



Reaching Further

## Rehabilitation and HIV

Can the past inform the future?





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"The farther backward you can look, the farther forward you can see."

Winston Churchill



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# A reconceptualization of rehab??







The Canadian Working Group on HIV and Rehabilitation (CWGHR) is born



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## Social work student interview:

Sometimes we would miss or we wouldn't acknowledge something as being important. And the resource tutor would say, "I think you're missing the big picture now. Yeah – he's got diarrhea today but what's really important? It's his money. So you can do all those wonderful things but he needs drug benefits and that's his biggest concern. So you can have all your professional lingo but right now the biggest thing you can do is work with him around this.



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## MD student journal:

For the first time I am seeing and feeling the breadth of health care. It's great... I really feel like my understanding of "health care" is opening up.



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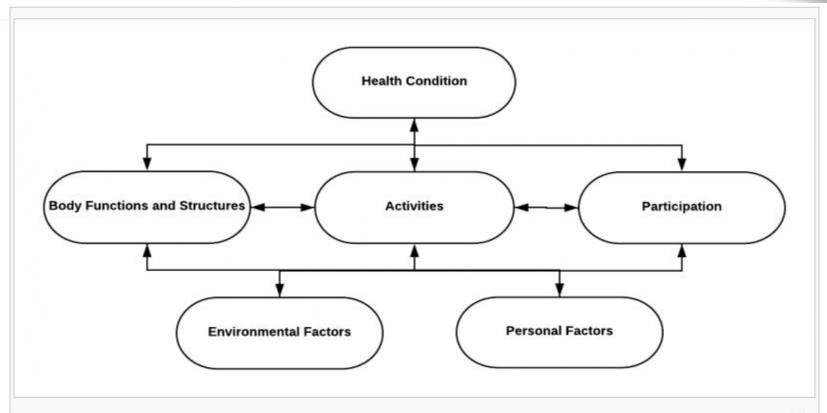
## Resource tutor interview:

I've got more confidence in myself. I realize I have lots to offer. I guess I've been exposed to AIDS for 12, 13 years and I guess I've forgotten how little people know about it.



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### **Health and Quality of Life Outcomes**



Research

Open Acces

Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia

Melanie Rusch\*<sup>1,2</sup>, Stephanie Nixon<sup>3</sup>, Arn Schilder<sup>1,4</sup>, Paula Braitstein<sup>1,2,4</sup>, Keith Chan<sup>1</sup> and Robert S Hogg<sup>1,2</sup>



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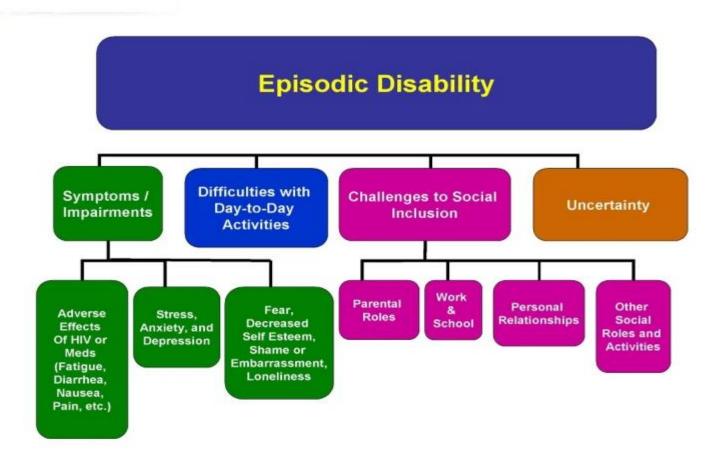
ORIGINAL ARTICLE

## Rehabilitation Professionals and Human Immunodeficiency Virus Care: Results of a National Canadian Survey

Catherine Worthington, PhD, Ted Myers, PhD, Kelly O'Brien, BScPT, Stephanie Nixon, PhD, Rhonda Cockerill, PhD, Tarik Bereket, MA



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Meanwhile in the UK.....









