HIV, Disability and Rehabilitation:

An Environmental Scan of Canadian Research in Sub-Saharan Africa

2010-2015

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Staff

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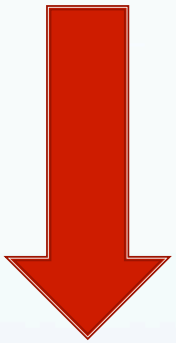
Funder

The CIHR Social Research Centre in HIV Prevention

Contents

Purpose

To identify and describe research on disability and/or rehabilitation in the context of HIV in Sub-Saharan Africa (SSA) that is being conducted by Canadians



- Provide an overview of the current research landscape
- Identify areas for possible collaboration
- Identify gaps in research

Why does this matter?

- Since the 1990's, Canada has spearheaded research, advocacy, education and practice related to rehabilitation in the context of HIV care, treatment and support.
- A growing number of Canadian researchers and advocates are asking what the lessons learned in Canada might have to offer people living with HIV in Sub-Saharan Africa (SSA). However, such efforts to date have been uncoordinated and non-strategic.
- This SRC-funded study explored the strengths and gaps in the current approach and the lessons learned by Canadian researchers engaged in this work.

Why are we doing this study?

- To create a comprehensive account of Canadian research on HIV and rehabilitation in SSA that is taking place
- To identify characteristics of this research
- To consider not only north-south lessons but also south-north lessons as part of shared innovation
- To foster collaboration among researchers working in this area

Methods

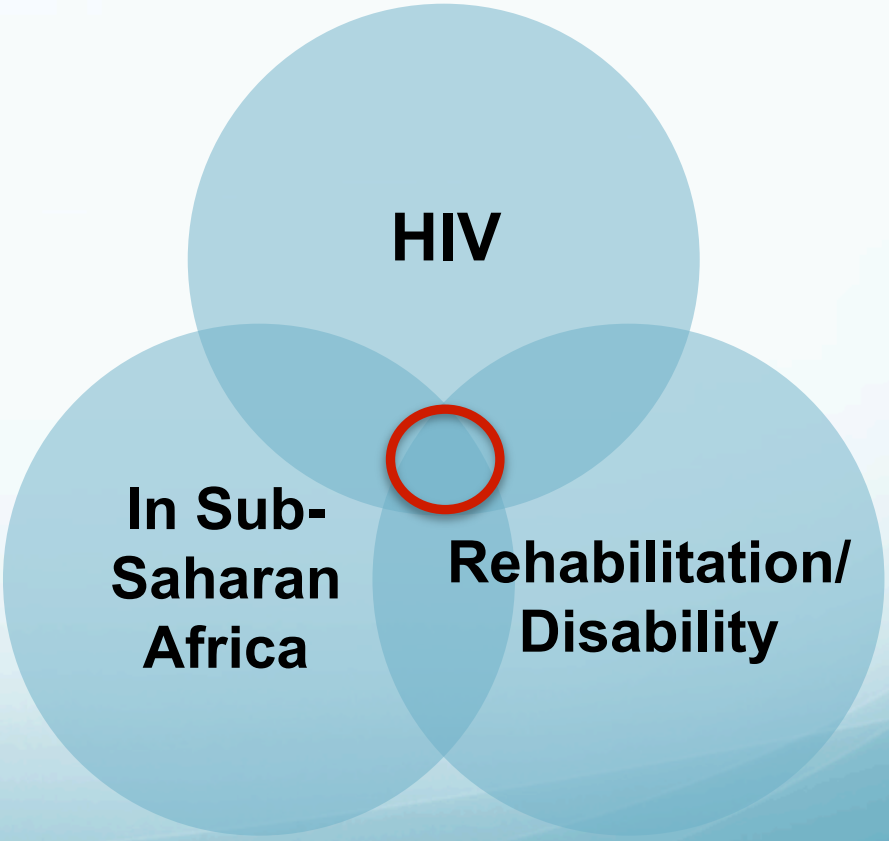
Which research projects did we look for?

- Researchers affiliated with a **Canadian** organization

  (e.g. university, NGO, community-based organization)

- Ongoing or within the **past five years** (2010-2015)

Focused on:



Definitions

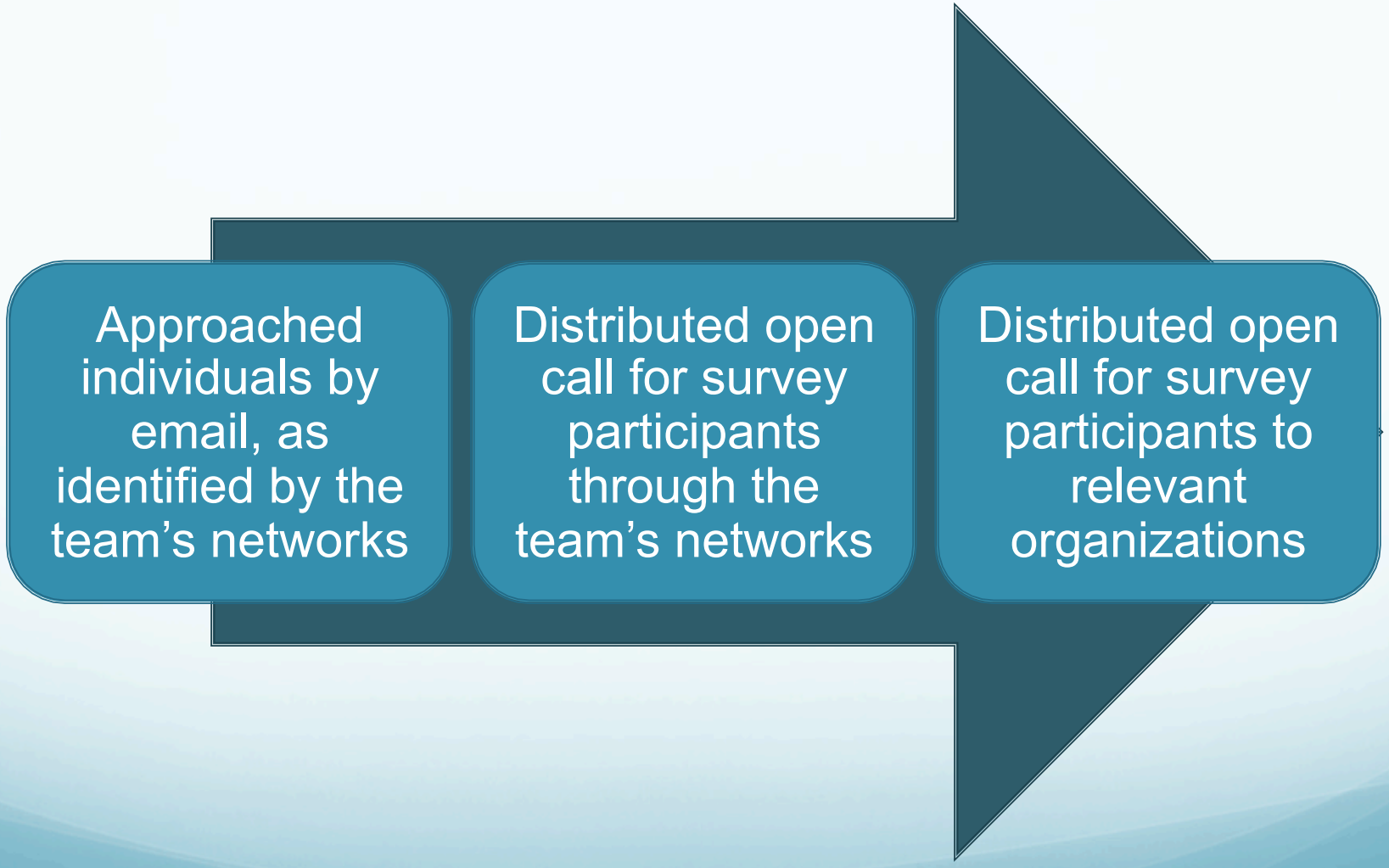
By **research**, we mean any planned inquiry, including both “big-R” research as well as monitoring and evaluation activities.

By **disability**, we mean any impairment, activity limitation or participation restriction, as conceptualized by the WHO ICF: http://ssa.hivandrehab.ca/section1/section1-3.php.

By **rehabilitation**, we mean any activity or program that addresses disability.

By **Sub-Saharan Africa**, we mean the countries as defined by the The World Bank: http://data.worldbank.org/region/SSA.

How did we find these projects?



