



**The Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) presents:
A Rapporteur Summary of the HIV and Rehabilitation Content presented at the 23rd Annual Canadian Conference on HIV/AIDS Research (CAHR 2014)**

Introduction on HIV and Rehabilitation

With more people living longer since diagnosis, HIV is now considered a chronic illness in developed countries such as Canada, Ireland, United States of America (USA) and the United Kingdom (UK). Many people with HIV are now aging with the health challenges of HIV, comorbidities and the side effects of treatment. Individuals may experience a range of health-related challenges known as disability, including symptoms and impairments (e.g. fatigue, weakness, pain), difficulties with day-to-day activities (e.g. household chores), challenges to social inclusion (e.g. ability to work) and uncertainty or worrying about future health as they age.

Rehabilitation is broadly defined as any service or health provider that may address or prevent impairments, activity limitations or social participation restrictions experienced by an individual. The role for rehabilitation is increasing in the context of HIV, comorbidities and aging and has the potential to improve health and quality of life outcomes for people living with HIV. As a result, the field of HIV and rehabilitation research is evolving to meet the current needs of people living with HIV in countries such as Canada, the UK, Ireland and USA where people may experience similar health-related challenges.

The Canadian Working Group on HIV and Rehabilitation (CWGHR)

www.hivandrehab.ca

The CWGHR is a national, multi-sectoral organization whose aim is to improve the lives of people living with HIV by advancing HIV rehabilitation, care, treatment and support. CWGHR works to bridge the traditionally separate worlds of HIV, disability and rehabilitation to promote quality of life through rehabilitation research, education and cross-sector partnerships.

Canada-United Kingdom HIV and Rehabilitation Research Collaborative (CUHRRC)

www.cuhrrc.hivandrehab.ca

CUHRRC is an international research collaborative comprised of researchers, clinicians, representatives from AIDS service organizations, policy stakeholders and people living with HIV from Canada, the UK, Ireland and USA. The aim of the collaborative is to build on the enthusiasm of individual members to facilitate the advancement of research ideas and activities related to HIV and rehabilitation research. CUHRRC believes that forming partnerships and exchanging knowledge is integral to building a synergy between the established clinical rehabilitation HIV knowledge in the UK and the strong HIV research foundation in Canada. In 2013, CUHRRC and CAHR announced a formal partnership. The aim of this partnership is to increase the awareness and translation of HIV and rehabilitation research among the HIV community.

International Forum on HIV and Rehabilitation Research

<http://www.hivandrehab.ca/EN/AGM2013/index.php>

In June 2013, CUHRRC in collaboration with CWGHR held the first ever *International Forum on HIV and Rehabilitation Research* in Toronto. The aim of the Forum was to identify new and emerging research priorities in HIV, disability and rehabilitation from the perspective of people living with HIV, clinicians, researchers and representatives from community organizations.

The **Framework of New Research Priorities in HIV, Disability and Rehabilitation** developed from the Forum and presented at CAHR 2014, reflects the increasing complexities of HIV associated comorbidities as well as the changing health system environment that influences rehabilitation care delivery. This *Framework* may be used by researchers, clinicians, people living with HIV, and the broader HIV community, as a foundation to inform future HIV, disability, and rehabilitation research.

Purpose of the Rapporteur Summary on HIV and Rehabilitation at CAHR 2014

This purpose of the rapporteur summary is to report on the HIV and rehabilitation content presented at the 23rd Annual Canadian Conference on HIV Research (CAHR 2014) in order to increase awareness of research in the field.

The rapporteur summary is broadly classified according to the six research priorities in the **Framework of New Research Priorities in HIV, Disability and Rehabilitation**: 1) episodic health and disability; 2) aging with HIV across the lifespan; 3) concurrent health conditions; 4) access to rehabilitation and models of rehabilitation service provision; 5) effectiveness of rehabilitation interventions; and 6) enhancing outcome measurement in HIV and rehabilitation research. The priorities are in no particular order of importance. Specific abstracts are referenced throughout, with a reference list available at the end of the summary.

Research Priority 1 - Episodic Health and Disability

Understanding the broad range of physical, cognitive, and mental health challenges, social participation restrictions, and uncertainty about the future experienced as a result of HIV, comorbidities and aging, and how these health challenges (or disability) may be episodic in nature.

