Advancing Research and Practice in HIV and Rehabilitation: A Framework of New and Emerging Research Priorities in HIV, Disability and Rehabilitation

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BACKGROUND

People living with HIV live longer and encounter physical, social, and psychological health-related challenges.
HIV+ persons face complexity related to social determinants of health, ageism, body image, stigma, mental health, and social support.
A constellation of symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion and participation, uncertainty and altered conceptualizations of time as experienced by an individual.
KEY DEFINITIONS:

REHABILITATION

Any service or provider that addresses or prevents impairments, activity limitations or participation restrictions experienced by an individual.

(Worthington et al, 2005)
A VERY BRIEF HISTORY

Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) is formed out of a meeting in London, UK to develop an international collaborative agenda to address the research priorities in HIV and rehabilitation. CUHRRC members include over 40 PHAs, researchers, clinicians, community organizations and policy stakeholders.

Canadian Working Group on HIV and Rehabilitation (CWGHR) conducts scoping study to identify research priorities in HIV and rehabilitation. (O’Brien et al, 2010)

1st International Forum on HIV and Rehabilitation Research (Toronto, Canada)
• 100+ participants
• 2 days
• 2 plenary sessions
• 6 research evidence panel sessions

A need is identified to translate current since the establishment of CUHRRC and revisit the priorities to integrate emerging issues in the field.

CIHR Funds the Forum.
2013 HIV REHAB FORUM GOALS

Identify new and emerging research priorities in the field

Translate research evidence on HIV and rehabilitation
92 PARTICIPANTS

FROM CANADA, THE UNITED KINGDOM, IRELAND AND THE USA
Research priorities, comments, and activities were documented before, during and after the event through:

(1) speaker and participant key messages
(2) rapporteuring online and on-the-spot
(3) reflective comments posted on open electronic board
(4) program evaluation forms

Information was analyzed and refined iteratively by independent reviewers and the core Forum team.
FRAMEWORK OF RESEARCH PRIORITIES

Priorities 1-3
Understanding the episodic; aging across lifespan; concurrent health conditions

Priorities 4-5
Describing rehab models and interventions, access, and effectiveness

Priority 6
Measuring outcomes, translating evidence to policy and practice. Using mixed methods, applying interdisciplinary sectoral/sectional lens.
RESEARCH PRIORITY 1
UNDERSTANDING EPISODIC DISABILITY

- Physical, cognitive, mental health
  *fluctuate daily and over time*

- Social
  *diminished labour force participation, increasing social exclusion*

- Conceptual and symbolic aspects
  *the uncertainty about the occurrence of episodes of wellness and illness, the inordinate anxiety about the future and aging, and the altered perceptions of ‘time’ (eg. to plan ahead)*
What is healthy aging with HIV across lifespan?

- What do resiliency, sexual health, self-efficacy look like?
- What do social participation, exclusion, and isolation look like?
- What is the cumulative impact of uncertainty and other cognitive and symbolic aspects of HIV over time?
RESEARCH PRIORITY 3
HAVING A COMPREHENSIVE UNDERSTANDING OF CONCURRENT HEALTH CONDITIONS

Mental Health
- Depression, anxiety, trauma, addictions

AIDS associated neurocognitive disorders (HAND)

Multi-morbidities and increasing complexity of disability
- Cardiovascular disease
- Diabetes
- Bone and joint disorders
- Frailty
- Hepatitis C
- Addictions
To investigate **facilitators and barriers to accessing rehabilitation** when navigating increasingly complex and fragmented health and social support systems in a climate of funding restraints.

To develop and evaluate **innovative and patient-oriented interventions and models of rehabilitation** that are cost-effective and sustainable.
To promote intervention research on:

- Exercise, smoking cessation, others
- Neurocognition and mental health
- Self-management strategies and adherence to cART
- Labour force participation (e.g., vocational rehabilitation)
RESEARCH PRIORITY 6
MEASURING OUTCOMES IN HIV REHAB

- To select culturally appropriate, sensitive and valid measures for diverse populations
- To examine screening tools for HAND
- To measure the “episodic” nature of HIV disability
- To use international, shared and validated measures
- To develop of patient-centred outcomes
METHODOLOGICAL CONSIDERATIONS TO IMPLEMENT RESEARCH PRIORITIES

Employ mixed **qualitative and quantitative** approaches

Engage **harder-to-reach or marginalized** populations

Promote **interdisciplinarity and inter-sectorality**

Adopt a cross-disability (**episodic illness**) approach

Integrate **complexity of comorbidity**

Apply an **international perspective**
CONTEXTUAL FACTORS TO KEEP IN MIND

Full demographics that reflect ethnic, social and sexual diversity

Environmental Factors
- Geographical

Socio-cultural aspects
- Stigma, social determinants of health

Systemic and institutional
- Legal, policy, social justice issues
- Housing and food security
- Poverty and social class
Need for research to be driven by the community, clinical practice and ensure evidence is translated into programs and policy

Developing evidence-informed recommendations

Using social media as a means for knowledge translation
The Framework of New Research Priorities in HIV, Disability and Rehabilitation may be used by researchers, clinicians, people living with HIV and the broader HIV community to outline a future plan for HIV, disability and rehabilitation research that will help increase our knowledge to enhance practice, programming and policy for people living with HIV.
Inter-sectoral, inter-disciplinary, and inter-sectional meetings promote patient centered, complex, intervention research.

Organizing a Forum is challenging and it builds academic and community mobilization capacity in a team.

Working across countries enhances regional and geopolitical understanding (seeing opportunities and challenges) within and across regions, clinical and social welfare systems, academic research environments, etc.
Forum Report

Knowledge Translation and Exchange (KTE) Library
Video recordings, speaker slides, rapporteur summaries

CUHRRC Website
http://cuhrrc.hivandrehab.ca/index.php
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