Results:
Overview

Overview

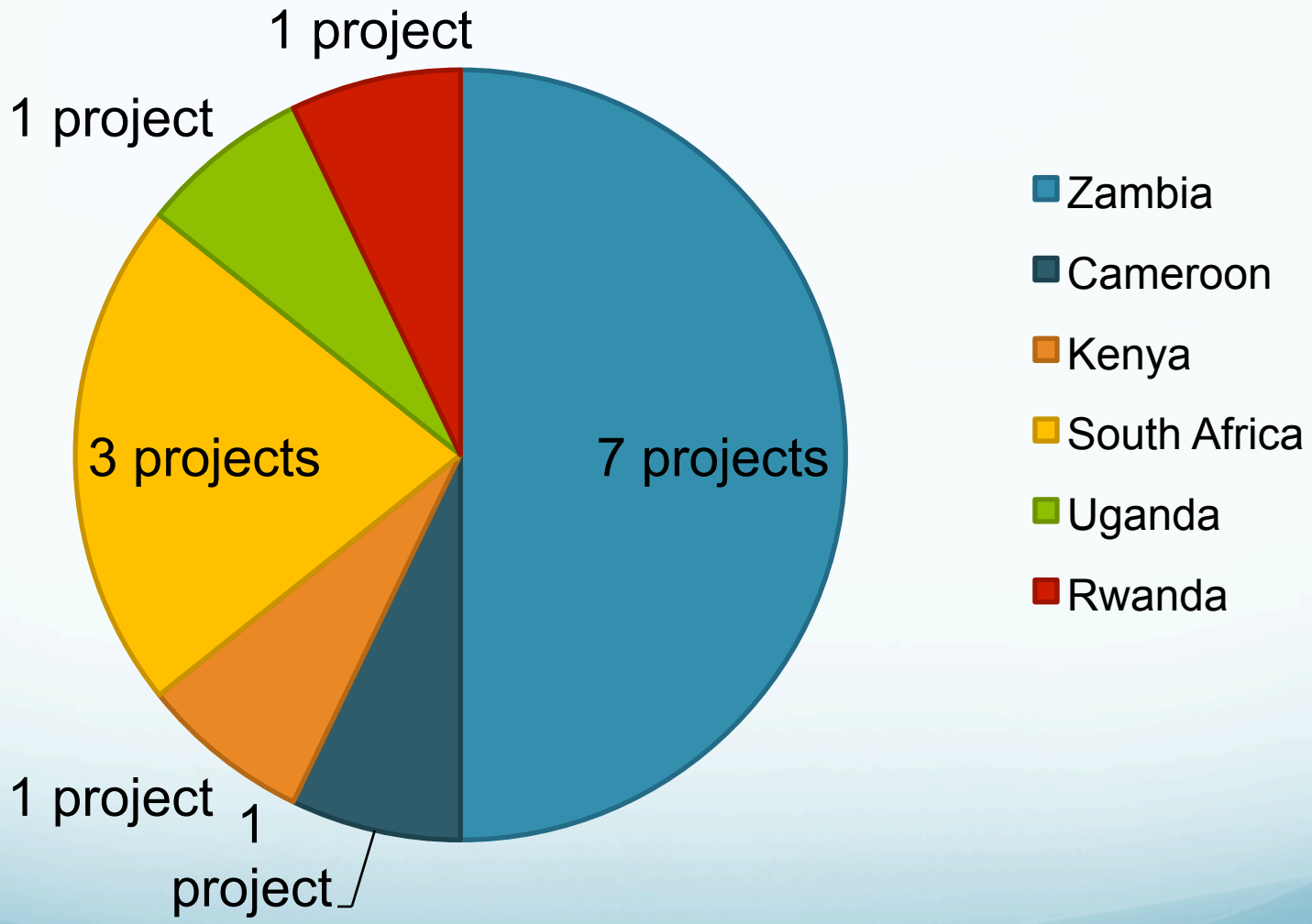
Total # of projects (2010-2015): 15

- 11 studies
- 4 published commentaries

Majority of projects conducted in Zambia

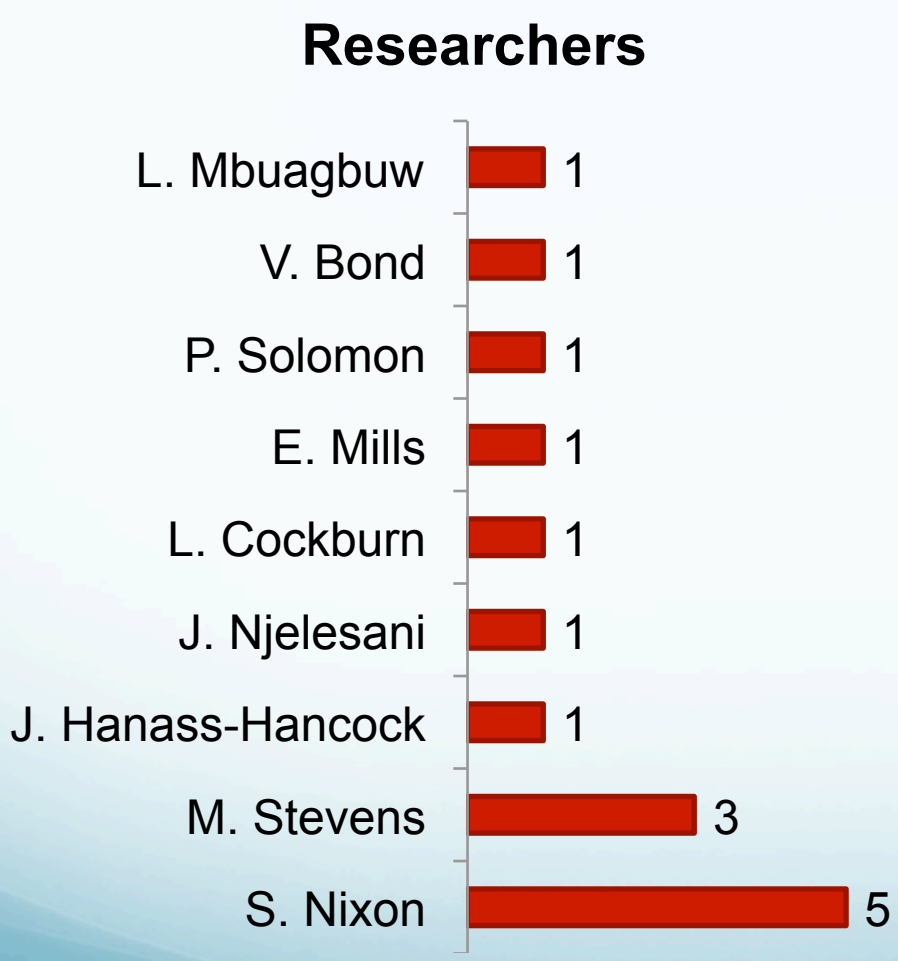
Most funded by Canadian Institute of Health Research (CIHR)

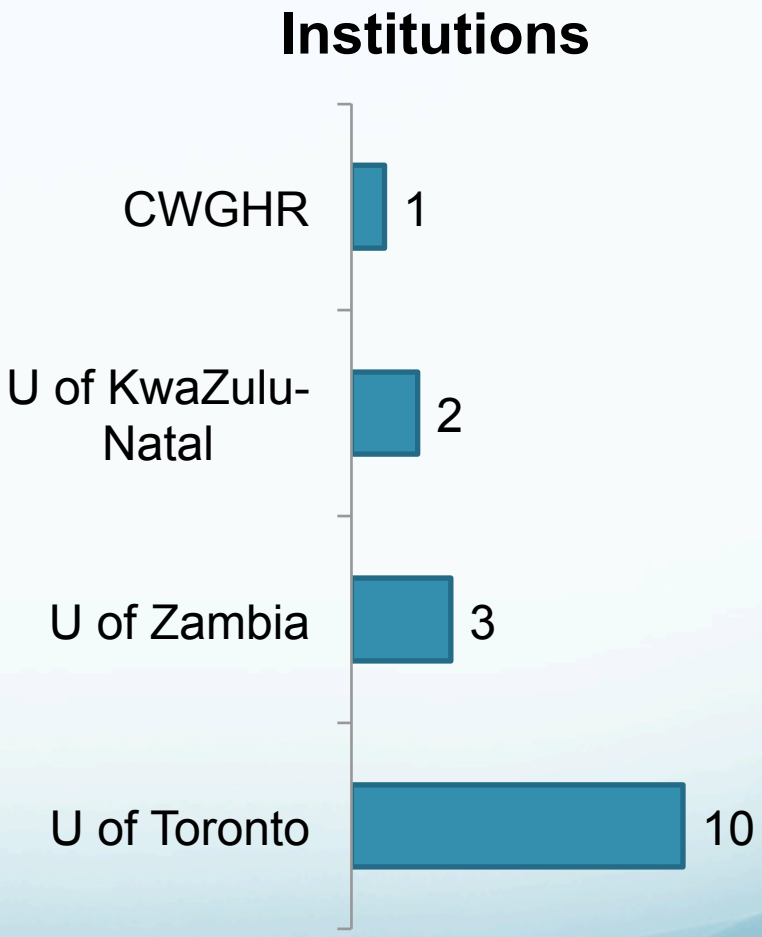
Where are these projects taking place?*



* Based on 11 empirical projects, some of which involve more than one country in SSA.

