

The Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) presents:

A Rapporteur Summary of the HIV and Rehabilitation Content presented at the 24th Annual Canadian Conference on HIV/AIDS Research (CAHR 2015)

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 over time living with HIV.

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) 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 Forums on HIV and Rehabilitation Research (2013 & 2014)

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. Please visit the <u>2013 Forum on HIV and Rehabilitation and CWGHR Annual General Meeting (AGM) Knowledge Transfer and Exchange (KTE) Library and view the <u>Forum Report</u> for more information.</u>

In October 2014, CUHRRC in collaboration with the Rehabilitation in HIV Association (RHIVA) held the 2nd International Forum on HIV and Rehabilitation Research in London, England. The goal of the Forum was to facilitate knowledge transfer and exchange (KTE) on HIV and rehabilitation research, clinical practice and service delivery, among people living with HIV, researchers, clinicians on HIV, representatives of community organizations, and policy makers in Canada, UK and Ireland; and to foster new research and clinical partnerships in HIV and rehabilitation internationally.

The evidence presented at the Forum highlighted: 1) a need for further research in HIV, disability and rehabilitation as people live longer and age with HIV and multi-morbidity; 2) a need for research evidence to inform policy and programming; 3) an increase in collaborative approaches to research and practice; and 4) that the need for rehabilitation in the context of HIV continues to increase in demand and complexity as people age with HIV and concurrent health conditions (e.g. mental health conditions, cardiovascular disease). Please visit the 2nd International Forum on HIV and Rehabilitation Research Knowledge Transfer and Exchange (KTE) Library and view the Forum Report and Summary of Evidence for more information and a summary of the research evidence presented.

Purpose of this Rapporteur Summary on HIV and Rehabilitation at CAHR 2015

This purpose of this rapporteur summary is to report on the HIV and rehabilitation content presented at the 24th Annual Canadian Conference on HIV Research (CAHR 2015) 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.

- For people living with HIV/AIDS (PHAs) who face instability related to the **social determinants of health**, time in hospital can serve as an escape from unstable housing, substance use, stigma, poverty and lack of social support (Brennan et al., 2015). Following discharge from a hospital setting, the transition back into the community can be of high stress to PHAs. Brennan and colleagues conducted interviews with nine participants discharged from in-patient care at Casey House across four time points to examine the hospital discharge transition period. Prior to discharge, the client and care team created a discharge plan which listed HIV-related health as a priority. Investigators found that upon discharge, participants returned to their unstable living situation which promoted the health outcomes that led to the recent hospitalization. The unstable and complex social and structural environments that PHAs face need to be taken into consideration during hospital admission and discharge.
- A paucity of evidence exists on the **predictors of neurocognitive decline** in individuals with good virological control (Yuen et al., 2015). To identify factors predicting neurocognitive decline in aviremic PHAs, Yuen and colleagues assessed 191 participants in the <u>CNS HIV Anti-Retroviral Therapy Effects Research (CHARTER) Study</u> with 15 neuropsychological tests every 6 months for 3 years. Among this group, 23 (12%) experienced neurocognitive decline during this period. Predictors of decline include low eGFR (predictor of vascular disease), low education and prolonged duration of HIV infection. Researchers found that neurocognitive decline was uncommon in this group and that programs targeting cardiovascular risk factors could be a useful strategy to minimize neurocognitive decline.
- People living with HIV may face poorer brain health compared with those not living with HIV due to effects of HIV or its' treatment on the brain, stress levels, coping skills, physical health and social support (Mayo et al., 2015). The Brain Health Now project is a multiple randomized controlled study using a cohort of 900 PHAs to understand brain health. Prior to implementing the interventions on cognitive training, exercise, self-management and treatments for insomnia and depression, researchers analyzed data from a subset of 123 participants. Researchers found that 50% of participants were at risk for clinical depression, 36% had low cognitive abilities, 30% were eligible for the insomnia intervention, 22% were sedentary and therefore eligible for an exercise intervention and 40% expressed some degree of dissatisfaction with life. This approach of combining interventions with an observational approach is unique and may be a novel way of gaining knowledge about people living with complex chronic disease.
- The concept of "episodic disability" (developed to describe the experience of PHAs in the era of combination antiretroviral therapy (cART)) contributed to employment and health care policies and practices in Canada for PHAs. However, the term has not been explored or defined in Sub-Saharan Africa (Nixon et al., 2015) despite increased access to cART. Nixon and colleagues conducted interviews with 35 PHAs at two time points to describe experiences of episodic disability in Zambia. Although participants did not identify their health-related experiences as episodic, they described fluctuations in their participation restrictions, activity limitations and impairments between the two interviews. Participants described four types of changes in disability: improvements, complete resolution, worsening and new onset. Policies, services and programs in Sub-Saharan Africa need to focus on episodic health and the issues people face when living longer with HIV.
- Individuals aging with HIV may experience cognitive impairments in speed of processing, attention and memory (Nam et al., 2015). Previous work by Nam and colleagues showed that participants' complaints about cognitive impairments may be overestimated relative to actual neurocognitive deficits in the presence of depression. Nam and colleagues completed a neuropsychological evaluation with 141 male participants from an HIV Associated Neurocognitive Disorders (HAND) study at St. Michael's Hospital (Toronto, Canada) to examine the relationship between neurocognitive health and depression. Researchers found that higher neuropsychological impairment and neuroticism significantly predicted higher cognitive complaints and that higher extraversion was negatively associated with complaints. Inclusion of depression diminished the effect size of both of these models making them insignificant. The presence of depression seems to be a strong

