A Tale of Rehabilitation in Two Countries: A Snapshot of HIV and Rehabilitation in Canada and the United Kingdom

British HIV Association Conference
Friday October 10th, 2014
Queen Elizabeth II Conference Centre
London, UK
In this session we will discuss the role and evidence for rehabilitation in the context of HIV and provide concrete examples of rehabilitation in clinical practice for people living with HIV.
Objectives

- To describe the role and evidence for rehabilitation in the context of HIV
- To highlight the strengths of rehabilitation research and practice in Canada and the United Kingdom
- To highlight ways in which to recognize need for rehabilitation, referral and access to rehabilitation for people living with HIV
The Panel

- Esther McDonnell
  - Rehabilitation in HIV Association (RHIVA), Chelsea and Westminster Hospital
  - Moderator

- Patty Solomon
  - McMaster University, Canada

- Kelly O’Brien
  - University of Toronto, Canada

- Francisco Ibáñez-Carrasco
  - Ontario HIV Treatment Network, Canada

- Darren Brown
  - Rehabilitation in HIV Association (RHIVA), Chelsea and Westminster

- Elizabeth Stevens
  - Birmingham Hearts of England NHS Trust
Definition of Rehabilitation

• “Any services or providers with the aim to reduce impairments, activity limitations or social participation restrictions experienced by an individual” (Worthington et al, 2008)

• “A dynamic process that enhances body structure and function, activity and social participation to improve the overall health and well-being of individuals.” (Canadian Working Group on HIV and Rehabilitation (CWGHR))
Role of Rehabilitation in HIV Care

- People living with HIV increasingly experience health related challenges related to the virus, co-morbidities, aging and side effects of treatment
- Disability associated with symptoms, day to day activities, challenges to social inclusion, uncertainty
- Shift to chronic and episodic illness
The Canadian Working Group on HIV & Rehabilitation (CWGHR)

- Inter-sectoral mandate established in 1998
- Advocacy to help health professionals, policy makers, educators and researchers to understand rehabilitation and HIV
- First scoping study on research priorities in HIV and rehabilitation (O’Brien et al, 2008)
- Through our UK link recognized the advance service delivery models in the UK
• CUHRRC formalized in 2009
• International Forum on HIV and Rehabilitation Research (2013)
• Established priorities in 3 key areas:
  - HIV and aging
  - measurement of episodic disability
  - evaluating the effectiveness of interventions
Strategic Collaboration

Combining research expertise in Canada with Clinical expertise in the UK and Ireland
Websites

CWGHR  www.hivandrehab.ca

CUHRRC  http://cuhrrc.hivandrehab.ca/
DEPARTMENT OF PHYSICAL THERAPY,
UNIVERSITY OF TORONTO, CANADA

Kelly O’Brien
Episodic Disability Framework

Dimensions of Disability

- Symptoms / Impairments
  - Adverse Effects Of HIV or Meds (Fatigue, Diarrhea, Nausea, Pain, etc.)
  - Stress, Anxiety, and Depression
  - Fear, Decreased Self Esteem, Shame or Embarrassment, Loneliness

- Difficulties with Day-to-Day Activities

- Challenges to Social Inclusion
  - Parental Roles
  - Work & School
  - Personal Relationships

- Uncertainty
  - Other Social Roles and Activities

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Episodic Disability Framework

Contextual Factors
Interact with and influence dimensions of disability (exacerbate or alleviate disability from the participant perspective)

Extrinsic Contextual Factors
- Social Support
  - Support from Friends, Family, Partners, Pets, Community
  - Support From Accessing Health Care Services and Personnel
- Stigma

Intrinsic Contextual Factors
- Living Strategies
  - Seeking Social Interaction With Others
  - Maintaining Sense of Control over Life
  - “Blocking HIV out of the Mind”
- Personal Attributes (Aging)
  - Attitudes & Beliefs

Program & Policy Support (income, housing)
Episodic Disability Framework

http://www.hqlo.com/content/6/1/76
**HIV Disability Questionnaire (HDQ)**

69 items + 1 (good day/bad day) item

**Physical Symptoms and Impairments**
- 20 items

**Mental Emotional Symptoms and Impairments**
- 11 items

**Difficulties with Day-to-Day Activities**
- 9 items

**Challenges to Social Inclusion**
- 12 items

**Cognitive Symptoms and Impairments**
- 3 items

**Uncertainty**
- 14 items

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**Statement**

Check the box that describes how you are feeling today.

<table>
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<th>I feel too fatigued or tired to do my usual activities.</th>
<th>Not at all (0)</th>
<th>Slightly (1)</th>
<th>Moderately (2)</th>
<th>Very (3)</th>
<th>Extremely (4)</th>
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Has this challenge fluctuated (or changed) over the past week?