- At the CAHR 2014 conference opening lecture, the Mark Wainberg Lecture 2014 recipient Richard Elliot (Executive Director, Canadian HIV/AIDS Legal Network) highlighted the importance of continued collaboration between HIV researchers and human rights activists to help inform policy around HIV and criminalization. The criminalization of HIV non-disclosure strips people living with HIV of their right to privacy and puts them at risk of life in prison, affecting their level of social participation and utilization of services due to HIV associated stigma reinforced by the law. The criminalization of HIV also drives people unaware of their status away from HIV testing, counselling and support, and partner notification. Symington et al. (2014) conducted a cross-sectional electronic survey with 204 people living with HIV to assist in creating legal information tools about privacy rights and HIV disclosure obligations in the context of employment, education, childcare and health care. From the survey responses, the Canadian HIV/AIDS Legal Network created and distributed legal resources along with hosting community educational sessions across Canada. As the legal needs of people living with HIV vary, increased access to legal information empowers people living with HIV with the practical tools they need to protect themselves (Symington et al., 2014).
- Adam and colleagues (2014) drew from 30 qualitative interviews with employed and unemployed people living with HIV in Ontario to examine the decision to stay with or return to work. Part of the Employment Change and Health Outcomes in HIV and AIDS (ECHO) study, results suggested remaining or returning to the workforce denotes control of one's self, and the desire for a better standard of living, when compared to the restrictions of being on a provincial disability financial assistance program. However, out of pocket prescription expenses, reduced access to subsidized treatment, provision of time off for illness (disclosure at work), and being able to afford stable housing are concerns associated with remaining or returning to the workforce for people living with HIV.

Disability in the context of HIV can be experienced in different aspects of life. Abstracts presented at CAHR 2014 addressing the decision to remain or return to work, and access to legal information illustrated how certain environmental and societal factors may influence the episodic nature of disability experienced by people living with HIV.

Research Priority 2 - Aging with HIV across the Lifespan

Exploring factors that contribute to healthy aging with HIV.

- Older adults living with HIV are more likely to adhere to treatment, remain in care, and exhibit resilience due to their longitudinal experience of living with HIV. However, older adults living with HIV face challenges including, but not limited to multiple comorbidities, loss of social support, isolation, and uncertainty about the future. The older HIV community possesses diversity in gender, ethnicity, sexual orientation, and time since diagnosis, and there is a need to increase programs and services specific for older adults with HIV in order to maintain or improve their health quality of life (Emlet et al. 2014; Betteridge et al. 2014)
- Due to premature onset of comorbidities such as cardiovascular disease, diabetes, bone and joint disorders and non-AIDS defining cancers, people living with HIV are aging at accelerated rates. Accelerated aging is leading some older adults living with HIV to seek care earlier from long term care facilities and community-based support from all types of organizations serving older adults. There appears to be a gap in knowledge about HIV for those working in the aging sector. At a 2014 CAHR ancillary event on HIV and Aging, Kate Murzin presented on a Canadian Working Group on HIV and Rehabilitation (CWGHR) led an intervention entitled *Working Together: HIV and Aging*. The *Working Together: HIV and Aging* intervention was delivered as a four-day, in-person intersectoral training for service providers in the Greater Toronto Area, with the purpose to increase knowledge on the concept of aging in the context of HIV. With assistance from the Center on HIV & Aging at the AIDS Community Research Initiative of America (ACRIA), CWGHR provided references to online resources on HIV and the aging population, overall health (physical, mental, cognitive and sexual), information

on services from long-term care/aging sector and AIDS service/community-based organizations, and HIV-related stigma that service providers could use in their day to day work with older adults living with and vulnerable to HIV. At the same event, Maureen Mahan (Education Development Coordinator, Casey House) presented on a collaborative project between Casey House Hospice and Re kai Long-term Care Centres. The purpose of this project was to develop an accessible and inclusive knowledge sharing and capacity building tool to offer education on HIV/AIDS expertise and clinical experience to long term care staff. The developed tool is a series of videos entitled *Compassionate Care in a Changing Landscape* where staff share personal and professional experience narratives from care providers at the frontline of care and people living with HIV. Medical and clinical staff specialized in the care of people living with HIV also share knowledge on HIV and transmission, expertise and clinical recommendations for care. The outcome from this tool is to encourage an environment of inclusion and reduce stigma for older adults living with HIV entering long term care facilities, and inform long term care staff about the basic skills to care for older people living with HIV. *For inquiries about the video series, please email: HIVandTCVideoSeries@caseyhouse.on.ca*