- predictor of cognitive complaints. This model needs to be examined further and may be included in future studies regarding cognitive complaints in HIV and HAND.
- Community organizations are employing more Peer Research Associates (PRAs) however, there are few published models of how to employ and work with PRAs (Baltzer Turje et al., 2015). Baltzer Turje and colleagues documented the Dr. Peter Centre's (DPC) (Vancouver, Canada) process of recruiting, hiring, training and mentoring two PRAs for a research project. An independent PRA was hired to interview the two PRAs and other key stakeholders. After completing a series of interviews with PRAs, DPC staff, external researchers, members of the Community Advisory Committee, and investigators developed six **Prezi Learning Modules** and disseminated them to Canadian community-based organizations, researchers and policy makers to help guide community based organizations that wish to work with PRAs. The Learning Modules were well received and had several advantages including: easy web-based dissemination, audio recordings for slides and the ability to cover multiple topics. Unique and relevant knowledge translation strategies are needed to effectively communicate new models that can improve the services provided and functioning of community organizations.
- Hepatitis C Virus (HCV) is both a risk factor for and comorbidity associated with HIV (Puskas et al., 2015). Individuals with HIV/HCV face health risks such as end-stage liver disease and mortality. Using data from the Longitudinal Investigations into Supportive and Ancillary Health Services (LISA) study, researchers analyzed sociodemographic and clinical characteristics of 912 individuals to examine differences between HIV/HCV coinfected and HIV mono-infected individuals as well as ART adherence. Of 912 individuals, 536 (59%) had both HIV and HCV. Co-infected individuals were more likely to have a history of IDU, incarceration and less likely to be optimally ART adherent (95% pharmacy refill compliance). Optimal ART adherence among those who had both HIV and HCV was associated with stable housing and accessing an adherence support program. Treatment facilities may look into integrating social services into their programs.
- Women living with HIV (WLHIV) experience depression (more than men) and stressors which may interfere with adherence to ART (Benoit et al., 2015). To examine the relationship between stress, depression and adherence in WLHIV, Benoit and colleagues conducted a cross-sectional study with 307 women from the Ontario HIV Treatment Network (OHTN) Cohort Study (OCS) using questionnaires and clinical charts. Of the participants, 66% had adequate adherence. No hazardous alcohol use and fewer stress events increased the likelihood of adequate adherence. The relationship between environmental stress and adherence was stronger in women aged ≥45 compared to those ≤35. Authors concluded that interventions focused on reducing stress and alcohol use may prove to increase adherence to ART among WLHIV.
- Limited qualitative evidence exists on how people with HAND experience cognitive impairment (Ibáñez-Carrasco et al., 2015). Heads Up! investigated the lived experience of HAND using participatory ethnographic methods. Ibáñez-Carrasco and colleagues recorded the steps taken to build an interdisciplinary team and implement a community-based research (CBR) strategy which included: reading the HAND and qualitative methods literature, designing an interview schedule, recruiting and training of PRAs, including clinical screening for HAND and a knowledge translation and exchange (KTE) strategy. Reading the literature greatly impacted the collaborative creation of the steps mentioned. These CBR steps outline how to effectively engage communities in studies and may be helpful to other teams looking to implement CBR strategies.
- The Episodic Caregiver Support Initiative aims to explore the needs and ideal model of support for caregivers of PHAs and other episodic disabilities in Ontario (Yates et al., 2015). To examine this, Yates (Canadian Working Group on HIV and Rehabilitation) and colleagues conducted a literature review, a survey with caregivers and people with episodic disabilities, an environmental scan and focus groups. Investigators highlighted the following categories that emerged from the results: unique aspects of caregiving in an episodic disability context, impact of episodic disability on different care relationships, access to supports, and the ideal system. Yates and colleagues developed a model to describe how caregivers need to be supported in education/information, job security and flexibility, income adequacy and security, health services, emotional wellness, and social supports. Overall, social systems have an increased role in supporting caregivers for people with episodic disabilities.

Research Priority 2 - Aging with HIV across the Lifespan

Exploring factors that contribute to healthy aging with HIV.

