cholesterol	261 (28%)
Addiction*	248 (26%)
Neurocognitive Decline (e.g. memory loss, confusion, trouble thinking clearly..)	209 (22%)
High Blood Pressure	177 (19%)
HPV (human papillomavirus)	139 (15%)
Asthma	138 (15%)
Peripheral Neuropathy	136 (14%)
Elevated Triglycerides	133 (14%)
Osteopenia or Osteoporosis (e.g. decreased bone density)	121 (13%)
Osteoarthritis (e.g. degenerative joint disease)	106 (11%)
Obesity	97 (10%)
Hepatitis C	95 (10%)

A green arrow pointing downwards, starting from the top right of the table and ending at the bottom right, highlighting the lower prevalence of obesity and hepatitis C compared to the other comorbidities listed.

HIV disability questionnaire scores




Disability Dimension	Median Presence (Range 0-100) (IQR) n=941	Median Severity Score (Range 0 to 100) (IQR) n=941	Median Episodic Score (IQR, range)
Physical	55 (35-75)	21 (11, 32)	10 (0,35) [0-100] n=657
Cognitive	67 (0, 100)	17 (0, 33)	0 (0,33) [0-100] n=866
Mental-Emotional	73 (36, 95)	27 (14, 48)	0 (0,36) [0-100] n=808
Uncertainty	79 (57, 93)	38 (21, 55)	0 (0,21) [0-100] n=811
Difficulties with Day-to-Day Activities	33 (0, 78)	11 (0, 31)	0 (0,22) [0-100] n=823
Challenges to Social Inclusion	67 (33, 92)	29 (12, 48)	0 (0,8) [0-100] n=798
Total	62 (41, 78)	25 (13, 40)	6 (0,26) [0-99]

Health services use



In the past year....	N (%)
Had Any Health Challenges Due to HIV, its associated treatments or other concurrent health conditions	405 (43%)
Received Care from Following Health Providers (>20% of participants)	
Family Doctor	830 (88%)
HIV Doctor or HIV Specialist	829 (88%)
Pharmacist	572 (61%)
Dentist, Dental Hygienist or Orthodontist)	569 (60%)
Nurse or Nurse Practitioner	540 (57%)
Eye Specialist (ophthalmologist or optometrist)	341 (36%)
Social Worker	311 (33%)
Psychiatrist	209 (22%)

A large green arrow pointing downwards, indicating a trend or direction in the data.

Rehabilitation services use



In the past year received care from the following....	N (%)
Physiotherapist (or Physical Therapist) 51% who saw a PT felt they needed to see them more often	157 (17%)
Occupational Therapist 55% who saw an OT felt they needed to see them more often	57 (6%)
Speech-Language Pathologist 50% who saw an OT felt they needed to see them more often	26 (3%)
Rehabilitation Doctor (Physiatrist) 46% who saw an OT felt they needed to see them more often	70 (7%)
Number of Participants Who Felt Rehabilitation Interventions Helped Reduce, Minimize or Prevent their Health Challenges with HIV	125 (71%)

Complimentary and alternative therapy



In the past year received care from the following....	N (%)
Complementary and Alternative Therapy Provider	256 (28%)
Most commonly saw....	
Chiropractor	155 (17%)
Naturopath	118 (13%)
Acupuncturist	153 (17%)
Massage Therapist	249 (27%)
Types of Treatment Interventions (most common) \geq30% of participants	
Acupuncture	170 (42%)
Counseling	159 (39%)
Health Promotion	124 (31%)
Pain Control	168 (42%)
Number of Participants Who Felt Rehabilitation Interventions they Received from CAM Helped Reduce, Minimize or Prevent their Day-to-Day Health Challenges with HIV (n=393)	243 (62%)

Complimentary and alternative therapy



In the past year used ...	N (%)
Community-Based (non-HIV specific) Organization	372 (40%)
Felt it Helped Improve Overall Health	241 (66%)
AIDS Service Organization	600 (64%)
Felt it Helped Improve Overall Health	425 (72%)

Social living strategies



In the past month, <u>most</u> (few times a week) or <u>All</u> of the time (everyday) (n=941)	N (%)
a) I spend time with friends, partner, extended or biological family, or pets	398 (42%)
b) I spend time with work (or volunteer) colleagues	180 (19%)
c) I spend time with people I know through religion or faith	72 (8%)
d) I spend time at community-based or AIDS service organizations either to volunteer or access their services	166 (18%)
e) I seek the company of others living with HIV (outside of organizations)	139 (15%)
f) I spend time interacting with others on the internet	288 (31%)
g) I seek the company of others by attending dinner parties or going out to restaurants	89 (9%)
h) I access a support group (either online, by phone or in person)	83 (9%)
i) I isolate myself from others	241 (26%)
j) I try to reduce or eliminate relationships or activities that I believe are harmful to me	374 (40%)
Overall # who feel social strategies helped them reduce, minimize or prevent day-to-day health challenges with HIV	
Yes	307 (33%)
Sometimes	303 (32%)

Living strategies



In the past month, <u>most</u> (few times a week) or <u>All</u> of the time (everyday) (n=941)	N (%)
I make sure I get enough sleep	570 (60%)
I make sure I eat well	614 (65%)
I exercise	349 (37%)
I pay attention to “the numbers” (viral load, CD4 count)	382 (40%)
I maintain a good balance or activity in my life	375 (40%)
I try to stick to a daily structure or routine	438 (46%)
I prioritize and try not to “overdo it” when it comes to my daily activities	410 (44%)
I focus on maintaining my health living with HIV	511 (54%)
I consider myself healthy living with HIV	564 (60%)
I focus on things such as work and friends because HIV is not my main focus in life	494 (52%)
I accept and value who I am – the good and the bad	562 (60%)
I have a positive outlook on life and use hope and optimism to live with HIV	515 (55%)
I accept that my health can fluctuate with ‘good days’ and ‘bad days’ living with HIV	569 (60%)
I choose to believe I can survive and overcome any challenges living with HIV	470 (50%)
I smoke cigarettes	284 (30%)
I try to avoid people or things that stress me out	473 (50%)
I take medications as discussed with my doctor	843 (90%)

Conclusions



- **Majority (72%) of participants living with**
 - >2 comorbidities in addition to HIV
- **Disability – highest presence and severity - uncertainty**
- **Majority access primary and HIV medical health providers**
- **Few access rehabilitation - physical therapy (17%), occupational therapy (6%), speech-language pathology (3%), or psychiatry (7%)**
 - Approximately half of which would like to see more often
 - 71% felt rehabilitation interventions were beneficial
- **28% access CAM providers, of which 62% felt was beneficial**
- **Majority of HHRS participants accessing HIV-specific (64%) or community-based (40%) organizations**
- **Living strategies include combination of social and positive attitudinal strategies to deal living with HIV**

Considerations and next steps



- **Not fully representative sample**
 - Primarily Ontario
 - English only
- **Descriptive highlights only**
- **Community-engaged approach was critical to the online survey methodology**
- **Challenges with web-based survey research in context of HIV**
- **Next Steps**
 - HHRS Team Meeting – April 2014
 - Structural Equation Modeling Analysis to explore relationships between disability, comorbidities, rehabilitation use, and living strategies
- **For more information contact**
 - Kelly O'Brien (kelly.obrien@utoronto.ca)

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