- Educating health and gerontology service providers, newcomers (students) of the health and community care system and long term care staff on HIV, treatment and support will help to ensure the needs of people living with HIV are better met, in addition to the reduction of fear and HIV associated stigma.
- A gap in knowledge about HIV and aging also exists among people working in the HIV community service sector. Furlotte et al. (2014) conducted a community-guided environmental scan through a bilingual online survey to provide a national snapshot of what key health and community organizations are doing to address the issue of HIV and aging. Ninety-two (92) contacts from AIDS Service Organizations, HIV clinics and community health centres participated in the environmental scan, answering questions about impact and prioritization of HIV and aging within their organizations and communities, and available referrals. Over time, programming has changed to emphasize aging with HIV and complex comorbidities, referrals to health, psychosocial and practical supports, and community collaborations including the aging sector. Organizations in the HIV sector are at different stages of gathering information, planning and implementing HIV and aging programs. Very few HIV and aging programs exist because participating HIV organizations cited existing programs and services already meet the needs of older adults living with HIV, scarce resources and unpreparedness due to recent nature of HIV and aging. There is a need for HIV organizations to evaluate their existing programs to determine if they truly meet the specific needs of people aging with HIV.

Health and social service providers have an important role to play in supporting older adults living with HIV in healthy aging with HIV.

Research Priority 3 – Concurrent Health Conditions

Examining the health-related consequences of concurrent health conditions and multiple morbidities experienced by people with HIV. Understanding the complexity of disability experienced based on the number and type of conditions may help to inform ways to prevent or mitigate disability associated with HIV and concurrent conditions across the lifespan.

- As people living with HIV are living longer after infection, more individuals are living with the physical, social and psychological consequences of the disease, long-term treatment and comorbidities associated with aging. Research on mental health issues, adverse effects to HIV and comorbidity treatments, and smoking related respiratory illness were some of the concurrent health conditions presented at CAHR 2014.
- Depression and anxiety are two mental health conditions highly reported among people living with HIV. Benoit et al. (2014) conducted a cross-sectional quantitative study to determine the relationship between mental health concerns and HIV status for Aboriginal women. Twenty-six (26) HIV-positive Aboriginal women completed questionnaires measuring socio-demographic characteristics, stress, depression, post-traumatic stress disorder (PTSD), wellbeing and social support. Approximately 80% of participants reported living with mental health issues, 70% reported severe depressive symptoms, and 83% reported severe levels of PTSD. Mental health issues are often associated with poor health and quality of life, and adverse treatment outcomes. The association between acute care utilization and co-morbid depression was assessed with participants in the Ontario HIV Treatment Network Cohort Study (OCS). Twenty-seven percent (27%) of

participants were identified with comorbid depression. Higher rates of mental health issues were more present among younger people living with HIV, women living with HIV (particularly women of ethnic or minority heritage), recreational drug users, and individuals experiencing HIV-related stigma (Choi et al. 2014). In the five years of the study, participants with depression were 1.7 times more likely to use urgent emergency room services, 1.4 times more likely to use non-urgent emergency room services and 1.6 times more likely to be hospitalized when compared to their non-depressed counterparts. Untreated Mental health issues may lead to unstructured treatment interruptions and other risky behaviours (Choi et al. 2014).