- The HIV, Health and Rehabilitation Survey (HHRS) aims to describe disability, comorbidities and rehabilitation services use among adults living with HIV in Canada. In this presentation, O'Brien and colleagues compared the number and type of comorbidities among older (≥50 years of age) versus younger adults (<50 years of age) (O'Brien et al., 2015). Nine-hundred and forty-one adults completed a cross-sectional web-based online survey that described disability, contextual factors, and concurrent health conditions. The majority of participants were taking ART (90%) and living with ≥2 concurrent health conditions (72%). Older adults with HIV had a higher median number of concurrent health conditions compared to younger adults and had lower maladaptive coping and stigma scores. Compared with younger adults, a greater proportion of older adults reported living with: joint pain, muscle pain, elevated triglycerides, high blood pressure, high cholesterol, bone and joint disorders and cardiovascular disease. Future research will explore the relationship between extrinsic and intrinsic contextual factors and comorbidities among adults with HIV.
- Aging PHAs, in both home and institutional care settings in Ontario, are at risk of developing comorbidities which may pose issues in disease management (Foebel et al., 2015). To describe the sociodemographic, clinical and social attributes of PHAs in home and institutional care settings, Foebel and colleagues conducted a quantitative analysis using data from the interRAl home care and minimum data set instruments in Ontario. Out of 837,652 individuals, 1091 PHAs (4%) live in long-term care (LTC), complex continuing care (CCC) (33%), and home care settings (HC) (63%). PHAs were less likely to be married, had less comorbidities and physical impairments, and poorer self-rated health than other populations in the same care settings. PHAs also exhibited more social isolation and received more medications than other populations in the same care settings. These findings may help to develop strategies and programs to provide better care across settings for aging adults with HIV.
- MacTavish and colleagues documented physical and mental health experiences among adults aging with HIV in order to inform AIDS service organizations (ASOs) about the perceived needs of aging PHAs (MacTavish et al., 2015). Investigators conducted 22 interviews with PHAs who identified that physical challenges were unrelated to HIV and that their mental health challenges were common prior to HIV diagnosis and remained unchanged after diagnosis. In addition, depression, suicide ideation and isolation were commonly experienced and drug addiction negatively affected future expectations. Participants indicated that ASOs should address lifestyle changes, drug addiction treatment and social support. ASOs may address these issues in their programs as well as direct PHAs to programs available to the aging population to deal with non-HIV-related issues.
- Mahan and colleagues conducted a program evaluation in order to evaluate a capacity building video series that aims to prepare LTC homes for an aging population of PHAs (Mahan et al., 2015). Investigators randomly assigned four LTC homes to either receive the educational videos in hard and soft copy formats (control) or to receive facilitated video training sessions with a registered nurse and a PHA. From 147 evaluation forms, investigators found that 81% of LTC staff in the control group and 86% in the facilitating training group "somewhat to strongly agreed" that they had acquired new information. Overall, the videos were effective however there were no significant differences between the two groups. Organizations may explore various methods of disseminating information about caring for older adults 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.

Asymptomatic Neurocognitive Impairment (ANI) is associated with a 2-6 fold increased risk for the
development of symptomatic HIV Associated Neurocognitive Disorder (HAND) (Rourke et al., 2015). Rourke
and colleagues assessed the neurocognitive health among 575 participants in the Ontario HIV Treatment
Network Cohort Study (OCS) and found 299 (52%) tested normal on neuropsychological (NP) testing and 276
(48%) tested positive for ANI (Rourke et al., 2015). Investigators conducted NP tests annually to assess

cognitive functioning. Over the follow up period (34 months), 99 participants (17%) showed progression to symptomatic HAND (60 of which had ANI at baseline). Participants who showed progression to HAND had higher rates of smoking, non-medicinal drug use, depressive symptoms and cardiovascular disease. Participants with ANI at baseline had an overall shorter time of progression to HAND than those who tested normal on NP testing at baseline who also progressed to HAND. Authors concluded that ANI is associated with a 2-fold increased risk for progression to symptomatic HAND. By increasing early treatment with combination antiretroviral therapy (cART) and addressing comorbidities, the risk for the development and progression of HAND may be delayed or lowered.

- Inflammatory effects of HIV and higher prevalence of risk factors may play a role in the high prevalence of cardiovascular disease (CVD) among people with HIV (Hughes et al., 2015). Hughes and colleagues conducted a pilot cross-sectional study to determine the prevalence and awareness of CVD risk factors and barriers to reducing CVD risk in PHAs. Sixty-four participants (engaged in HIV care for ≥6 months) completed a survey which evaluated participants' knowledge about general CVD risk factors and assessed personal risk factors. The mean number of CVD risk factors reported among respondents was 2.2. Smoking, poor diet, lack of exercise and family history were more commonly named by participants as risk factors while dyslipidemia and hypertension were less recognized as risk factors. The most common barriers to reducing CVD risk among respondents were lack of motivation (31%), chronic disease (17%) and lack of energy (14%). Overall, despite the higher prevalence of risk factors and higher risk of mortality due to CVD risk factors in adults with HIV; awareness of these risk factors was low. Information regarding risk factors associated with CVD need to be included in educational interventions for this population.
- Chronic Obstructive Pulmonary Disease (COPD) is a common comorbidity associated with HIV (Ghadaki et al., 2015). Ghadaki and colleagues conducted questionnaires with 247 participants regarding respiratory symptoms and diseases. Of the 247 participants, 163 (66%) were current or former smokers. Smoking had a significant effect on respiratory symptoms and respiratory diseases (including COPD). Among PHAs who smoked, 40% met the Canadian Thoracic Society (CTS) criteria for COPD screening while only 12% self-reported a diagnosis of COPD. There is a need to focus on recognition of and screening for COPD in the PHA population.
- Men who have sex with men (MSM) are at a high risk of contracting anal infection with oncogenic, high-risk HPV (HR-HPV) which are both risk factors for anal cancer (Grennan et al., 2015). Grennan and colleagues conducted a behavioural questionnaire and collected anal swabs from a group of 442 HIV-positive (67%) and HIV-negative MSM (33%). HPV presence was more common in the HIV-positive MSM group (88%) than the HIV-negative MSM group (78%). HR-HPV presence was also more common in the HIV-positive MSM group (68%) than the HIV-negative MSM group (52%). HPV is a significant health concern for MSM, especially HIV-positive MSM. There is a need for a large-scale anal cancer screening and HPV vaccination program for MSM.
- Women living with HIV (WLHIV) are more susceptible to cervical cancer caused by oncogenic HPV due to their impaired immune system (Burchell et al., 2015). Burchell and colleagues tracked annual rates of Pap cytology testing in 4,734,823 women in Ontario of which 2600 (1%) were living with HIV. Overall, Pap cytology testing rates for WLHIV were low despite the heightened risk of cancer and guidelines recommending that WLHIV need to undergo annual screening. There is a need for further research to identify the barriers that exist for cytology screening for WLHIV to inform future programs.