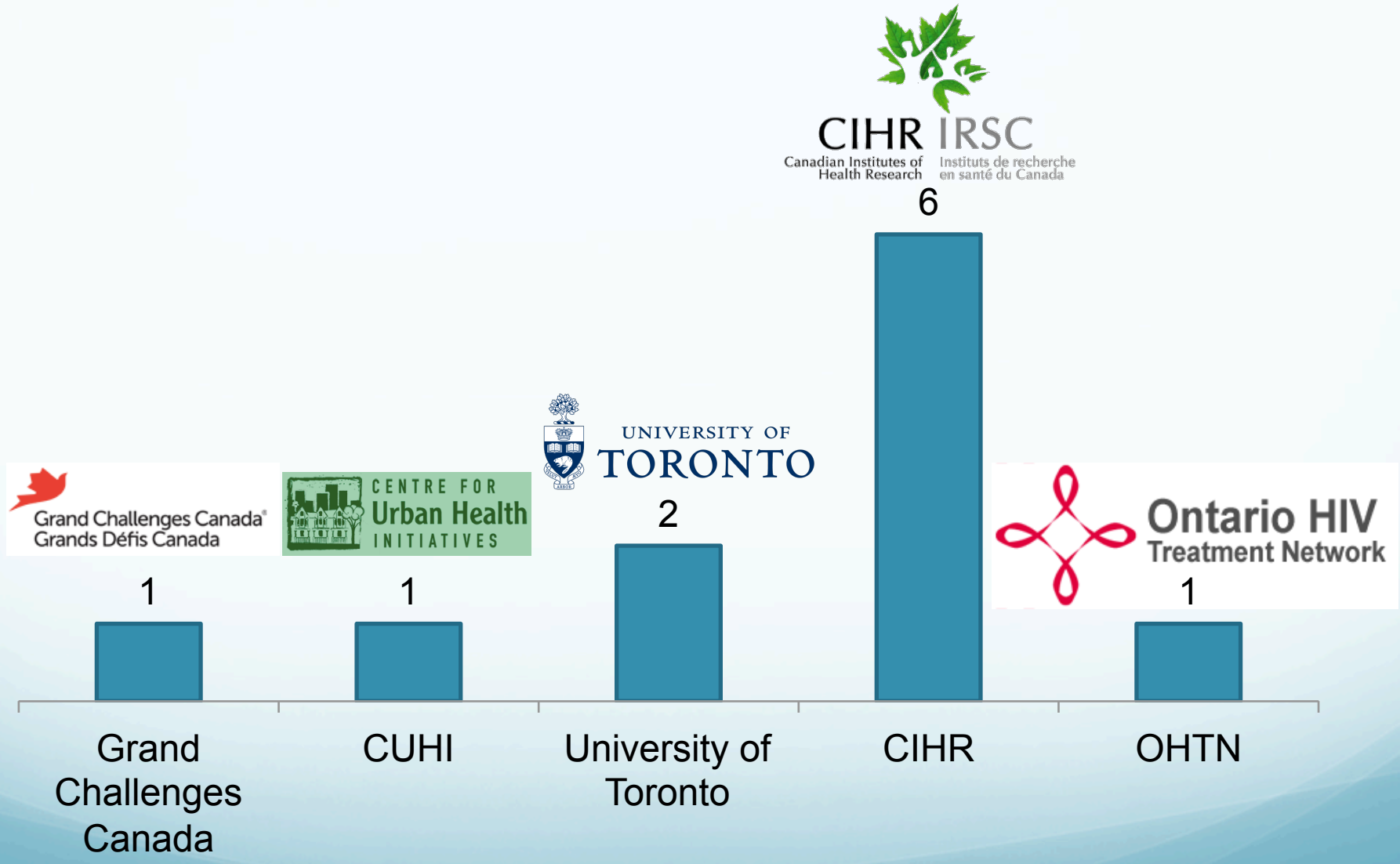
Who is leading these projects? *





* Based on 11 empirical projects, several of which involve more than one lead researcher or institution.

Who is funding these projects? *



* Based on 11 empirical studies, several of which involve more than one funding source. Studies were not excluded based on funding source but all were funded by Canadian sources.

Results:
Details of Individual Projects

List of Projects (n=15)

1. The Sepo I Study: Exploring the Experiences of People With Disabilities in Zambia who are HIV-Positive. (Nixon)
2. From Research to Practice: A Comprehensive Anti-Stigma Intervention for HIV and Disability in Zambia. (Nixon)
3. The Sepo II Study: Exploring the Functioning, Disability and Health of Women and Men Living With HIV in Zambia: Shifting Perspectives for a Longer Term Approach to HIV Care in Southern Africa. (Nixon, Solomon & Bond)
4. A Critical Occupational Approach: Offering Insights on the Sport-for-Development Playing Field. (Njelesani)
5. Adapting a Canadian eModule on HIV-related Disability and Rehabilitation for Health Workers in Sub-Saharan Africa. (Nixon)
6. Research and Advocacy Planning Meeting (Nixon)
7. HIV-related Disability in HIV Hyper-Endemic Countries: A Scoping Review. (Hanass-Hancock)
8. Rehabilitation Interventions for Children Living With HIV: A Scoping Review. (Stevens)
9. Research on Rehabilitation Interventions for Adults Living With HIV: A Scoping Review. (Stevens)
10. An Examination of the Activity and Participation of Children Living with HIV in Lusaka, Zambia Using the International Classification of Functioning, Disability and Health (ICF) Within a Critical Ethnographic Approach (Stevens)
11. A Systematic Review of Recent Health and Disability Related Research in Cameroon (Cockburn & Mbuagbuw)
12. (Commentary) The Essential Role of Physiotherapists in Providing Rehabilitation Services to People Living with HIV in South Africa. (Cobbing)
13. (Commentary) The Increasing Chronicity of HIV in Sub-Saharan Africa: Re-thinking ‘HIV as a Long-Wave Event’ in the Era of Widespread Access to ART. (Nixon)
14. (Commentary) Rehabilitation: A Crucial Component in the Future of HIV Care and Support. (Nixon)
15. (Commentary) Meeting the Challenges of Disability and HIV in East Africa (Mills)

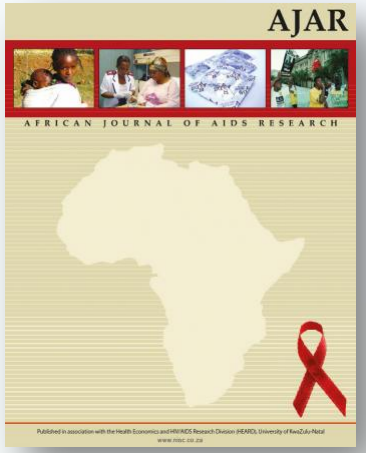
1) Sepo 1: Exploring the Experiences of People With Disabilities in Zambia who are HIV-Positive

Purpose: To conduct a pilot study that explores the perceptions and experiences of people living with disabilities who are HIV+ regarding health equity issues related to HIV care for people with disabilities (PWD) who are HIV+.

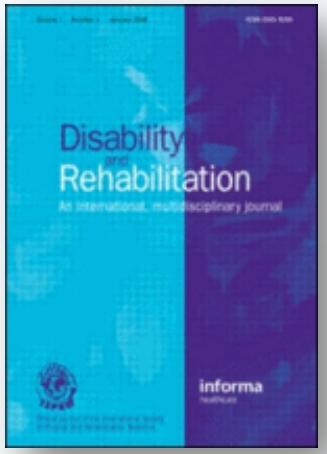
Click here for a link to a poster that describes the study's main findings, and here for the study's report.

Team Members	Institutions	Country	Funding Sources	Time Frame	Sample Size
Stephanie Nixon, Deb Cameron, Jill Hanass-Hancock, Francisco Ibanez-Carrasco, Eli Manning, Janet Parsons, Phillimon Simwaba, Patty Solomon, Karen Yoshida	University of Toronto, University of Zambia, University of KwaZulu-Natal	Zambia	CUHI Research Interest Group Seed Grant Award; Deans Fund University of Toronto, CIHR Catalyst Grant	Nov. 2009 – March 2011	32

1) Sepo 1: Key Outputs



Njelesani J, Nixon SA, Cameron D, Parsons J, Menon JA. **Experiences of work among people with disabilities who are HIV-positive in Lusaka, Zambia**. African Journal of AIDS 2015, 14(1):51-56



Yoshida K, Hanass-Hancock J, Nixon SA, Bond V. **Using intersectionality to explore experiences of disability and HIV among women and men in Zambia**. Disability and Rehabilitation. 2014, Early online: 1-8

Wickenden A, Nixon SA, Yoshida K. **Exploring the impact of the intersection of HIV, disability and gender on the sexualities of women in Zambia**. African Journal of Disability. 2013; 2(1), Art. #50, 8 pages

1) Sepo 1: Key Outputs (cont'd)

Parsons JA, Bond VA, Nixon SA. **Are we Not Human? Stories of Stigma, Disability and HIV from Lusaka, Zambia and Their Implications for Access to Health Services.** 2015;10(6):e0127392 doi:10.1371/journal.pone.0127392

Nixon SA, Cameron C, Hanass-Hancock J, Simwaba P, Solomon P, Bond V, Menon JA, Richardson E, Stevens M, Zack E. **Perceptions of HIV-related health services in Zambia for people with disabilities who are HIV-positive**. Journal of the International AIDS Society. 2014; 17:18806.

2) From Research to Practice: A Comprehensive Anti-Stigma Intervention for HIV and Disability in Zambia

Purpose: To further explore (building upon Sepo I findings) and begin to address stigma and discrimination experienced by persons with disabilities who are living with HIV.

Key Output: Click here for a report from this workshop.

Team Members	Institutions	Country	Funding Sources	Time Frame	Participants
Stephanie Nixon, Virginia Bond, Jill Hanass Hancock, Phillimon Simwaba, Patty Solomon	University of Toronto	Zambia	CIHR	2011	22

3) Sepo 2: Exploring the Functioning, Disability and Health of Women and Men Living with HIV in Zambia

Purpose: To conceptualize HIV within a rehabilitation paradigm in a hyper-endemic country in order to advance practice, education, policy, advocacy and research that enhances the lives of people living with HIV.