- Increased number of concurrent health conditions, can increase prescribed medications in addition to HIV, which can lead to drug toxicities. The effects of drug toxicity from prescribed medications may contribute to the development of comorbidities observed in people living with HIV (Costiniuk et al. 2014). Tuberculosis drug-induced liver injury (TB-DILI) is the most common adverse event leading to therapy interruption. The management of TB-DILI in an area of high HIV prevalence was described using hospital records from King Edward VIII Hospital Infectious Disease clinic, in Durban South Africa. Fifty-one (51) individuals with TB-DILI (including 45 HIV co-infected) were identified, and 80% were re-administered TB treatment medication at full dose. Twenty-seven percent (27%) of individuals who were re-administered TB treatment medication at full dose experienced re-current TB-DILI, exhibiting signs of jaundice. Re-administering TB treatment medication at full dose may be associated with a greater risk of recurrent TB-DILI, thus further study is needed to determine a strategy to re-administer TB treatment medication to HIV co-infected individuals (Costiniuk et al. 2014).
- Smoking is associated with impaired immune response and increased risk to respiratory disease. Rollet-Kurhajec et al. (2014) evaluated the impact of smoking tobacco and other drugs on respiratory outcomes using a Canadian multicenter prospective cohort of HIV/HCV co-infected patients. Primary respiratory outcomes such as first episode of pneumonia, upper respiratory tract infection and respiratory symptoms were based on patient self-reported reasons for using a walk-in clinic or emergency room, and having an overnight hospital stay. At baseline, of 1151 patients in the cohort, 52% reported smoking marijuana, 22% drugs other than marijuana and 76% cigarettes (median duration of cigarette smoking 30 years); 7% reported at least one episode of pneumonia, 4% upper respiratory tract infection, and 11% respiratory symptoms. Development of pneumonia is associated with aging and impaired immunity, and smoking drugs other than marijuana and cigarettes is associated with developing upper respiratory tract infections and respiratory symptoms. Efforts to reduce both tobacco and other drug use are essential to reducing the high rate of self-reported respiratory illness among HIV/HCV co-infected patients (Rollet-Kurhajec et al. 2014).

Examining and understanding the health related consequences of concurrent conditions across the life span of people living with HIV may help develop methods to identify the role for rehabilitation and prevent or mitigate disabilities associated with HIV and concurrent conditions.

Research Priority 4 - Access to Rehabilitation and Models of Service Provision

Rehabilitation is broadly defined as any service or health provider that may address health challenges experienced by an individual due to HIV or other related concurrent conditions. This priority includes facilitators and barriers to accessing broad health and social services for people living with HIV as well as the development and evaluation of innovative models of health service delivery to better address the health-related needs of people living with HIV.

- With HIV shifting from a terminal illness to a chronic disease, people living with HIV require comprehensive care across longer life spans. It is important for service providers to adapt to HIV as a complex chronic condition requiring increased access to nontraditional HIV care, and co-management and integration across health care and community service providers (Johnston et al. 2014).
- Stigma in the health care setting is a barrier to accessing care for people living with HIV (Gagnon, 2014). Gagnon (2014) conducted 21 semi-structured in-depth interviews to examine symbolic and structural stigma experienced by people living with HIV in the health care setting. Three types of stigma experienced included: 1) *Episodic Stigma*: varies depending on type of service accessed and/or enlightenment of health care provider; 2) *Symbolic Stigma*: discrimination is usually experienced when a patient is automatically categorized to a set of undesirable characteristics such as injection drug user or sex-worker; 3) *Structural Stigma*: based on the assumption that the patient poses an immediate threat to the health of the staff. Stigma in the health care

setting regardless of the type can lead to unauthorized disclosure, where every staff member is informed about the patient's HIV status, and also can lead to rescheduling or cancellation of appointments by health care workers (Gagnon, 2014).

- Limited access to care is another barrier to the utilization of available services. Across Canada an estimated 70% of people living with HIV are represented by homosexual men and injection drug users. People living with HIV who do not identify as either homosexual male and/or injection drug user may feel available services are not catered to meet their needs. Utilizing services can become difficult when people with HIV feel they do not fit the profile of the catchment population and when services are not easily accessible or convenient. For example, women represent 25% of all people living with HIV across Canada, but yet Carter et al. (2014) reported they feel they have to navigate place and social spaces in an attempt to access care. Using a community-based and critical feminist approach, four focus groups were conducted with 28 women living with HIV to explore how women negotiate place and space in attempting to access care in British Columbia, Canada. Women living in rural communities often have to travel long distances in order to access women specific HIV care. At locations where women specific HIV care is not available, women feel they have to transform their needs to match the services available at the organizations. The participants of this study said they employ strategies of their own such as developing peer support groups and virtual communities to resist being socially marginalized by limited services (Carter et al. 2014).
- People who identify as Aboriginal represent 9% of people living with HIV across Canada. Aboriginal people living with HIV are not a homogenous population, and may live on reservation, rural or remote communities. Programs to engage Aboriginal people living with HIV provided by the Canadian Aboriginal AIDS Network and regional Aboriginal and/or non-Aboriginal AIDS Services Organizations are limited to Southern Canada (McLeod et al. 2014).