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.

A standard of best practices for clinical policies and procedures for supervised injection services (SIS) in
integrated health care settings does not exist for individuals who use illicit drugs in Canada despite the
recognized importance of integrating health care and harm reduction (HR) services (Baltzer Turje et al., 2015).
 Since 2002, The DPC has been integrating SIS into their health care services and programs for PHAs. Over time,
the DPC developed policies and procedures that include addressing the role of other professional disciplines,
parameters of nursing involvement and dealing with emergencies. Although the DPC developed these policies
and procedures in consultation with the College of Registered Nurses of British Columbia (CRNBC), this process

- of developing policies and programs that combine SIS and other professional disciplines is extremely complex. There is a need for an evaluation of the policies and procedures implemented by organizations that are integrating SIS with health care so that those organizations that wish to provide SIS are able to do so with a guideline of best practice standards.
- Limited research exists regarding resiliency in two-spirited, HIV-positive Aboriginal men (Brennan et al., 2015). Brennan and colleagues described how HIV positive Aboriginal men experience specific concerns such as colonization, racism, homophobia and violence. This study brought researchers together to understand how two-spirited men with HIV understand factors such as skills, resources and knowledge that contribute to their resiliency. Researchers conducted 3 Aboriginal sharing circles (focus groups) utilizing the medicine wheel to discuss factors that affected participants' health, wellness and resiliency. Participants highlighted divergent views between the research and Aboriginal community as it pertained to their health, wellness and resiliency. The paths of resiliency identified as important to health, wellness and resiliency were: 1) worldview; 2) finding one's strengths; 3) walking towards balance; 4) recognizing one's true power; 5) living the way of a good life; 6) self-care; and 7) living our truth. These findings may help researchers to understand the needs and concerns that two-spirited HIV positive Aboriginal men face and therefore may inform future programs and policies.
- Due to lower incomes, poorer health outcomes and experiences with stigma and discrimination, PHAs face greater challenges with **food security** (Globerman et al., 2015). Globerman and colleagues administered a self-administered questionnaire to PHAs in order to assess food insecurity and the impact on the daily lives of PHAs. Of the 649 participants, 447 (69%) were experiencing food insecurity. Factors associated with food insecurity included: Non-Caucasian ethnicity, unemployment, household income less than \$20 000, depression, substance use, injection drug use and higher levels of stigma. In the future, it is important to develop programs and policies that address these underlying factors as well as develop community partnerships to prevent food insecurity among PHAs.
- Since limited research exists regarding the definition of women-centered HIV care and how it affects health status, researchers measured differences in health utilities in women who perceived their HIV clinic as women-centered care (WCC) compared to those who did not (non-WCC) (Keshmiri et al., 2015). Utility values ranged from 0 to 1 (0=worst health state, 1=perfect health). Women (n=995) enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) rated whether they perceived the care they received from their HIV clinic in the past year as WCC. Overall, 54% perceived their HIV clinic as women-centered. The WCC group had a significantly higher mean utility value compared to the non-WCC group. These results suggest that WCC can have a positive effect on women's health. Clinics may use these findings to explore offering WCC.
- There is an increasing recognition that harm reduction (HR) strategies and services should be included in HIV care (Barnes et al., 2015). To date, evaluation of HR programs tends to focus on physical health outcomes and utilization of the HR services provided. To explore health care providers' views on the benefits and challenges of implementing HR strategies, Barnes and colleagues surveyed staff at two HIV/AIDS dedicated facilities in Canada that implement a HR policy. Researchers conducted a survey with 64 health care providers and found that in addition to evaluating physical and mental health of participants, it is important to evaluate engagement in the health care system and build positive client relationships. Researchers also highlighted a need for clear procedures and support when implementing HR programs with staff. These findings have implications for other clinics and health care organizations who wish to evaluate their HR services.
- Women living with HIV face reproductive concerns regarding fertility and parenthood that may not be properly addressed by health care providers (Fernet et al., 2015). Fernet and colleagues explored the impact of health-care services and satisfaction with care providers on psychological distress in 100 mothers living with HIV (MLHIV). Of the participants, 45% reported clinical psychological distress. Variables significantly associated with psychological distress in this population included resilience, quality of communication with the care providers, resources and HIV disclosure concerns. Special attention is needed for MLHIV as they face unique challenges regarding their family's needs. Health care providers may be able to provide more substantial care by inquiring about their overall quality of life (QOL).
- For PHAs who face psychosocial and medical challenges, **discharge from a hospital** can be a high-stress period which can result in hospital re-admission (Chan-Carusone et al., 2015). Researchers conducted a mixed-methods case study with 9 participants to explore factors that impact the discharge and transition period of PHAs who received in-patient care at Casey House (Toronto, Canada). Researchers conducted interviews at 4

time points (one week pre-discharge to one month post-discharge). Participants had complex medical and psychosocial challenges including a mean of five medical comorbidities. Discharge plans outlined medication adherence strategies and referrals (average of 7 referrals and 15 medications). Through the interviews, researchers found that there were discrepancies between the discharge plan and reality including minimal referral uptake, lack of social support, substance use relapse and poor medication adherence. These findings may influence research, policy and clinical practice in the delivery of hospital discharge services for PHAs.