Team Members	Institution	Country	Funding Sources	Time Frame	Sample Size
Stephanie Nixon, Patty Solomon, Ginny Bond, Anitha Menon, Francisco Ibanez-Carrasco, Margaret Maimbolwa, Jill Hanass-Hancock	University of Toronto	Zambia	CUHI Operating Grant	October 2011 – September 2015	35

3) Sepo 2: Key Outputs

6 poster presentations:

1. Nixon SA, Bond V, Solomon P, Hanass-Hancock J, Ibanez Carrasco F, Maimbolwa M, Menon A, Musheke M, Mwaba C, Simwaba P, Siwale M, Cameron C, Zack E**.**
   The Sepo II Study: Experiences of 'Functioning, Disability and Health' of women and men living with HIV in Lusaka, Zambia, 20th Canadian Conference on Global Health October 2013 Ottawa

2. *Mwaba C, Musheke M, Bond G, Maimbolwa M, Menon A, Simwaba P, Cameron C, Solomon P, Hanass-Hancock J, Ibanez Carrasco F, Nixon SA. **The 'Functioning, Disability and Health' experiences of people living with HIV receiving antiretroviral therapy in Lusaka, Zambia: Implications for HIV care**, Zambia National Health Research Conference, 2013 Lusaka

3. Hanass-Hancock J et al,
   The Sepo II Study: Experiences of ART adherence and/or defaulting among women and men living with HIV in Lusaka, Zambia. 3rd Structural Drivers of HIV Conference, 2013 Cape Town

*See appendix for this poster.

3) Sepo 2: Key Outputs (cont'd)

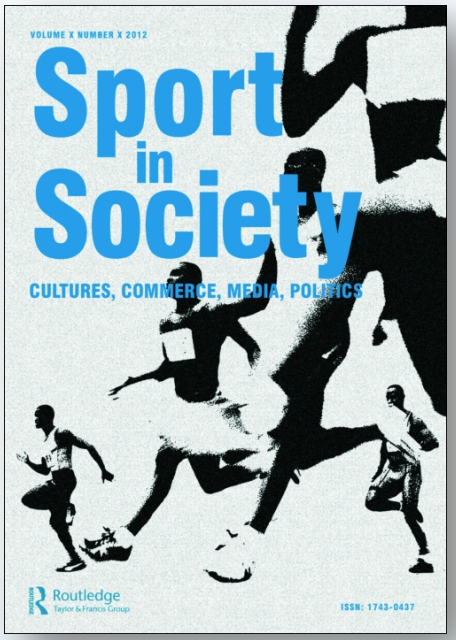
4. Nixon SA, Bond V, Solomon P, Hanass-Hancock J, Maimbolwa M, Menon A, Siwale M, Simwaba P, Zack E, Ibanez Carrasco F, Musheke M, Mwamba C, Cameron C. **The Sepo II Study: Using a Disability Framework to Examine Experiences of ART among Women and Men Living with HIV in Lusaka, Zambia.** 23rd Annual Canadian Conference on HIV/AIDS Research 2014 St. John's

5. *Nixon SA, Bond V, Solomon P, Hanass-Hancock J, Maimbolwa M, Menon A, Ibanez Carrasco F, Cameron C, Mwamba C, Musheke M, Siwale M, Simwaba P, Sinyinza R, Zack E, Tesfamichael A, Cleaver S. **The Sepo II Study: HIV-related disability study points to the need for new models of HIV care in Zambia.** 2014 20th International AIDS Conference Melbourne

6. *Bond V, Tesfamichael A, Solomon P, Mwamba C, Musheke M, Cameron C, Maimbolwa M, Menon A, Hanass-Hancock J, Nixon S. **The persistence and resistance of HIV-related stigma in the era of ART: Experiences of people living with HIV and on ART in Lusaka, Zambia.** 2014 20th International AIDS Conference Melbourne

*See appendix for this poster.

4) A Critical Occupational Approach: Offering Insights on the Sport-for-Development Playing Field

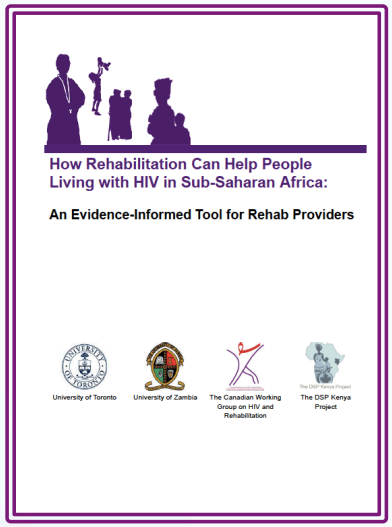


Purpose: To explore sport-for-development using a critical occupational approach (conducted as part of PhD thesis)

Njelesani J, Gibson BE, Cameron D, Nixon SA, Polatajko H.
A Critical Occupational Approach: Offering Insights on the Sport-for-Development Playing Field. Sport in Society. 2014;17(6):790-807.

Team Members	Institutions	Country	Time Frame	Sample Size
Njelesani, J., Cameron, D., Gibson, B. E., Nixon, S., & Polatajko, H.	University of Toronto, University of Zambia	Zambia	2008-2012	27

5) Adapting a Canadian eModule on HIV-related Disability and Rehabilitation for Health Workers in Sub-Saharan Africa



Purpose: To adapt an online educational tool, the HIV and Rehabilitation eModule, for rehab professionals in SSA from a Canadian prototype.

Click image for link to the eModule.

Team Members	Institutions	Country	Funding Sources	Time Frame	Sample Size
Stephanie Nixon, Esther Munalula Nkandu, Elisse Zack, Margaret Mweshi, Carlius Okidi	University of Toronto, University of Zambia, CWGHR, Disability Service Programme	Zambia	Grand Challenges Canada	October 2013 – March 2015	63

5) eModule: Key outputs

* “It is an eye-opener that there is a relationship between rehab and HIV”: Perspectives of PTs and OTs in Kenya and Zambia. CAHR, 2015.

* Adapting CWGHR’s eModule on HIV and Rehabilitation for Sub-Saharan Africa: Results of Phase 1. CAHR, 2014.

* See appendix for this poster.

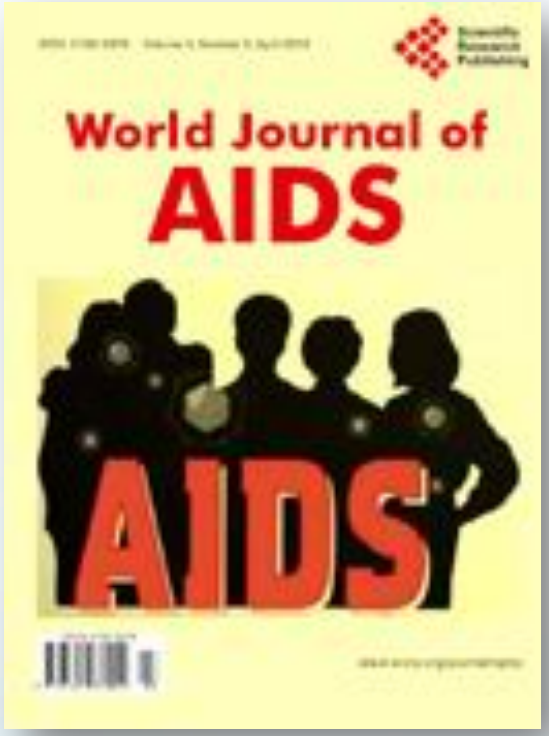
6) Research and Advocacy Planning Meeting

Purpose: To bring together experts from the advocacy and research communities to identify pressing issues in HIV and disability in Zambia and opportunities for addressing these priorities through advocacy and research.

Key Output: Click here for link to the meeting report.

Team Members	Institution	Country	Funding Source	Time Frame	Participants
Stephanie Nixon, Sarah Flicker, Patty Solomon	University of Toronto	Zambia	Ontario HIV Treatment Network (OHTN)	February - March 2010	Academics, clinicians, civil society

7) HIV-related Disability in HIV Hyper-Endemic Countries: A Scoping Review



Purpose: To examine the extent, nature and range of disability among people living with HIV in HIV hyper-endemic countries.

Key output: Hanass-Hancock J, Regondi I, van Egeraat L, Nixon S. **HIV-related disability in HIV hyper-endemic countries: a scoping review.** World Journal of AIDS. 2013; 3:257-279.