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#### **Environmental Contextual Factors** 1) Episodic Health and Disability 1A) Dimensions of Disability / Epissodic Disability · Physical, cognitive, mental health consequences of HIV Social Participation (labor force participation) Uncertainty (worrying about the future, aging, interaction with 'time'). 4) Access to Rehabilitation and Models of Rehabilitation Service Provision 18) Experience of Episodic Disability and Health over Time . Dimensions of disability that are episodic Facilitators and barriers to accessing rehabilitation. Development and evaluation of innovative models of Daily episodea versus larger fluctuations in health rehabilitation health service delivery Episodic Health and Disabillity Rehabilitation across the Life Course 2) Aging with HIV Across the Life Course 5) Effectiveness of Rehabilitation Interventions Healthy or successful agging with HIV Social participation (social engagemeent, isolation, mental. Methodological Advances Neurocognitive interventions health; labor force participation - complexities of Mental health interventions retrement, financial security) Self-management interventions Labor force participation interventions. 6) Enhancing Outcome Measurement Interventions to address uncertainty Culturally appropriate, sensitive, valid and reliable Development of Evidence-Informed Recommendations 3) Concurrent Health Conditions measures Improved screening tools Mertal Heatty How to measure the episodic nature of Neurocognitive Health Multi-morbidities and increasing complexity of disability Use of international, shared and validated Also includes conditions not specific to older adults Enhancing use and development of patient Methodological Considerations reported outcome measures. Qualitative and Quantitative approaches Engaging Harder-to-Reach populations · Collaborations with other sectors (e.g. gerontology) · HIV-specific versus cross-disability approach Personal Contextual Facctors Community-Engaged Research Social Determinents of Health Correlex Concurrent Health Conditions International collaborations Knowledge Translation and Exchange - Translating Research into Practice, Programs and Policy

Figure 1 Framework of research priorities in HIV, disability and rehabilitation.



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## Research Priorities - 2008

- 1. Episodic disability and health
- 2. Aging with HIV across the life span
- Concurrent health conditions
- Access to rehabilitation
- 5. Effectiveness of rehabilitation
- 6. Enhancing outcome measurement









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O'Brien et al. AIDS Res Ther (2020) 17:21 https://doi.org/10.1186/s12981-020-00280-5

## AIDS Research and Therapy

RESEARCH Open Access



Research priorities for rehabilitation and aging with HIV: a framework from the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC)

Kelly K. O'Brien<sup>1,2,3\*</sup>, Francisco Ibáñez-Carrasco<sup>4</sup>, Patricia Solomon<sup>5</sup>, Richard Harding<sup>6</sup>, Darren Brown<sup>7</sup>, Puja Ahluwalia<sup>8</sup>, Soo Chan Carusone<sup>9</sup>, Larry Baxter<sup>10</sup>, Charles Emlet<sup>11</sup>, Gayle Restall<sup>12</sup>, Alan Casey<sup>13</sup>, Amrita Ahluwalia<sup>14</sup>, Adria Quigley<sup>15</sup>, Alex R. Terpstra<sup>16</sup> and Nkem Ononiwu<sup>1</sup>



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#### Research Priorities in HIV, Aging, and Rehabilitation

#### (A) Multimorbidity, Episodic Health, and Disability Aging with HIV

#### Nature, Extent and Impact of Disability associated with Concurrent Health Conditions and Chronic Inflammation among People Aging with HIV

Multimorbidity, increasing complexity and potential episodic nature of disability

Mental health challenges

Neurocognitive health

Uncertainty and planning for the future aging with HIV Chronic Inflammation

Examining associations between chronic inflammation, and episodic disability aging with HIV.

#### 2) Fraility

Examining the <u>prevalence</u>, <u>severity and impact</u> of frailty among older adults with HIV (including development of screening tools for frailty) and;

Relationships between disability, chronic inflammation, and frailty aging with HIV.

#### 3) Community and Social Participation Aging with HIV

Social isolation among older adults with HIV.

Employment, retirement and other life transitions. Financial security for older adults with HIV.

Accessible, safe and supportive <u>housing</u> options for adults aging with HIV.