- Retention in care is associated with improved health outcomes. Szadkowski et al., (2015) assessed the frequency of and risk factors for missing physician visits to highlight possible gaps in care. A total of 1585 participants were included in this observational study of whom 602 were participants in the OCS and 983 were patients attending the Toronto General Hospital Immunodeficiency clinic. All participants had ≥1 kept visit and ≥12 months of follow up at the clinic between 2004 and 2014. Overall, 15% of physician visits were missed; 70% of participants missed ≥1 visit and the median rate of missed visits per participant was 11%. Factors associated with missed visits included younger age, ethnic minority, longer HIV duration and the winter season. Efforts should be made to maximize clinic attendance for PHAs in care.
- Healthcare providers should understand how the effects of colonialism interact with the social determinants of health to create disparities in the Aboriginal population in Canada (Hojjati et al., 2015). Hojjati and colleagues identified the content and methods of delivery that should be included in health care curricula related to post colonialism and health. Investigators conducted interviews with 19 individuals with insight into post colonialism and health in Canada. Results indicated that post colonialism would be a useful tool for health care providers to address health inequities in this population. Regarding content, three key questions should be posed in healthcare curricula: 1) What experiences related to colonization have Aboriginal communities faced in Canada?; 2) How do structures rooted in colonialism continue to contribute to health inequities in Canada?; and 3) How do Canadian health care provider's own experiences of privilege and oppression shape their practice? Results also indicated that Aboriginal instructors who are experts on these topics should present the content in an interactive manner. Inclusion of this content may improve quality and access to care, advocacy and overall health equity for PHAs.
- Gender and societal inequities have resulted in women experiencing a higher vulnerability to HIV/AIDS and increased vulnerability to poor HIV-related health outcomes. Hence, there is a need for emphasis on womencentred care (WCC) (Puskas et al., 2015). Puskas and colleagues followed 3612 HIV-positive men (79%) and women (21%) in British Columbia and found that a lower proportion of women achieved optimal ART adherence (54%) than men (76%). Specifically, Aboriginal women and women who injected drugs were less likely to attain optimal adherence. There is a need for increased accessibility to WCC and support to enhance ART adherence among women living with HIV.
- Despite an increase in the proportion of HIV positive men in Ontario infected via heterosexual transmission, a paucity of research exists that describes the experience of heterosexual men affected by HIV (Wheeler et al., 2015). Investigators analyzed data from the Ontario HIV Treatment Network Study (OCS) with 552 (20%) heterosexual men, 2023 (74%) gay men and 171 (6%) bisexual men. Researchers found that injection drug use history was higher among heterosexual men (32%) compared to bisexual (16%) or gay (11%) men in the sample. Compared to gay and bisexual men, heterosexual men were more likely to have significantly lower CD4 counts, detectable viral loads, HCV and were more likely have to have had a late diagnosis. The proportion of participants who had initiated ART was similar across all three groups. Factors affecting heterosexual men in this sample reflect a lower perception of HIV risk and a lower acceptance of regulatory testing. It is important to further explore the trends in heterosexual men so that timely HIV diagnosis and initiation of cART may occur.
- "Our Youth, Our Response" (OYOR) is a study created to promote prevention of HIV and HCV in Atlantic Canadian youth (Gahagan et al., 2015). Gahagan and colleagues conducted three stages of data collection and analysis. The first stage was a policy scan of existing HIV/HCV prevention documents; the second stage included interviews with key informants from relevant sectors (education, health, corrections); and the third stage involved focus groups with youth and organizations. Investigators found that sexual health curricula in schools is not standardized, policies and programs on HIV/HCV prevention do not differentiate between the needs of adult and youth and limited access to youth centres with HIV/HCV testing exists. Stigma, discrimination and a lack of harm-reduction services for youth further complicate these issues. There is a need