- Yes
- No
HIV and Aging - Disability

- Uncertainty
- Symptoms and Impairments
- Difficulties with Day to Day Activities
- Challenges to Social Participation
Rehabilitation Interventions in HIV

Evidence-informed recommendations for rehabilitation with older adults living with HIV: a knowledge synthesis

Kelly K O'Brien, Patricia Solomon, Barry Trentham, Duncan MacLachlan, Joy MacDermid, Anne-Marie Tynan, Larry Baxter, Alan Casey, William Chegwidden, Greg Robinson, Todd Tran, Janet Wu, Elisse Zack

Overarching Recommendations on Rehabilitation for Older Adults with HIV (n=8)

1) Rehabilitation Professionals (RPs) should be prepared to provide care to older adults with HIV who present with complex comorbidities...

2) RPs should adopt an individualized approach to practice, sensitive to unique values, preferences and needs of older adults with HIV...

3) Multidisciplinary rehabilitation is strongly recommended across continuum of care...

4) RPs should consider the role of extrinsic contextual factors (stigma, ageism, HIV disclosure, social supports)...

5) RPs should consider the role of intrinsic contextual factors (self-management, spirituality)....

6) Aerobic and resistive exercise may be recommended for older adults with HIV who are medically stable and living with comorbidities....

7) Cognitive rehabilitation interventions may be recommended for older adults with HIV with mild cognitive impairments and stroke...

8) In absence of high level evidence RPs should refer to high level evidence for recommendations on interventions for a specific comorbidity....

Stream A Recommendations
HIV Aging and Rehabilitation
Derived from 41 low or very low level evidence articles

Recommendation Theme
Preparedness of Rehabilitation Professionals 1
Approaches to Rehabilitation Assessment and Treatment (physical, mental, neurocognitive, uncertainty, social inclusion) 7
Extrinsic Factors to consider with rehabilitation of older adults with HIV (ageism, stigma, disclosure, social support) 3
Intrinsic Factors to consider with rehabilitation of older adults with HIV (self-management, spirituality) 2
Rehabilitation Approaches (interprofessional practice, CAM) 2
Rehabilitation Interventions (exercise) 1
Total # Recommendations 16

Stream B Recommendations
Rehabilitation Interventions in Comorbidities
Derived from 108 high level evidence articles (meta-analyses or systematic reviews)

Recommendation Classification
Bone and Joint Disorders
Exercises, rehabilitation, self-management 4
Cancer
Exercise 4
Stroke
Rehabilitation, cognitive rehabilitation, electrophysical modalities 7
Cardiovascular Disease
Cardiac rehabilitation, exercise 6
Mental Health
Exercise, psychotherapy, models of care and housing models 4
Cognitive Impairment
Exercise, cognitive rehabilitation 3
COPD
Pulmonary rehabilitation, inspiratory muscle training, exercise 3
Diabetes
Exercise 1
Older Adults
Exercise 3
HIV
Exercise 1
Total # Recommendations 36

52 Detailed (Specific) Evidence-Informed Recommendations
Effect of aerobic and progressive resistive exercise for adults with HIV.

19 included studies

Results: Exercise may lead to improvements in cardiopulmonary fitness (VO2max), body composition (leg muscle area, % body fat, arm and thigh girth) and depression symptoms.

No change in CD4 count or viral load

E-Module for Evidence-Informed Rehabilitation
Canadian Working Group on HIV and Rehabilitation

www.hivandrehab.ca

Comprehensive >200 page electronic resource to increase capacity of rehabilitation professionals to work in HIV care.

Notable Sections

• Aging and concurrent health conditions,
• Cognitive rehabilitation,
• Evidence-informed rehabilitation interventions,

Acknowledgements

Canadian Institutes of Health Research, HIV/AIDS Research Initiative

Canadian Working Group on HIV and Rehabilitation
Francisco Ibáñez-Carrasco

DIRECTOR, EDUCATION AND TRAINING
THE ONTARIO HIV TREATMENT NETWORK
Current approaches to Rehabilitation Research in the context of HIV in Canada
Community Based Research (CBR)

- Engages “subject” as “agent” in one or all aspects of research process
- The Canadian Institutes of Health Research (CIHR), has invested a great deal of resources in HIV CBR for the past decade.
- CBR operationalizes the Greater Involvement of Persons Living with HIV principles (GIPA 1994).
- Seeks social change at various levels (community, culture, policy, etc.)
- CBR is closely linked with education
The Living Well Lab, Vancouver British Columbia, Canada

- A longitudinal, combined methods approach assessed the health- and quality-of-life-related outcomes and experiences of complementary and alternative medicine users. 207 participants living with HIV completed outcome packages (5 time points) over 18 months, which focused on changes in physical and emotional states, satisfaction with services and social support. Interviews were conducted at baseline, 9- and 18-month time points. Quantitative analyses were descriptive while content analysis and thematic coding were used in the qualitative analysis.