Available care does not mean accessible care. Removing barriers that limit access to rehabilitation and models of service provision will help to improve the quality of life for people living with HIV.

Research Priority 5 - Effectiveness of Rehabilitation Interventions

Evaluating the effectiveness of rehabilitation interventions in order to prevent or mitigate disability experienced by people living with HIV.

- Evaluated programs and services presented at CAHR 2014 included the Canadian AIDS Treatment Information Exchange (CATIE) information exchange tool (www.catie.ca), transition from pediatric care to adult clinic programs, a Canadian youth living with HIV camp, and Posit Science's Brain Fitness Intervention.
- CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C, connecting people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life. CATIE evaluated their main knowledge exchange tool www.catie.ca with an online survey posted on their website. Survey respondents reported increased knowledge of HIV and hepatitis C due to information accessed on the website, used the information to impact programming, and found the website was useful in providing information that helps organizations plan and deliver programming (Challacombe et al. 2014).
- An increased number of perinatal- infected youth are transitioning from pediatric care to adult clinics, and the transition process is an important part of this cohort's care (Brophy et al. 2014). In April 2013, HIV care providers from across the Canada, national and international experts on transition and adolescent HIV cohort research and HIV-infected youth who recently transitioned from pediatric to adult care were brought together to discuss transition and identify priorities to advance a Canadian research agenda (Brophy et al. 2014). An evaluation of the transition process resulted in the need for operational definitions of transition success, with a common approach to transition preparation, and shared tools for specific activities among organizations providing this service. Adult care transition programs should be prepared to adequately deal with challenges such as antiretroviral resistance and non-adherence, engagement in care, and mental health issues associated with transitioned youth living with HIV. It is important for transition programs to focus on developmental readiness, health literacy, acceptance of diagnosis, family support, communication between providers, and post-transition interventions (Brophy et al. 2014).

- Organized by the Western Canadian Pacific AIDS Society, Camp Moomba is a free 1 week summer camp in British Columbia for 100 youth living with or impacted by HIV ages 6-17 from across Canada. The purpose of this study by Alimenti et al (2014) was to demonstrate the impact of Camp Moomba on the youth's well-being by analyzing testimonials collected from campers, parents, counselors, camp staff and health care providers. Camp Moomba offers a unique opportunity for youth living with or impacted by HIV to make friends and have fun while building resilience in an environment free of stigma. Youth living with HIV who met at Camp Moomba tended to stay connected and provide support for each other year round through social media and texting. Participating in this camp contributes to the well-being of youth living with or impacted by HIV, and it empowers them as they become young adults. The success of Camp Moomba led the Western Canadian Pacific AIDS Society to continue to offer the camp experience, and expand off camp programs in the future.
- The effect of HIV on the brain can lead to cognitive problems such as HIV-associated neurocognitive disorder (HAND), and milder problems such as trouble focusing and remembering. With the use of anti-retroviral therapy the rate of neurocognitive problems have significantly reduced, but as people living with HIV live longer, milder forms of neurocognitive problems are now more prevalent. Brain Fitness is an exercise intervention that can help improve memory, attention, brain speed, people skills, intelligence and navigation skills to reduce cognitive slowing and difficulties performing everyday activities. The Brain Fitness intervention was piloted with 15 men living with HIV with no history of mental illness other than depression and no current significant substance use (Rourke et al. 2014). Each participant completed a neuropsychological battery that included measures of attention and working memory, psychomotor efficiency, learning and memory, and executive functioning before and after 10 weeks of on-line auditory brain fitness exercises. Overall, there was an 87% reduction in total neurocognitive symptoms and 83% improvement in well-being following the Brain Fitness intervention. Results support the need for the implementation and evaluation of a randomized controlled trial to determine the effectiveness of brain fitness exercises to prevent and reverse neurocognitive impairments in HIV (Rourke et al. 2014).