- to organize and combine existing policy and programming expertise within communities in Atlantic Provinces to increase access to testing options, harm reduction services and education for youth.
- A women centered approach to care is recommended to better address the needs of women living with HIV (WLHIV) (Carter et al., 2015). Carter and colleagues examined whether receipt of WCC influenced health-related quality-of-life (HQOL) among WLHIV using data from 981 women in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) study. Participants were provided with the following definition of WCC: "Supports women living with HIV to achieve the best health and well-being as defined by women; addresses a women's unique health and social concerns, and recognizes that they are connected; is flexible and takes the different needs of women into consideration." Fifty-three percent (53%) of participants perceived their HIV clinic to be women-centered while 57% perceived their doctors' care to be women-centered. Receipt of perceived WCC from an HIV clinic was associated with higher mental health QOL scores while overall, mental and physical QOL were lower than estimates for the general population. Results indicate that WCC has the potential to reduce gender inequities and improve health outcomes for WLHIV.
- Transgender sex workers living with HIV face immense barriers in accessing health care (Lyons et al., 2015). Lyons and colleagues investigated the frontline health care experiences of transgender sex workers who use drugs and/or engage in sex work in Vancouver. Researchers conducted interviews with 33 transgender sex workers and found that 18 (55%) were HIV positive. All participants reported experiencing stigma and discrimination when accessing services. The impact of this discrimination is that participants avoided accessing frontline health services to avoid negative encounters. Overall, transgender sex workers face multiple barriers when accessing HIV health related services suggesting the need for a training program for health care professionals on how to provide a stigma and discrimination free environment as well as promote transgender centered care.
- The Children's Hospital of Eastern Ontario (CHEO) and the AIDS Committee of Ottawa (ACO) developed a formal partnership to share experience and expertise to **enhance awareness about support services** for PHAs who access care at CHEO (Haoua et al., 2015). Members of the ACO proposed the idea of offering ACO services within the CHEO HIV clinic to enable ACO workers to attend the clinic and the clinic social workers to attend ACO support groups. Haoua and colleagues conducted a program review after 6 months and found that 47 families who were not previously accessing community services had gone to the clinic setting. Issues identified in this program include: immigration, medication access, isolation and system navigation. This unique partnership enabled sharing of expertise and resources which allowed for increased access to services for participants. This partnership may be used as a model for other clinics and community organizations.
- To describe service user and characteristics of clients at the Dr. Peter Centre (DPC) (Vancouver, Canada), researchers administered a self-reported questionnaire to 96 clients living with HIV (Fernando et al., 2015). Researchers found that 52% reported ever being incarcerated, 76% reported ever being homeless, 73% reported ever being diagnosed with substance use disorder, 73% reported diagnosis of depression, 57% reported diagnosis of anxiety, 91% reported being on HAART and 71% reported receiving treatment for a mental health condition. The most important services offered at the DPC were meals, consultation with the nurse practitioner and medication support. Further research is needed to examine other contextual and demographic factors on the health of clients at the DPC.
- Program science is a novel approach to addressing HIV prevention and treatment however few models effectively guide the use of this approach of integrating science and community-based practice (Otis et al., 2015). Otis and colleagues conducted a multiple-case study with the aim of creating a model to apply program science principles to address HIV and its impact at the population level. Findings indicated that there are four processes of knowledge and community mobilization: 1) partnerships to bring stakeholders together in an equitable manner; 2) co-production of knowledge as a shared goal and specific to each stage of implementation; 3) knowledge mobilization and exchange to generate action; and 4) capacity building. This model provides a process for mobilizing knowledge and communities that program science researchers may consider when addressing HIV prevention and treatment.
- In the past, strategies to improve access to healthcare for PHAs have been informed by the views of health care providers and decision makers and have had limited success (Asghari et al., 2015). Asghari and colleagues conducted a scoping review on the perspectives of PHAs concerning access to healthcare services to produce an action plan to guide future programs on access to care for PHAs. Of 20,694 references retrieved, 67 met the

- inclusion criteria. Data synthesis is in progress. Researchers developed a literature repository to assist others in developing and implementing healthcare programs that account for PHAs perspectives.
- The Dr. Peter Centre (DPC) (Vancouver, Canada) introduced a Nurse Practitioner role to its' programs with the aim of engaging individuals in their healthcare and increasing adherence to HIV treatment (MacHattie et al., 2015). MacHattie and colleagues examined the **Nurse Practitioner role at DPC** and identified six role elements in relation to harm reduction services which included: facilitation of access to services, case management, clinical services, participant education and support, support for multidisciplinary teams, and use of evidence-based practice. The Nurse Practitioner role contributes to addressing barriers to care, HIV/AIDS management and the delivery of effective and consistent engaged care. While further research is needed to examine the impact of the Nurse Practitioner role, findings indicate that the role is fundamental when working with priority populations.
- The Canadian Working Group on HIV and Rehabilitation (CWGHR) conducted a pilot study where they placed occupational therapy (OT) students in community-based HIV organizations (CBHOs) (Murzin et al., 2015). The objectives of this pilot were to: 1) increase access to OT for PHAs who access CBHOs; and 2) familiarize OT students with the role of OT in the care of PHAs. Nine students completed practicums in CBHOs where they developed and implemented programs, increased awareness about the role of OT and provided clinical support for PHAs. At the end of their practicum, students and their supervisors completed an online survey and findings indicated that working together had increased the knowledge and capacity to deliver care to PHAs. This pilot may serve as a model to other community organizations to demonstrate how intersectoral partnerships can be mutually beneficial students and CBHOs.
- Women living with HIV (WLHIV) face a high amount of HIV-related stigma which can influence their lives and
 compromise access to health and community care (Medjuck et al., 2015). Positive Women's Network (PWN)
 offers five annual peer supporting trainings that focus on stigma with 48 participants. Participants found that
 the discussion helped distinguish between external and internal sources of stigma and they developed a
 resource sheet on coping with stigma. More interventions and support services are needed to address HIVrelated stigma in women.
- A lack of women-specific HIV services is available in Canada (Medjuck et al., 2015). The Positive Women's Network (PWN) provides leadership, support and health education to women living with HIV (WLHIV) and is the only women-specific HIV organization in British Columbia. PWN conducted a needs assessment with 34 WLHIV seeking care and ASOs about providing services to WLHIV. Following the needs assessment, PWN conducted a survey regarding their programs and resources with 36 individuals who accessed PWN services. Findings from these two projects indicate that there is a need for childcare policy and subsidies, individualized support, women-only safe spaces and best practices for working with this population. There is also a need to engage WLHIV as peer workers. Investigators propose using these findings to develop support services for WLHIV to help them overcome barriers they may face when seeking care.
- The Dr. Peter Centre (DPC) (Vancouver, Canada) conducted a survey with DPC clients to assess the impact of the DPC's **health-equity approach on adherence to ART**. The survey used a set of eight health-equity indicators (HEI) to measure clients' perception of the DPC. Of the 74 participants who completed the survey, 46% were optimally adherent to ART. The HEIs ranked the highest by participants were feeling: welcomed by staff (96%), respected by staff (96%), and cared for by staff (89%). Although the HEIs did not attain statistical significance and therefore did not explain ART adherence, the health equity approach adopted by DPC is well received by participants.
- Universities Without Walls (UWW) is an online and in-person training program that bridges academic research and "on the ground" work through a course that focuses on research ethics, community-based research (CBR), interdisciplinary, and community service learning (Hastings et al., 2015). Hastings and colleagues evaluated UWW by having 61 graduates complete a "retrospective post-then-pre" evaluation and a brief written reflection of the fellowship. Investigators found four key themes that described the impact of the experience with UWW: 1) developed a community of practice with other researchers and mentors; 2) increased confidence in conducting CBR; 3) enhanced professional skills to link research with community practice; and 4) increased self-reported knowledge, skills and experience along the core UWW components from "novice/advance beginner" to "competent/proficient." UWW encourages their fellows to participate in HIV research to employ what they have learned, build confidence and promote the inclusion of PHAs in research.