#### (B) Rehabilitation Interventions for Healthy Aging across the Lifespan

- 4) Strategies for Chronic Disease Management and Healthy Aging with HIV Conceptualizing healthy aging with HIV in relation to goals, values, preferences, and expectations of people aging with HIV; and how 'healthy aging' may differ depending on context (length of time since diagnosis, length of time on treatment, age, and environmental and personal factors). Examining impact of living strategies, including resilience and selfmanagement in the context of chronic disease management for healthy aging with HIV.
- Examining Facilitators and Barriers to Access and Engagement in Rehabilitation

Evaluating <u>educational interventions</u> aimed to increase knowledge about the role and evidence for rehabilitation for healthy aging with HIV with health professionals, community organizations, and people aging with HIV. Examining <u>factors that influence</u> the nature and extent of <u>engagement</u> in rehabilitation interventions.

#### (C) Outcome Measurement in HIV and Aging Research

7) Advancing the Development, Property Assessment and Use of Screening Tools (e.g. frailty) and Patient Reported Outcome Measures (PROMs) Using PROMs to enhance patient-

centeredness of research and care with adults aging with HIV Advancing development and use of culturally safe and age appropriate valid and reliable PROMs with people aging with HIV.

#### 6) Determining the Effectiveness of Rehabilitation Interventions to Support Healthy Aging with HIV

Intervention-based research that considers the design, evaluation and translation of interventions that address intersecting physical, social and mental and emotional health challenges (disability) faced by people aging with HIV Examining effect of exercise for older adults with HIV (optimal frequency, intensity, time, type, and outcomes). Examining effect of neurocognitive health interventions.

Identifying and evaluating optimal models of rehabilitation service delivery including engagement of interdisciplinary teams in clinic and community-based care settings.

Examining the <u>role of technology</u> (wireless activity monitors, online apps, websites, social media, online tele-coaching) in augmenting engagement in interventions for adults aging with HIV.

#### METHODOLOGICAL CONSIDERATIONS (lens through which to approach the research priorities)

Stigma reducing strategies incorporated into research approaches to better engage older adults with HIV in research.

<u>Culturally safe</u>, <u>anti-oppressive</u>, <u>and age-sensitive interventions</u> to engage adults living with HIV from different ethnocultural backgrounds and geographical regions. <u>Community-engaged approaches involving people aging with HIV throughout all stages of the research; and adopting Strategies for Patient Oriented Research(SPOR).</u>

Consider cost effectiveness outcomes in rehabilitation intervention research with older adults with HIV.

Consider using comparison groups similar to sample populations of people aging with HIV.

Use patient-reported outcome measures (PROMs) that are valid, reliable, culturally appropriate, and age-sensitive.

#### KNOWELDGE TRANSLATION and EXCHANGE

Mobilizing research into practice, programs, and policy to enhance access to timely and effective rehabilitation interventions for people aging with HIV.

Fig. 1 Framework of Research Priorities in HIV, Aging and Rehabilitation







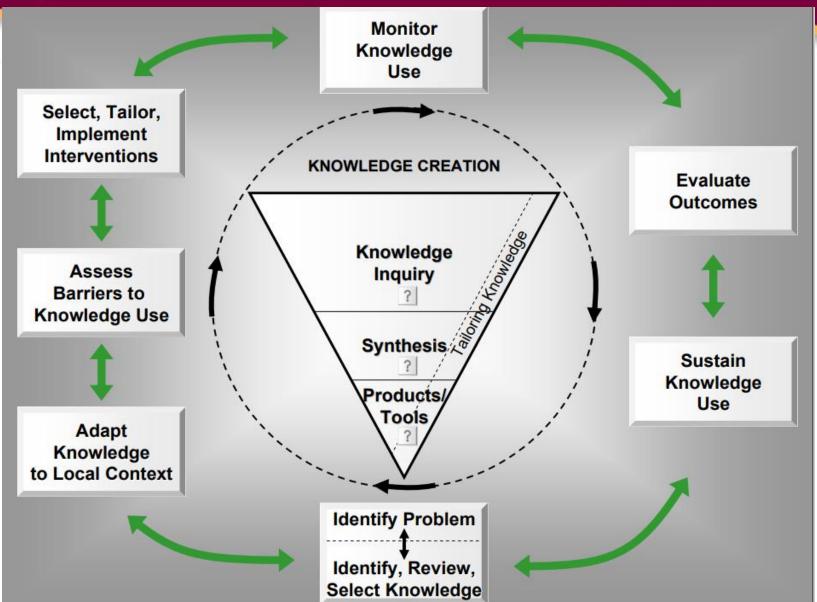














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## The E-Module: An HIV & Rehab Resource

How Rehabilitation Can Address the Needs of People Living with HIV.