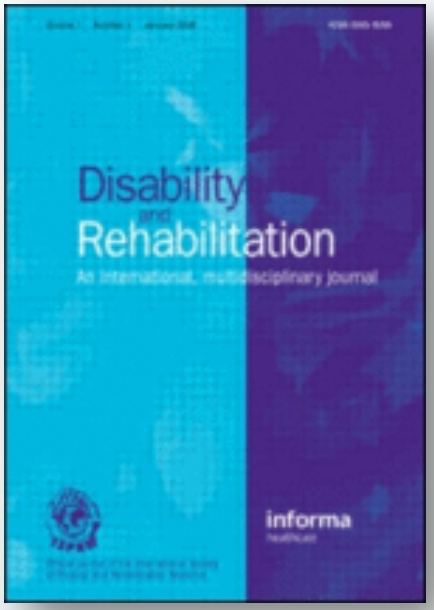
Team Members	Institutions	Country	Time Frame
Jill Hanass-Hancock, Ilaria Regondi, Leonie van Egeraat, Stephanie Nixon	UKZN (HEARD), University of Amsterdam, University of Toronto	South Africa	2013

8) An Examination of the Activity and Participation of Children living with HIV in Lusaka, Zambia using the International Classification of Functioning, Disability and Health (ICF) within a Critical Ethnographic Approach

Purpose: To explore the activity and participation of children living with HIV who are receiving antiretroviral therapy and living in residential settings in Lusaka, Zambia using a critical ethnographic approach.

Team Members	Institutions	Country	Funding Source	Time Frame	Partici-pants	Key Outputs
Marianne Stevens, Stephanie Nixon, Anitha Menon, Bonnie Kirsh, Janet Parsons, Stan Read	University of Toronto, University of Zambia, MOH Zambia, HEAL Project Zambia	Zambia	CIHR Fellowship HIV/AIDS Priority	January 2010 to April 2013	Children between the ages of 10-14 living in Lusaka, Zambia who are receiving ART	2 Posters: 1. Canadian Child Health Clinician Scientist Program Conference, Vancouver, June 2014 2. GDRS Research Showcase, May 2014

9) Rehabilitation Interventions for Children Living with HIV: A Scoping Review



Purpose: To report the extent, range and nature of rehabilitation interventions for children living with HIV.

Key output: Stevens M, Kirsh B, Nixon SA. **Rehabilitation interventions for children living with HIV: a scoping review.** Disabil Rehabil. 2014;36(10): 865-74.

Team Members	Institutions	Countries	Funding Source	Time Frame	Participants
Marianne Stevens, Stephanie Nixon, Bonnie Kirsh	University of Toronto	South Africa, Uganda	CIHR Fellowship HIV/AIDS Priority	2012-2014	Children under the age of 18 years living with HIV and receiving a rehabilitation intervention

10) Research on Rehabilitation Interventions for Adults Living with HIV: A Scoping Study

Purpose: To report the extent, range and nature of research on rehabilitation interventions for adults living with HIV.

Team Members	Institution	Countries	Funding Source	Time Frame	Participants	Key Outputs
Marianne Stevens, Stephanie Nixon	University of Toronto	Rwanda, South Africa	CIHR Fellowship HIV/AIDS Priority	2014 - 2015	Adults over the age of 18 years living with HIV and receiving a rehabilitation intervention	Manuscript under review

11) A Systematic Review of Recent Health and Disability-related Research in Cameroon

Purpose: To review all health-related research about the Cameroonian population from 2005-2015.

Team Members	Institutions	Country	Funding Sources	Time Frame
Lynn Cockburn, Lawrence Mbuagbuw, Adidja Amani, Mary Bi Suh Atanga, Dr. Apollinaire Tsopmo, Ms. Goli Hashemi, Prof Daniel Daly, Dr. Eta Mbong, Dr. Ndong Ignatius Cheng, Dr Alfred Njamnshi, Dr. Pierre Ongolo-Zogo, Dr. Henri Kamga, Dr. Doris Kamgwa, Dr. Matthieu Kamgwa, Mbi Valeri Oben, Christine Danielle Evina, Hilda Bih, Minal Ray, Lorena Wallace, Kimberly Skead	University of Toronto, University of Bamenda	Cameroon	N/A	Ongoing

12-13) Commentaries

SOUTHERN AFRICAN JOURNAL OF HIV Medicine

12) Cobbing S, Chetty V, Hanass-Hancock J, Jelsma J, Myezwa H, Nixon SA. **The essential role of physiotherapists in providing rehabilitation services to people living with HIV in South Africa.** South African Journal of Physiotherapy 2013;69(1):22-25.

GLOBALIZATION AND HEALTH

13) Nixon SA, Hanass-Hancock J, Whiteside A, Barnett AS. **The Increasing Chronicity of HIV in Sub-Saharan Africa: Re-thinking "HIV as a Long-Wave Event" in the Era of Widespread Access to ART.** Globalization and Health 2011; 7(41)

14-15) Commentaries

SOUTH AFRICAN JOURNAL OF PHYSIOTHERAPY

14) Nixon SA, Forman L, Hanass-Hancock J, Mac-Seing M, Munyanukato N, Myezwa H, Retis C.
Rehabilitation: A Crucial Component in the Future of HIV Care and Support. South African Journal of HIV Medicine 2011; 12(2):12-17.

JAIDS JOURNAL OF ACQUIRED IMMUNE DEFICIENCY SYNDROMES

15) Luyirika E, Kikule E, Kamba M, Buyondo F, Batamwita R, Featherstone A, Mills EJ.
Meeting the Challenges of Disability and HIV in East Africa.
Journal of Acquired Immune Deficiency Syndromes 2011; 57(3):e68-e69.

Implications

Areas of Strength

Research foci that are novel and important in SSA:

- Disability experienced by people living with HIV
- Role of rehabilitation in addressing HIV-related challenges
- Attention to both adults and children living with HIV
- Stigma and discrimination related to HIV and/or disability
- How lessons about HIV and rehabilitation learned in Canada might have relevance in SSA

Funders:

- Wide diversity of funding sources

Areas to Build Upon

Study teams:

- Majority of studies involve the same researcher indicating room for diversity in study leadership
- Many but not all study teams included investigators from SSA and/or community-based partners

Countries:

- Most research conducted in the same country (Zambia), which has both benefits and limits for the field
- Several studies were conducted across multiple countries and as such, those findings may be applicable to the broader region

Knowledge translation:

- Projects commonly shared results through academic outputs (peer-reviewed articles and conference posters), but many were lacking materials designed for non-academic audiences

Areas to Build Upon (cont'd)

Study design:

- Studies were mainly empirical qualitative studies or scoping reviews
- No intervention studies or operational research

Budgets as an indication of scope:

- All projects were funded by Canadian sources and had budgets less than CAD $300,000 and multiple projects had no formal budget, indicating room for growth in terms of project size and scope

Limitations

The challenge of defining “disability”:

- For this study, we defined “disability” broadly as any impairment, activity limitation or participation restriction, as conceptualized by the World Health Organization International Classification of Functioning, Disability and Health (ICF)
- Researchers may not have self-identified their work as related to disability in this way.

Areas not addressed in this scan that will require future attention:

- Research on HIV, rehabilitation and disability in SSA that does not involve Canadians
- Research on HIV, rehabilitation and disability in Canada that involves partners from SSA
- Focus on the African partners in the included studies other than as co-leads
- Gender-based analysis
- Research conducted prior to 2010

Appendices

Appendices

1. Poster: The Intersectionality of HIV and Disability in Zambia: Results from the Sepo Study.

2. Poster: Nixon SA, Bond V, Solomon P, Hanass-Hancock J, Maimbolwa M, Menon A, Ibanez Carrasco F, Cameron C, Mwamba C, Musheke M, Siwale M, Simwaba P, Sinyinza R, Zack E, Tesfamichael A, Cleaver S. The Sepo II Study: HIV-related disability study points to the need for new models of HIV care in Zambia. 2014 20th International AIDS Conference Melbourne

3. Poster: Mwaba C, Musheke M, Bond G, Maimbolwa M, Menon A, Simwaba P, Cameron C, Solomon P, Hanass-Hancock J, Ibanez Carrasco F, Nixon SA. The 'Functioning, Disability and Health' experiences of people living with HIV receiving antiretroviral therapy in Lusaka, Zambia: Implications for HIV care, Zambia National Health Research Conference, 2013 Lusaka

4. Poster: Bond V, Tesfamichael A, Solomon P, Mwamba C, Musheke M, Cameron C, Maimbolwa M, Menon A, Hanass-Hancock J, Nixon S. The persistence and resistance of HIV-related stigma in the era of ART: Experiences of people living with HIV and on ART in Lusaka, Zambia. 2014 20th International AIDS Conference Melbourne

5. Poster: “It is an eye-opener that there is a relationship between rehab and HIV”: Perspectives of PTs and OTs in Kenya and Zambia. CAHR, 2015.

6. Poster: Adapting CWGHR’s eModule on HIV and Rehabilitation for Sub-Saharan Africa: Results of Phase 1. CAHR, 2014.

The Intersectionality of HIV and Disability in Zambia: Results from the Sepo Study

Stephanie Nixon [1-3], Cathy Cameron [1,2], Deb Cameron [2], Jill Hanass-Hancock [3], Francisco Ibanez-Carrasco [4], Eli Manning [4], Janet Parsons [5], Phillimon Simwaba [6], Patty Solomon [7], Karen Yoshida [1,2]

1 International Centre for Disability and Rehabilitation, 2 University of Toronto, 3 Health Economics and HIV/AIDS Research Division (HEARD) University of KwaZulu-Natal, South Africa, 4 Universities Without Walls, 5 St. Michael's Hospital, Toronto, 6 Disability and HIV/AIDS Trust, Zimbabwe, 7 McMaster University

Objective: To present results of Phase I of the Sepo Study, which explored experiences of people with disabilities in Lusaka, Zambia who are HIV-positive.