- Funded by the Canadian Institutes of Health Research (CIHR 2006-2008)
CBR example

HEADS UP!, Toronto and Vancouver British Columbia, Canada

- A series of 24 in-depth semi-structured interviews with participants screened for HIV/AIDS associated neurocognitive disorder in three clinical sites. The grounded theory analysis will complement plethora of existing HAND clinical measures from the perspective of the “patient” and will allow us to work on “knowledge transfer and exchange” (KTE) that influences clinical and non-profit frontline work.

- Funded by the Canadian Institutes of Health Research
The Population Health Intervention Research Initiative for Canada (PHIRIC) aims to increase the quantity, quality and use of population health intervention research (PHIR). PHIRIC is guided by a strategic alliance of individuals and organizations who facilitate the necessary alignment of organizational priorities, investments and activities.

Population health interventions are policies, programs and resource distribution approaches that impact a number of people by changing the underlying conditions of risk and reducing health inequities. Examples of such interventions include introduction of organizational changes in workplace design, housing policies to reduce homelessness, immunization programs and new taxes on products such as tobacco.

In the context of HIV research, “Program Science” refers to the process of using scientific research to improve the design, implementation, and evaluation of public health programs related to HIV.

Researchers and service providers work together to identify the type of information that will be helpful for improving HIV-related programs. The needs of HIV-related programs drive the research being done, and the research is, in turn, used to inform the development and refinement of HIV-related programs.

Program Science is useful for answering questions about how HIV service providers can use limited resources most effectively; how researchers can better monitor and evaluate the impact of HIV-related programs; how researchers and service providers can best understand and respond to HIV transmission dynamics within specific populations.
Thank you
Darren Brown

REHABILITATION IN HIV ASSOCIATION (RHIVA), CHELSEA AND WESTMINSTER
What is the Kobler Rehabilitation Class

#RehabHIV14

1) Physical Health
2) Mental and Social Well-Being
3) Reducing barriers to addressing these issues
4) Signposting to available support services

The Kobler Rehabilitation Class

Twice weekly Supervised Group Exercise

The Self-Management Programme

Cardiovascular Exercise
Progressive Resistance Training
Flexibility Training & Guided Relaxation

x2 Staff
Specialist (Band 7 Physiotherapist)
Senior (Band 6 Physiotherapist)

x2 week
Tuesday 2pm
Friday 11am

Physiotherapy Gym
What is the Kobler Rehabilitation Class

#RehabHIV14

The Self Management Programme

- Goal Setting
- Confidence & Self-Management
- Fatigue Management
- Healthy Diets
- Stop Smoking Support
- Body Image Concerns (Living Well)
- Community Services & Support (Positively UK & Living Well)
- Community Based Exercise (YMCA & local services)
- Community Organisations
- Community Organisations
- Symptom Control Dr.
- Advanced Nurse Practitioner
- Health Advisors
- Occupational Therapist
- Occupational Therapy
- Psychologist
- Psychologist
- Dietician
- Smoking Cessation Nurse

OUTCOME MEASURES
- WEEK 0
- WEEK 10
- HEIGHT
- WEIGHT
- BODY SHAPE
- HEART RATE
- 6MWT
- STRENGTH
- FAHI
- FLEXIBILITY
- GOALS

WEEK >10 WEEKS
Who is Referred?
#RehabHIV14

AVERAGE AGE

32 MIN
52

75 MAX

MUSCULOSKELETAL
ONCOLOGICAL
CARDIOMETABOLIC
DECONDITIONING
PSYCHOLOGICAL
RESP
NEURO
PAIN
FATIGUE
Goals

#RehabHIV14

BODY-IMAGE

MOBILITY

HEALTH/FITNESS

SOCIAL

FUNCTIONAL

PAIN

EMPLOYMENT

PARTICIPATION

SLEEP

STRENGTH

FLEXIBILITY

FATIGUE
Access to Rehabilitation
#RehabHIV14
Discussion and Questions
Conclusions and Take Home Messages
2nd International Forum on HIV and Rehabilitation Research

#RehabHIV14
@CUHRRC; @RehabHIV; @HIVandRehab
Thank you for Attending!

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Canadian Institutes of Health Research (CIHR), HIV/AIDS Research Initiative Canadian Working Group on HIV and Rehabilitation (CWGHR)
Chelsea and Westminster Hospital
Rehabilitation in HIV Association (RHIVA)
British HIV Association (BHIVA)
Three Flying Piglets

THREE FLYING PIGLETS