A resource by <u>Realize</u> Canada. Select a section to explore the resource. Acronyms are defined the first time they appear in each section.

#### ABOUT THE E-MODULE

This section describes what this resource is about, why and how it was created, who it is for and how it can be used. Click...

### SECTION 2 – WHAT DO REHABILITATION PROVIDERS NEED TO KNOW ABOUT HIV?

This section briefly reviews current knowledge regarding HIV infection and its treatment. Click or tap a sub-section title to navigate to the full section content.

### Section 4 – UNIQUE NEEDS OF SPECIFIC POPULATIONS AND OTHER CONSIDERATIONS

This section will describe some of the unique

### Section 1 – What is the role of Rehabilitation in the context of hiv?

This section describes the role of rehabilitation in the context of HIV. Click or tap a section title to navigate to the full section content.

## Section 3 – What are the rehabilitation interventions that can help people Living with hiv?

This section provides an overview of the rehabilitation interventions that can help people living with HIV. Click or tap a sub-section title to navigate to...

SECTION 5 – WHAT ARE THE CONCEPTS AND TOOLS FOR MEASURING REHABILITATION OUTCOMES IN HIV?

## CIHRRC

Canada-International HIV & Rehabilitation Research Collaborative

**ABOUT** 

**MEMBERS** 

RESEARCH

KNOWLEDGE TRANSLATION

**FORUMS** 

**NEWS & UPDATES** 

CONTACT

### **Knowledge Translation**

CIHRRC activities include facilitating knowledge transfer and exchange on HIV and rehabilitation research, clinical practice and service delivery among people living with HIV, researchers, clinicians, educators representatives of community organizations and policy stakeholders in Canada and internationally.

Knowledge translation occurs in the forms of e-updates, presentations, publications, fact sheets, and CIHRRC International Forums on HIV and Rehabilitation Research.

CIHRRC Partners and Supporters















#### CIHRRC Twitter

#### Tweets from @CIHRRC



@CIHRRC · May 10

Replying to @CIHRRC

- @KellyOBrien25 @Kelly\_B5
- @Giving\_It\_Raw @RHardingCSI
- @LiamT\_Tweets @andrew\_d\_eaton
- @commsbizchat @EmmaStanmore
- @darrenabrown @solomon\_patty
- @EACSociety @ukcab
- @NazProjectLdn @APPG\_HIV\_AIDS
- @TackleHIV @HIVOutcomes
- @GeorgeHouseTrst
- @BritishHIVAssoc #AgeingwithHIV
- #RehabHIV









#### CIHRRC

@CIHRRC · May 10

Dr. Patty Solomon will kick off the 5th International Forum on HIV and



### Knowledge Translation

HIV in Motion activities include knowledge transfer and exchange on HIV and rehabilitation research, clinical practice and service delivery among people living with HIV, researchers, clinicians, educators representatives of community organizations and policy stakeholders in Canada and internationally.



Knowledge translation occurs in the forms of the Community of Practice webinars, e-updates, presentations, publications, fact sheets, and via collaboration with the Canada-International HIV and Rehabilitation Research Collaborative.















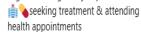
#### Tweets from @HIVinMotion

ta HIV in MOTION Retweeted

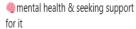




For some people living with HIV, stigma can negatively impact:







This doesn't need to happen. Learn more about what we do to tackle this: nat.org.uk/our-work/issues



## School of Rehabilitation Science Reaching Further



# Recommendations for International Collaborative in Rehabilitation Research

17. Consider feasibility when balancing the scope and growth of a collaborative in relation to available resources in a given funding environment.









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I never worry about action, only inaction.

Winston Churchill