Evaluating services and programs will help to determine their effectiveness in preventing or mitigating disability experienced by people living with HIV.

Research Priority 6 - Enhancing Outcome Measurement in HIV Rehabilitation Clinical Practice and Research

Enhancing the use and development of patient centered outcomes in HIV, disability and rehabilitation research. This can help to facilitate communication among clinicians and evaluate the effectiveness of various interventions.

- As people are living longer with HIV, they are at risk of developing comorbidities such as neurocognitive impairments, frailty, and mental health issues such as depression. Developing and enhancing the use of patient centered outcome measurements can evaluate the effectiveness of various interventions and help facilitate communication among clinicians. At CAHR 2014 authors presented on the evaluation of pre-existing patient centered outcomes measurements (Berger's HIV Stigma Scale and the Center for Epidemiological Studies Depression Scale (CES-D)) and the development of new patient centered outcome measurements (HIV Disability Questionnaire (HDQ), and Health Care Provider HIV/AIDS Stigma Scale).
- Validated HIV stigma scales are needed to assess levels of stigma and evaluate interventions in order to reduce HIV related stigma. A revised 10-item Berger's HIV Stigma Scale was assessed for construct validity among 249 people living with HIV in Colombia (n=103) and Canada (n=146) (Montano et al. 2014). High levels of HIV related stigma, particularly with disclosure and public attitude stigma were found among people living with HIV in both countries. The revised 10-item stigma scale was found to possess construct validity with people living with HIV in Colombia and Canada; thus it can be used to assess stigma in both geographical settings, and implement and evaluate anti-stigma interventions among people living with HIV (Montano et al 2014).
- The lack of validated depression screening scales in Colombia could explain why depressive symptoms are not routinely assessed in clinical practice (Mueses et al. 2014). Mueses et al (2014) tested the reliability and construct validity of the CES-D by administering it at 3 occasions to 104 people living with HIV attending the Corporacion de Lucha Contra el Sida clinic in Cali, Colombia. Based on the results, the authors concluded the

CES-D to be a valid and reliable instrument to screen for depressive symptoms for people living with HIV in Colombia (Mueses et al. 2014).

- The HIV Disability Questionnaire (HDQ) is a 69-item self-administered questionnaire developed to measure disability experienced by adults living with HIV (O'Brien et al. 2014). The HDQ measures disability experienced from health symptoms (physical, cognitive and mental-emotional), difficulties with day-to-day activities, uncertainty about the future and difficulties participating in society. The authors assessed internal consistency reliability and construct validity with 235 adults living with HIV in Canada (n=139) and Ireland (n=96). Internal consistency coefficients for both Irish and Canadian participants were greater than 0.90*, and of the 40 construct validity hypotheses, 32 (80%) and 22 (55%) were confirmed by the Canadian and Irish participants respectively. Results suggest the HDQ demonstrates internal consistency reliability and construct validity when administered to adults living with HIV in Canada and Ireland.
- HIV- related stigma is a pressing concern among people living with HIV, because it is associated with minimal or zero utilization of care and services, low levels of adherence, and increased risk of comorbidities such as depression. The Health Care Provider HIV/AIDS Stigma Scale (HPASS) is a 30-item tool developed to assess HIV stigma in health care providers. The HPASS measures stigma expressed in three subscales: prejudice, stereotyping and discrimination. Initial validation of the HPASS was assessed with 224 medical and nursing students across Canada. The HPASS demonstrated excellent internal consistency (Cronbach alpha= 0.94*), and strong test-retest reliability (correlation coefficient =0.93~), and convergent and divergent validity, indicating it can be used to assess HIV stigma, and inform training, intervention, and self-evaluation of stigmatizing attitudes, beliefs, and behaviours among health care providers.

**Cronbach alpha is considered acceptable if coefficient is greater than or equal to 0.70.*

~Test-retest reliability is performed when you want to measure if a construct will change over time. Correlation coefficient is good if greater than or equal to 0.70

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For more information about CUHRRRC (www.cuhrrc.hivandrehab.ca) or contact Nkem Iku, CUHRRRC Coordinator (nkem.iku@utoronto.ca).

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