Methods: For Phase I, ten people with disabilities who are living with HIV were recruited to participate in in-depth semi-structured interviews exploring dimensions of their experiences of having a disability and being HIV-positive.

- Interviews were conducted in local languages by Zambian fieldworkers, two of whom are sign language interpreters, two of whom are HIV workers, and two of whom are women with disabilities.
- Interviews with people who are deaf were conducted by a sign language interpreter trained in our research methods who vocalized into an audio-recorder while the participant signed.
- Interviews were digitally-recorded, transcribed verbatim and translated into English if necessary.
- Descriptive analysis was conducted by a subset of the research team that included Northern and Southern, and junior and senior partners.
- Descriptive results were then analyzed thematically by the full international research team and the Zambian fieldwork team.
- Ethics approval was received from the University of Toronto, University of KwaZulu-Natal and University of Zambia.

Results: Participants included 10 Zambians (5 men, 5 women, aged 29-61) with mobility (4), visual (4), hearing (1) or intellectual impairments (1). Years since HIV diagnosis ranged from 6 mos to 9 yrs.

Double the load:

Participants described life with both a disability and HIV.

In response to being asked if HIV is itself a disability: "Not at all. That's very different. A disability is a disability, whilst HIV is a disease on itself, these two are different." -46-year old man, deaf since childhood

"Yes, sometimes I think, This time, I'd have been in town, ordering things. Or by this time, I'd have been at the river, ordering the fishes, I come and sell. But the disease and the disability have stopped me from progressing." – 36-year old woman, blind and HIV+ since 2003

When asked how his experience with HIV might be different from an able-bodied person with HIV: "I don't think there's any difference because a virus is a virus whether one is disabled or able bodied. So I think, in my case, I don't see any difference because life goes one. I've accepted my status." -46-year old man, deaf since childhood

The need for more accessible HIV services:

Participants described how communication and other challenges related to their disabilities presented obstacles to accessing HIV-related supports; however, most did have access to ARVs.

"What I can say is that, uh, some NGOs are not aware about the importance of the sign language interpreter to a deaf person. And they'll usually put up a quarrel, saying that the interpreter is an extra cost. So, without an interpreter who's our mouth piece, then, that has become difficult. So these NGOs are making it difficult. For instance, if one is sick for a long time and uh, they need to access help, they need to access support and medicine, these NGOs should, should do something to help us." - 46-year old man, deaf since childhood

"... to access information, that's where the problem is ... news items that we get on radio, as I'm sitting here, I hear that government has done this and put on such policies but, implementation....Oh yes. I think they're trying their best. ... I regularly listen to radios, radio programs, even the television yeah. I do listen to the same programs. Yeah they're doing their best yes, I do listen to their programs, I don't think I missing anything (laughs)." – 36-year old man, blind and HIV+ since 2005

HIV and disability within a hierarchy of more pressing needs:

Participants frequently discussed basic needs that were at least as significant as their experiences of HIV or disability.

"What is needed more especially is food. Mealie meal and money for food because I don't have any business. I can't go to town to order, since I'm blind. I used to sell second-hand clothes." – 61-year old woman, blind and HIV+ since 2009

"Because of the medicine that I take, they are too strong, so you need to be eating often." – 29-year old woman, intellectual disability and HIV+ since 2003

"So that is where the problem is: if you take medication and you don't eat. It also becomes a problem, that's why you find that a lot of people stop, just maybe. Because it gives a lot of hunger. You find that hunger, in the stomach you start feeling strange. " – 36-year old man, HIV+ and mobility impairment from stroke since 2006

"There're some challenges that I face, say, in terms of maybe transport fare to go to the hospitals. That has been a problem to me because I can't do, I can't get finances on my own. Yes, so it's quite ah, a challenge on that part."– 36-year old man, blind and HIV+ since 2005

"... it's to support the family the, that's what I've been trying to. That's the care that I'd really want to get. Eh, support my children to go to school. That's the only investment maybe that's what I'd think for first, before anything else."– 36-year old man, blind and HIV+ since 2005

The simultaneous onset of disability and HIV:

Although we had intended to recruit people with longstanding disabilities who had become HIV-positive in recent years, in practice our team ended up recruiting several people whose disabilities and HIV diagnoses occurred around the same time, suggesting to us that their disabilities may have been caused by HIV. For these participants, learning to cope with a disability was a newer challenge and was complicated by concurrent issues related to living with HIV as well.

"It was difficult because one, I had a problem with my eyes, and then just go to the clinic to be told that, I'm in that position again [HIV+]. So I had two things to handle at a time now. So it was very difficult for me yes, very difficult." – 36-year old man, blind and HIV+ since 2005

The way forward:

Despite the difficult circumstances described by all participants, there were many moments of hopefulness and resilience during the interviews, including calls for disability rights and empowerment from those participants with disabilities since childhood.

"I think integration, it has to be for all, even us people with disabilities...Integration... maybe there're some people with disabilities who say no, me, I can't do this but to us, some of us that have been entrepreneurs before, I know for sure that I can be given something, then definitely, I can, I mean, I, I can make a change in my life." – 36-year old man, blind and HIV+ since 2005

"I'm a mobiliser at our community in [city].. We work as volunteers, helping the clinic, at ART." – 56-year old man, paralyzed since childhood

"Create employment for the deaf. The deaf, since they are experienced also, they can be teaching in the capacity building, uh, over sign language, because it's hard to pay the interpreter for transport, far, for refreshment and for the interpretations." -46-year old man, deaf since childhood

Next Steps

- In recent years, research has begun to explore issues of vulnerability to HIV among people with disabilities and the related implications for HIV prevention, but this is the first study exploring care, treatment and support issues for people with disabilities who are living with HIV.
- Preliminary results point to the need for issues of people with disabilities to be integrated into thinking about HIV specifically and development more broadly.
- These results lay the foundation for Phase II of the Sepo Study in which we will interview 15 more people with disabilities who have become HIV-positive, as well as 15 key informants from the health and disability sectors.
- Future steps include engagement with African and Caribbean communities in Canada to explore possible relevance of these findings within a Canadian context.
- Knowledge translation and exchange in Canada and Southern Africa is ongoing as we continue to cultivate partners with a stake in this research while simultaneously generating proposals for related studies in line with our emerging programme of research.

Funded by the Canadian Institutes of Health Research, the Centre for Urban Health Initiatives, and the University of Toronto Dean's Fund, as well as in kind contributions from the Health Economics and HIV/AIDS Research Division, the Disability and HIV/AIDS Trust, and the International Centre for Disability and Rehabilitation.

The Sepo II Study: HIV-related disability study points to the need for new models of HIV care in Zambia

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Background

With an HIV prevalence rate of 19.7% in Lusaka, Zambia, free public access to ART since 2004 is having a profound impact on the experiences of people living with HIV. Consequently, the HIV response must adapt to understand and meet the new needs associated with living with HIV as a chronic and potentially disabling condition. To inform this response, the Sepo II Study explored the experiences of functioning, disability and health among women and men receiving ART in Zambia using a rehabilitation framework (see Figure 1).

Methods

Sepo II is longitudinal, qualitative study with three waves of in-depth, semi-structured interviews 4-6 months apart with participants from public and private health care facilities in Lusaka, Zambia. Thirty-five participants were purposively recruited for variability across gender (17 men and 18 women), time on treatment (1 – 13 years), and SES (see Table 1). A qualitative, interpretive analysis was conducted of the first wave of interviews. Interviews were translated and transcribed, and analyzed by our international team of researchers and community activists using the collaborative "DEPICT" method of analysis (Flicker & Nixon, 2013).

Figure 1: International Classification of Functioning, Disability and Health (ICF)

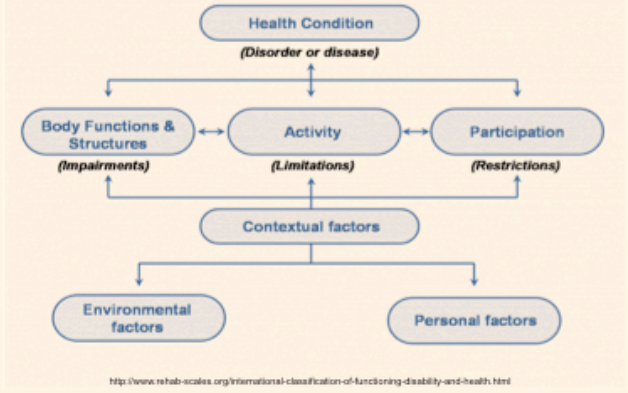

Table 1: Participant Characteristics by Study Site and Overall

Characteristic	Chawama Health Centre n=28	Lusaka Trust Hospital n=7	Overall n=35
Age	21-56 yrs Avg 40	36-54 yrs Avg 43	21-56 yrs Avg 41
Sex	15 women 13 men	3 women 4 men	18 women 17 men
Time on Treatment	1-13 yrs Avg 5 yrs	3-12 yrs Ave 8 yrs	1-13 yrs Avg 6 yrs

Sepo Study Research Team
Lusaka, Zambia, January 2014

Results

Body Functions and Structures

Participants reported diverse and widespread impairments that affected multiple body systems (e.g., numbness, memory issues, pain, fatigue, dizziness, vision problems). All participants, except one, reported at least 1 impairment. More than half the sample reported experiencing more than 3 impairments. Some impairments predated HIV, were resolved by ART, are side effects of ART and some are unrelated to ART or HIV. Some impairments are current and others episodic. A 41 year old woman described the numbness she experiences as *"numbness I feel it on my legs … it comes and goes, but currently it is not consistent [previously] it was frequent like every week I would feel my legs becoming numb"*.