- Canada's Source for HIV and Hepatitis C Information (CATIE) strengthens the frontline response to HIV and HCV by supporting tailored knowledge transfer and exchange (KTE) activities (Challacombe et al., 2015). Investigators evaluated five different methods of KTE activities to assess knowledge exchange outcomes including relevance, usefulness, increased knowledge and application of knowledge. KTE methods included a health magazine written by and for PHAs and a deliberative dialogue on policy and programming implications of emerging biomedical research. Investigators found that the methods of KTE were relevant (96%-100%), useful (87%-100%), and resulted in increased knowledge (94%-98%) that was applied to the frontline response (94%-98%). Tailored KTE methods provide information in a useful and appropriate manner for the intended audience and can strengthen the frontline response to HIV and HCV.
- In 2011, the Ontario HIV Treatment Network (OHTN), the Canadian Association for HIV Research (CAHR) and the Canadian Institutes of Health Research (CIHR) formed a partnership to create The Learning Place for Community Based Research in HIV/AIDS (TLP) (Ibáñez-Carrasco et al., 2015). TLP was formed as a result of the lack of consensus on the content of an HIV CBR curriculum. TLP is an instructional website that promotes blended learning and hosts educational events for PRAs. Since its inception, 10 CBR teams provided positive reports of having integrated TLP materials into their training, the online modules were used 70 times in 2014 and over 100 individuals attended the events sponsored by TLP. TLP is a model for interdisciplinary collaboration and aims to inform HIV CBR.
- Now that HIV is considered a chronic disease, the Canadian Working Group on HIV and Rehabilitation (CWGHR) is working to ensure **equitable access to rehabilitation** for PHAs to meet the new challenges associated with living with HIV as a chronic condition (Murzin, 2015). CWGHR conducted 65 consultations with stakeholders from the HIV community, the Canadian Association of Occupational Therapy and the Canadian Physiotherapy Association to identify the challenges, opportunities and recommendations with ensuring access to rehabilitation for PHAs. Key issues raised include the lack of coordination between chronic illnesses, disability and rehabilitation sectors; little integration for rehabilitation services in the continuum of health and social care; cost and coverage issues; government delisting of services and funding cut and impeding health and social policies. In response to these findings, CWGHR is coordinating a "Pan-Canadian Rehabilitation Network" to foster collaborations in education, research, policy change and programming initiatives

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. *This section also includes information about clinical interventions or studies in addressing HIV infection and its health-related consequences.

- Dr. Deborah Persaud (John Hopkins University School of Medicine) presented on 'HIV Latency in a Perinatal Infection: Opportunities and Challenges towards Remission and Cure.' Dr. Persaud discussed that a major challenge for the field of HIV cure research is that currently, the way to assess remission and cure is to withdraw ART and follow to assess virus rebound. This is an ethical challenge as evidence does not exist regarding biomarkers that show when the virus has diminished. Currently, virologic rebound occurs within 2-3 weeks after the discontinuation of treatment. The explanation for this uniform pattern of viremia rebound is best explained by the persistence of HIV in resting memory CD4+T cells. This reservoir is established early in infection and is the dominant source of virus production in patients on combination therapy. The most important reservoir in HIV infected adults is in the central memory T cells (resting memory CD4+T cells are heterogeneous) which undergo self-renewal and homeostatic proliferations. They do not express anti-viral proteins and therefore cannot be targeted by immune surveillance mechanisms. Current strategies towards an HIV cure include: 1) latency reversing agents; 2) combination therapies; 3) immune checkpoint blockage; 4) immune modulating drugs; 5) very early treatment; and 6) very early treatment and immunotherapies. For a perinatal HIV cure, viral replication needs to be curtailed before T cell development. Infants need to be treated very early on (prior to 2 months) to ensure low reservoir size, low viral diversity and minimal HIV-specific immune responses.
- Labour force participation is a challenge for PHAs (Oliver et al., 2015). Although low employment rates are
 reported following HIV diagnosis, improved employment outcomes are reported following vocational
 counselling. ASOs provide services related to vocational counselling and are involved in the provision of HIVspecific employment opportunities. With the guidance of a community advisory committee, researchers

conducted interviews with 31 PHAs who were successfully engaged in the labour force to explore the benefits and challenges of community vocational rehabilitation services. Researchers developed nine thematic categories that summarized the findings: greater involvement of people living with HIV/AIDS (GIPA) principles, social and emotional support, support groups, skill development, benefits counselling, anti-oppressive practice, peer support, outreach and advocacy, and HIV-specific services. These results will serve as resources to community organizations interested in HIV and employment as well as to those interested in developing effective vocational programs to assist PHAs.