Activity

Few activity limitations were reported except among participants who experienced a catastrophic disability (e.g., stroke). A 45 year old man stated that *"currently there is nothing that I fail to do, climbing, running, doing work, cycling a bicycle"* and a 43 year old woman said that *"I can do everything; farming I still do, sweeping I sweep, chores I still do, running, I run, washing I wash, thinking, I still think properly, eating just everything, everything I do."*

Participation

Far-reaching participation restrictions were identified including those related to parental roles and providing for children, and challenges associated with livelihood and underemployment that had implications for meeting basic needs (food, school fees, shelter). Reports of stigma were pervasive and influenced social supports. Participants also expressed uncertainty about the current and future welfare of their children, availability of treatment, and fragility of health. A 36 year old woman described the importance of her role as parent and uncertainty *"… there is always this thing at the back of your mind. … will I live to see my children grow up and be independent? At least when I die I should leave them independent … I think any mother living with HIV would always have that at the back of their mind."*

Conclusions

These findings suggest shortcomings in the dominant model of HIV care, which centres on management of ART and promotion of adherence. These services are necessary but not sufficient. HIV services also need to address the health- and life-related impacts of living longer with HIV, including counseling beyond VCT and adherence and the quality-of-life-promoting roles for rehabilitation within the HIV care continuum.

The 'Functioning, Disability and Health' experiences of people living with HIV receiving antiretroviral therapy in Lusaka, Zambia: Implications for HIV care

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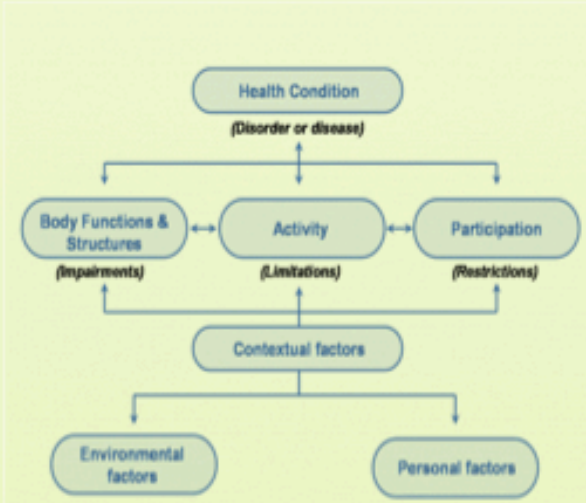
BACKGROUND

Antiretroviral therapy (ART) has become widely available in Zambia transforming HIV into a chronic health condition requiring extended and continuous care. This study uses the Episodic Disability Framework (EDF) and the World Health Organization's International Classification of Functioning, Disability and Health (ICF) to explore the experiences of living with HIV.

Episodic Disability Framework

O'Brien K, Bayoumi AM, Strike C, Young N, Davis AM. Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. Health and Quality of Life Outcomes. 2008; 6:76.

International Classification of Functioning, Disability and Health (ICF)



http://www.rehab-scales.org/international-classification-of-functioning-disability-and-health.html

METHODS

- A 3-year qualitative, longitudinal study of 17 men and 18 women receiving antiretroviral therapy (ART) at one public and one private health facility in Lusaka, Zambia.
- Participants purposively recruited to ensure diversity in terms of socio-demographic characteristics and length of time on ART. Three rounds of in-depth interviews are being conducted four to six months apart. Findings drawn from first round interviews conducted between December 2012 and April 2013.

RESULTS

Findings suggest both positive and negative impact of HIV and treatment:

Body Function and Structure Impairments: Include: numbness, weakness and fatigue and changes to physical body shape. In some cases, HIV and treatment aggravates pre-existing health conditions such as eye problems and memory loss, with the latter impacting negatively on adherence to treatment.

"Okay I have not accepted these things that are happening to my body, I used to walk properly now I can't maybe it is the ARVs that I drink" (34 year old woman)

Activity Limitations: Including reduced ability to walk long distances and engagement in physically demanding jobs thus unable to meet basic needs including food, shelter and school fees.

"Sometimes you feel like why I am not doing this, you feel so frustrated…. ''It is very irritating you just feel so tired from nowhere you just feel so tired. Others are not feeling tired…I get irritated and frustrated." (22 year old young man)

Participation Restrictions: Stigma, discrimination and exclusion related to HIV status and/or disability. This reduced after regaining their physical health, thus facilitating re-integration in social life.

"It hasn't been an easy experience, we face discrimination, segregation, stigmatization and people look down on you and they think you can't do anything since you are HIV positive. They regard you as retarded and you are unable to participate in most activities, they sideline you." (40 year old woman)

Uncertainty: People who have been on ART for a shorter period experience 'feelings of uncertainty' about their lives:

''Some thoughts are very difficult. I just feel like committing suicide, why? Because I feel like my life is very awful, very miserable. I can't live for long and sometimes I just feel like crying." (22 year old young man)

"I just accepted and started taking medicine and feeling better. Am saying I will die a natural death this disease won't kill me no I have refused or even thinking it will kill me because am taking medicine.'' (56 year old male)

However, HIV treatment restored physical health and led to resumption of social and livelihood activities.

CONCLUSIONS: This study conceptualizes HIV within a rehabilitation paradigm. Counselling on HIV needs to pay closer attention to body impairment and activity limitation experiences, and a need for linkages to other forms of health care such as physiotherapy to mitigate the effects of HIV and treatment.

ZAMBART PROJECT

7th National Health Research Conference, 14—16 October 2013, New Government Complex, Lusaka, Zambia

Acknowledgements: The study participants, the participating health institutions and the Ministry of Health, Zambia. This work was supported by the Canadian Institutes of Health (Ref: #114907), as well as in-kind contributions from the Health Economics and HIV/AIDS Research Division, the Disability, HIV/AIDS Trust and the International Center for Disability and Rehabilitation.

The Persistence and Resistance of HIV-related Stigma in the Era of ART: Experiences of People Living with HIV and on ART in Lusaka, Zambia

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BACKGROUND

It was anticipated that the wider availability of anti-retroviral treatment (ART) would significantly reduce HIV-related stigma for people living with HIV (PLWH) in Sub-Saharan Africa. Drawing on qualitative research in Zambia with a cohort of PLWH on ART using two rehabilitation frameworks (International Classification of Functioning, Disability and Health, Episodic Disability Framework) to explore HIV and disability, we reflect on how ART has reshaped HIV-related stigma.

METHODS

From December 2012 to December 2013, a cohort of 35 PLWH on ART were recruited from one public (n=28) and one private (n=7) health facility in Lusaka, Zambia. Semi-structured interviews explored how living with HIV on treatment impacts their body, activities and participation. Themed data analysis was conducted using a collaborative coding and analysis process and NVivo software.

RESULTS

Although no direct questions about HIV stigma were asked, almost every participant (30/35) spontaneously spoke about stigma, particularly when recalling their testing experiences and participation restrictions.

As illustrated in **Figure 1**, PLWH described the following experiences of stigma over time on ART:

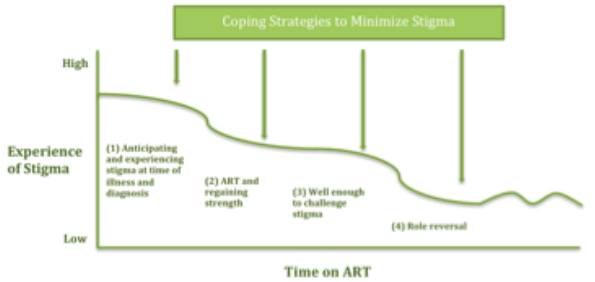
(1) anticipating and experiencing stigma around diagnosis and when ill
A 45 year old male stated that *"since I got sick in the previous days, people used to avoid me, there was no sharing a cup with me."*

(2) taking ART and gaining physical and mental strength
A 33 year old woman encourages others that *"if you take this medicine you will return in form just like them and people won't even be knowing that you are sick with HIV. It's just a virus, it's not a disease. That is how I became encouraged. I kept on taking medicine until I got better."*

(3) being well for long enough to start challenging stigma because '*it could happen to you*'
A 41 year old woman stated that *"I manage to live where people are talking about me because [I] am better than I was when I wasn't taking medicine. I even look better than those who say am sick [and] because I look better than them, that strengthens me."*

(4) role reversal: people who previously stigmatised them (e.g., kicking them out of the house, imposing restricted contact with eating utensils, name-calling) either dying themselves from HIV, feeling ashamed and/or seeking their advice and support regarding HIV experienced by themselves or others. This role reversal provides a sense of comeuppance or pride.
One 51 year old man described this by saying *"I think those people who were stigmatising us, me and my wife, instead of continuing, I think now they saw something that these are the people who can help us, whenever they have a problem actually they would come to consult to us."*

Figure 1: Experiences of Stigma over Time on ART



Coping strategies - resistance

Participants demonstrated the following strategies for coping with stigma:

Solution-focused
- Learning how to care for oneself and adhere to ART
- Being productive at work
- Practical support received from friends, family, ART clinic staff, support groups
- Living a '*normal*' life like others

Emotion-focused
- Reminding yourself that many people have HIV; "*we are many*"
- Perception that it is "*just a virus*"
- Finding peace of mind and not allowing themselves to be demoralized
- Emotional support from others

ART as a source of stigma - persistence

Although ART is a powerful tool for coping with and challenging stigma, visible signs of being on ART (e.g., pill-taking, clinic visits, bodily changes) conversely precipitated stigma. Stigma jeopardised critical relationships (e.g., losing children's respect, being left by partner), precipitated moves in residence, encouraged social withdrawal, had an emotional toll (including suicidal thoughts in 3 PLWH) and, brought several participants close to stopping ART. The implications of stigma were hardest for younger PLWH and for women.