- O'Brien et al., (2015) conducted an update of a Cochrane Collaboration systematic review to examine the safety and effect of aerobic exercise interventions on immunological and virological, cardiopulmonary, weight and body composition, strength, and psychological outcomes in adults living with HIV. Randomized controlled trials comparing aerobic exercise with no exercise or another intervention were included. Twenty-four studies met the inclusion criteria (n=956 participants). Researchers found that exercisers showed statistically significant improvements in selected outcomes of cardiopulmonary status, body composition, strength, depression symptoms and quality of life compared to non-exercisers. Participants exercising at a greater intensity showed greater improvement. Researchers concluded that performing aerobic exercise or a combination of aerobic and resistive exercise at least 3 times/week for at least 5 weeks is safe and beneficial for adults living with HIV who are medically stable.
- Social media is a popular HIV prevention tool as it supports interactions between individuals and allows users to shape their online environment (Condran et al., 2015). Researchers examined peer-reviewed research on social media interventions to prevent transmission of HIV to promote sexual health. Researchers summarized information from 236 articles and found that Facebook was a popular method to disseminate information and engage participants in discussions regarding sexual health and HIV prevention. Further research is needed however these findings provide considerations for developing prevention interventions through social media.
- Investigators explored the perspectives of Physiotherapists (PTs) and Occupational Therapists (OTs) in Kenya and Zambia regarding their role in caring for PHAs (Nixon et al., 2015). Nixon and colleagues assessed an HIV teaching tool for rehabilitation providers (adapted from CWGHR's Canadian "E-Module on Evidence-Informed HIV Rehabilitation") by conducting a questionnaire, survey and 10 focus groups with a total of 63 participants. Investigators found that participants described rehabilitation as excluded from HIV training, policy and care. Participants also indicated that rehabilitation requires the involvement of community-based providers. Although HIV policies in Sub-Saharan Africa recognize the association between disability and HIV, rehabilitation remains unrecognized and is therefore not incorporated into the HIV response. Investigators suggest incorporating HIV training into rehabilitation education in Sub-Saharan Africa.

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.

- A neurocognitive assessment and interview by a trained clinician is considered the "gold standard" for detecting and diagnosing HAND (Patocs et al., 2015). This process is time-consuming, requires expertise and is subjective. The **Global Deficit Score (GDS)** is an alternative quantitative method that helps to inform the clinical picture of HAND however it does not account for confounders or contextual factors. Researchers examined clinical diagnosis and GDS scores in a sample of 117 PHAs to evaluate the concordance of GDS scores with clinical diagnosis. Researchers observed 81% concordance between a clinic diagnosis of impairment and GDS-determined impairment, 82% sensitivity and 79% specificity. Participants who were labelled impaired from only the GDS were of lower age, lower cognitive complaints and lower depression scores. Participants who were labelled impaired clinically only had higher scores on cognitive complaints. These factors should be considered when using GDS to determine impairment score.
- Cognitive screening instruments are more useful for more severe forms of HAND that for milder forms (Rourke et al., 2015). Rourke and colleagues tested the validity of four screening tests for HAND (Cogstate Brief Battery (Cogstate), HIV Dementia Scale (HDS), Computer Assessment of Memory and Cognitive Impairment (CAMCI) and Montreal Cognitive Assessment (MoCA)) against the gold standard for HAND diagnosis. A sample

of 104 participants completed the four screening tests in addition to the gold standard neuropsychological battery. A Neuropsychologist conducted the clinical diagnosis of HAND for participants. Overall, HAND was diagnosed in 60 participants (58%). After comparing the sensitivity and specificity of each screening test to clinical diagnosis, researchers concluded that the MoCA test had the best accuracy, followed by Cogstate, CAMI, and HDS. Further research needs to be conducted regarding the clinical utility and generalizability of these findings.

- The International Classification of Function, Disability and Health (ICF) can be used as a content analysis tool to understand the construct and dimensions of HQOL measures (Vajravelu et al., 2015). Since there are no content comparisons of HIV specific HQOL measures with the ICF, Vajravelu and colleagues conducted a content analysis of the items of the Medical Outcome Study-HIV (MOS-HIV), the Multidimensional Quality of Life-HIV (MQOL-HIV) and the HIV Disability Questionnaire (HDQ). Four raters individually linked 145 items from the measures based on standardized linking rules. Raters found that the content of all three measures was highly linkable with ICF. Researchers found that the HDQ had the best representation among the three measures and therefore provides a more precise description of disability experienced by PHAs. Researchers recommend that those interested in measuring HIV-specific disabilities utilize the HDQ.
- The Patient Assessment of Chronic Illness Care (PACIC) survey assesses patient centered care delivered
 through the Chronic Care Model (Kelly et al., 2015). Kelly and colleagues tested the validity of PACIC in 49 PHAs
 by conducting a telephone survey which included items from the PACIC, socio-demographic characteristics and
 questions assessing satisfaction with care. Findings indicated that the PACIC had good face and construct
 validity in chronic HIV care. Further research needs to be conducted to validate the PACIC in a larger group of
 PHAs.
- People aging with HIV face deteriorating cognition however it is difficult to attribute this to their health situation or natural aging (Askari et al., 2015). Researchers created an item bank reflecting the cognitive concerns expressed by people with HIV by conducting interviews and neurocognitive questionnaires with 234 PHAs. In total, 136 areas of cognitive concern were identified covering all 15 standard neurocognitive domains. The most common concerns are memory (n=40), attention (n=15) and language and executive function (n=12). Researchers found a lack of relationship between self-reported cognitive concerns and results on neurocognitive testing. These findings will contribute cognitive concern items that can be compared to existing cognitive questionnaires.

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