ZAMBART PROJECT

CONCLUSIONS: By '*taking the medicine*' and regaining health and normality, these PLWH in Zambia mustered the strength to mobilize against stigma. Whilst ART can enhance the ability of PLWH to resist stigma, however, it should also be recognized as an added source of stigma itself. Hence stigma, despite ART, persists.

20th International AIDS Conference, 20-25 July 2014, Melbourne, Australia

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"It is an eye-opener that there's a relationship between rehab and HIV":

Perspectives of physiotherapists (PTs) and occupational therapists (OTs) in Kenya and Zambia

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Background

The advent of HIV treatment in Canada in the 1990s meant many **people with HIV lived longer but with more disability**. Thus, the field of **HIV and rehabilitation** was born and is central to Canada's response. A similar pattern is emerging in Sub-Saharan Africa (SSA) where an estimated 23.5 million people are living with HIV (69% of the global HIV burden). Current approaches to HIV in SSA are largely biomedical. Reframing HIV in a rehabilitation model addresses the broader health and life-related consequences of living with HIV. **There is currently no comprehensive HIV and rehabilitation educational tool designed for health workers in SSA.** Therefore, we adapted the CWGHR online educational *'E-module for Evidence-Informed HIV Rehabilitation'* (http://www.hivandrehab.ca) for health workers in Sub-Saharan Africa. **The purpose of the adapted E-module (ssa.hivandrehab.ca) is to increase clinical knowledge of rehabilitation providers in SSA on rehabilitation strategies to address challenges related to living with HIV to improve health and reduce disability.**

Objective

This poster presents results of the pilot study of the adapted E-module with rehabilitation providers (PTs and OTs) in **Nyanza province, Kenya, and Lusaka, Zambia**. In particular, we describe participants' **perspectives regarding their role in the care of people living with HIV** (PHAs). HIV prevalence in both pilot locations is greater than 15% among adults. ART access is growing in these settings, resulting in **many people living longer with HIV and the resulting comorbidities and disablement**. Therefore, the need is great for HIV and rehab training across the health care continuum.

Methods

- Pilot testing to assess the adapted HIV teaching tool for rehabilitation providers in Sub-Saharan Africa.

- Conducted in Nyanza Province, Kenya and Lusaka, Zambia
- Adult HIV prevalence > 15%

- Included:
  1. demographic questionnaire on educational background and current clinical practice
  2. survey on knowledge, awareness and confidence related to HIV and rehabilitation
  3. survey to obtain additional feedback on the resource (e.g., ease of use, language, clarity of information presented and relevance)
  4. focus groups to discuss the teaching tool
- Interpretive analysis of focus group data regarding participants' perspectives on their role providing rehabilitation for PHAs
- Ethics approval received from University of Toronto, University of Zambia and Kenya Medical Research Institute (KEMRI)

Canadian resource on HIV and rehabilitation

adapted for Sub-Saharan Africa

ssa.hivandrehab.ca
online open access

Rehabilitation has "**not been incorporated in the management of HIV**".

"This resource offers a new dimension for providing health care to HIV patients" and is **"long overdue".**

Conclusions

- Formal HIV policies (e.g., national strategic plans) in Sub-Saharan Africa now frequently recognize disability within the HIV continuum, yet **rehabilitation providers remain marginalized if not excluded from the HIV response** in many settings.
- **Incorporating HIV training into undergraduate and continuing rehabilitation education** is a crucial next step for the HIV response in Africa.

Results

Participants

- 63 rehabilitation professionals (52 PTs, 11 OTs)
- 10 focus groups (5 in Kenya, 5 in Zambia)
- October-November 2014
- 49% men and 51% women
- 22-60 years old (average 39 years Kenya and 34 years Zambia)
- All participants had post-secondary education (3 masters, 18 degrees, 36 diplomas, 6 missing)
- Most participants were in active practice and worked in a hospital
- ~1/3 treated 11 or more clients/day

Findings

- This was the **first exposure** to the role of rehabilitation with PHAs for many participants, despite the high local HIV prevalence.
- Participants described how rehabilitation is considered a ***"last resort and not preventive"*** and that they often provide only end-of-life care to individuals with HIV and that ***"there is a need to provide care to prevent disability and not wait for disability to manifest and then take action"***.
- Participants described rehabilitation as largely **excluded** from HIV trainings, policy meetings and care (except end-of-life).
- These rehabilitation professionals primarily provided rehabilitation care in hospital settings which are harder for patients to access due to distance, lack of transport, financial costs and other barriers.
- They emphasized the **need for better interdisciplinary practice** as they often work in isolation.
- They stressed the need for engagement of **community-based, non-professional providers** (e.g., community health workers, traditional healers).
- Participants also noted that **linkages do not exist** between HIV patient support centres, organizations providing HIV care and services, and rehabilitation.
- Participants noted new insights regarding HIV also **broadened their perspectives** on rehabilitation for other conditions.

Acknowledgements: Financial support for this work was provided through a grant by Grand Challenges Canada. *Conflict of interest Disclosure: We have no conflicts of interest.*

Adapting CWGHR's eModule on HIV and Rehabilitation for Sub-Saharan Africa (SSA): Results of Phase 1

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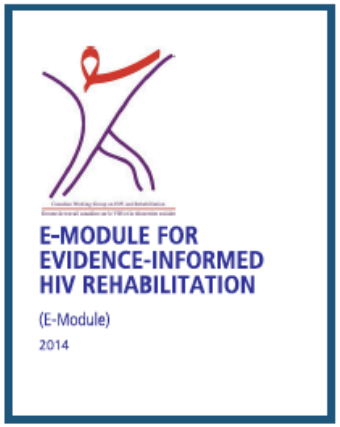
Background and Objective

- The advent of HIV treatment in Canada in the 1990s meant people with HIV lived longer but with more disability.
- In response, the field of HIV and rehabilitation was born and is central to Canada's response.
- A similar pattern is emerging in Sub-Saharan Africa (SSA) where an estimated 23.5 million people are living with HIV (69% of the global HIV burden).
- Current approaches to HIV in SSA are largely biomedical.
- Reframing HIV in a rehabilitation model addresses the broader health and life-related consequences of living with HIV, which is a new concept in SSA.
- There is currently no comprehensive HIV and rehabilitation educational tool designed for health workers in SSA.

- This is a Grand Challenges Canada-funded project to adapt the CWGHR online educational *'E-module for Evidence-Informed HIV Rehabilitation'* for health workers in Sub-Saharan Africa (SSA) to improve health and reduce disability for people living with HIV (PHAs) in that region. This presentation describes Phase 1 results.



Methods

Participants: A team of content experts from Kenya, Zambia and the region were engaged to conduct a detailed content review of the eModule.

Data collection: Reviewers were asked to identify:
- sections that need to be changed and why
- what content is not included that should be
- how the eModule could be used to improve the lives of individuals living with HIV in SSA
- who would benefit most from using the eModule
- suggestions for how the adapted eModule could be structured and organized.

Data analysis: Reviewers' recommendations were examined by the project team and used to inform revision CWGHR's eModule for SSA

Results

- Detailed content review was conducted from December 2013 to January 2014 by 9 African reviewers with expertise in disability, HIV and/or rehabilitation in SSA
- Reviewers recommended revision of eModule content to better reflect:
  - The epidemiology of HIV in SSA
  - The differences between services and access within the (under-resourced) public and (well-resourced) private healthcare sectors in SSA
  - The triple burden of unemployment, poverty and inequality and their impact on PHAs
  - The challenges of providing services in under-resourced rural and remote communities
  - Issues related to co-infections, food security and access to basic needs (e.g. clean water)
  - The role of traditional medicine
- They also recommended making the resource accessible to SSA through consolidating material, modifying the language level, and providing a print option to reflect limited internet access in SSA
- Reviewers highlighted that rehabilitation is delivered by a range of providers in SSA and therefore the resource should be inclusive of these other providers (e.g. community rehabilitation workers)

Conclusions

- We will use these findings to adapt the eModule (phase 2) and then pilot (phase 3) the adapted version for knowledge and feasibility with rehabilitation students in Zambia and community-based rehabilitation providers in Kenya to ensure that the content and layout meet the needs of rehabilitation workers, is structured in a way to inform clinical practice and is culturally appropriate.
- The pilot will also help identify and inform future strategies for dissemination and implementation.

Acknowledgements: Financial support for this work was provided through a grant by Grand Challenges Canada. *Conflict of interest Disclosure: We have no conflicts of interest.*

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