



Scoping the Field: Identifying Key Research Priorities in HIV and Rehabilitation

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Canadian Working Group on HIV and Rehabilitation

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EXECUTIVE SUMMARY

Background: HIV is increasingly experienced as a lifelong, episodic disease, characterized by unpredictable cycles of wellness and illness. There is a need to develop the field of research, clinical practice, and policy for HIV rehabilitation, to address the range of impairments, activity limitations, and participation restrictions associated with the disease and its treatments.

Objective: To identify key research priorities related to HIV and rehabilitation that will advance policy and practice for people living with HIV in Canada.

Methods: We conducted a scoping review of the published and grey literature, followed by focus group and interview consultations with 28 stakeholders including people living with HIV, researchers, educators, clinicians, and policy makers with expertise in HIV and rehabilitation, across Canada and internationally. We asked participants their thoughts and perspectives on research priorities in HIV rehabilitation. All discussions were audiotaped and transcribed verbatim. Qualitative content analysis was used to identify key emergent themes that related to research priorities in HIV and rehabilitation.

Results: The *Framework of Research Priorities in HIV and Rehabilitation* was developed to identify important topics in HIV and rehabilitation research. In this framework, research priorities fell into three overlapping themes: A) living with HIV across the lifespan (e.g. aging with HIV, concurrent health conditions, changing outlook over time), B) disability (e.g. impairments, activity limitations and participation restrictions), and C) rehabilitation (e.g. access to services, effect of rehabilitation interventions, and impact of education of health care providers on HIV and rehabilitation). These research priorities may be explored through environmental contextual lenses (e.g. urban versus rural, developing versus developed countries, stigma, legal, policy and social justice issues) and/or personal contextual lenses (e.g. gender, ethnocultural backgrounds), using different methodological approaches (e.g. using a mixed methods study design, considering cross-disease versus HIV-specific approaches, incorporating longitudinal study designs (to explore disability over time), increasing the number of treatment effectiveness studies (to explore the impact of interventions), and pursuing outcome measure development). Additional consultation identified six top research priorities from this framework field which included: 1) disability and episodic disability, 2) concurrent health conditions living with HIV (e.g. mental health, bone and joint disorders, cardiovascular disease), 3) HIV and the brain (e.g. mild to moderate memory and concentration problems, minor cognitive motor disorder), 4) labour force and income support issues, 5) access to and effect of rehabilitation, and 6) development and evaluation of outcome measurement tools.

Conclusions: Despite increasing evidence in this field, there is a need for future research in the area of HIV and rehabilitation. Six key priorities for HIV and rehabilitation research were identified through a collaborative scoping review process that integrated perspectives of multiple stakeholders in the field. These priorities propose a future plan for HIV and rehabilitation research that may increase our knowledge to collectively enhance future practice, programming and policy for people living with HIV in Canada.

INTRODUCTION

At the end of 2005, an estimated 58,000 people were living with HIV in Canada, an approximately 16% increase from the estimated 50,000 at the end of 2002 (1). The incidence of HIV may have increased slightly with an estimated 2300-4500 new infections in 2005 compared with 2100-4000 in 2002 (1).

In industrialized countries such as Canada, there has been an improvement in health and life expectancy for many people living with HIV who have access to, and can tolerate, combination antiretroviral therapy (2). As a result, more individuals may be living with a range of health-related consequences of HIV, its associated conditions or treatments. For many, HIV is now experienced as a chronic and episodic illness characterized by unpredictable periods of wellness and illness. Treatment now focuses on learning to live with HIV instead of preparing for death. A survey undertaken in 2004 documented a remarkably high prevalence of disablement among people living with HIV in British Columbia. At least 80% of respondents experienced a minimum of one impairment, activity limitation or participation restriction in the past month (3). As a result, there is a need for health care communities to respond to the changing needs of people living with HIV and specifically an increasing role for rehabilitation (4). Rehabilitation professionals can assist people living with HIV in managing disablement ranging from addressing adverse effects of medication, fatigue, pain, neuropathy, cognitive problems as well as income and vocational support.

Traditionally, however, rehabilitation professionals have not been actively involved in the field of HIV clinical practice and research. Despite the important role that rehabilitation professionals have to play in the care and treatment of persons living with HIV, only a minority of physical therapists, occupational therapists and speech-language pathologists currently work with HIV clients (5). Furthermore, with the exception of the small amount of evidence that documents physical disablement (3, 6, 7) and limitations in role function (3, 8, 9), relatively little research focuses on rehabilitation in HIV care. This is in stark contrast to other diseases such as arthritis and heart disease where access to rehabilitation professionals is an important component of optimal care. Hence, we must develop ways to enhance research and clinical practice in the area of rehabilitation and HIV in order to advance practice and policy for people living with HIV in Canada.

Overall, the field of rehabilitation in the context of HIV is still emerging. Understanding the key research priorities in rehabilitation and HIV is an initial step to building research evidence that will improve the care, treatment and support for people living with HIV.

OBJECTIVE

The primary objective of this initiative was to identify **key research priorities** related to HIV and rehabilitation that will advance policy and practice for persons living with HIV in Canada.

BACKGROUND

As people living with HIV are living longer, they may be living with increased disablement due to HIV, its associated conditions and treatments. Furthermore, the ways in which this disablement manifests may be unpredictable and episodic in nature. As a result, there is a need for health care communities to respond to the changing needs of people living with HIV and this includes recognition of the increasing role for rehabilitation.

The Canadian Working Group on HIV and Rehabilitation (CWGHR), a national charitable organization that promotes innovation and excellence in rehabilitation in the context of HIV, is working to respond to this need. CWGHR understands rehabilitation in its broadest sense of (re)integration (back) to living in society for those living with HIV and its accompanying challenges (10). Rehabilitation may be defined as any services and activities that address or prevent impairments, activity limitations and participations restrictions experienced by an individual (4). CWGHR's mandate is to develop rehabilitation resources, new knowledge, and awareness through multi-sector collaborations to enhance the quality of life for people living with HIV.

In 2006, CWGHR received funding from the Public Health Agency of Canada to carry out a program of research and consultation to identify key research priorities related to HIV and rehabilitation to enhance policy and practice. In early 2008, as part of this initiative, CWGHR also received funds from the Canadian Institutes of Health Research (CIHR) for a one day consultation workshop in which to share preliminary findings and identify the top priorities for a future plan of HIV and rehabilitation research.

We used scoping review methodology including a literature review and key informant consultation to gain perspectives on key research priorities in the context of HIV. Having conducted this review, we were able to develop and provide recommendations for research to advance future research in the area of rehabilitation in the context of HIV/AIDS in Canada.

METHODS

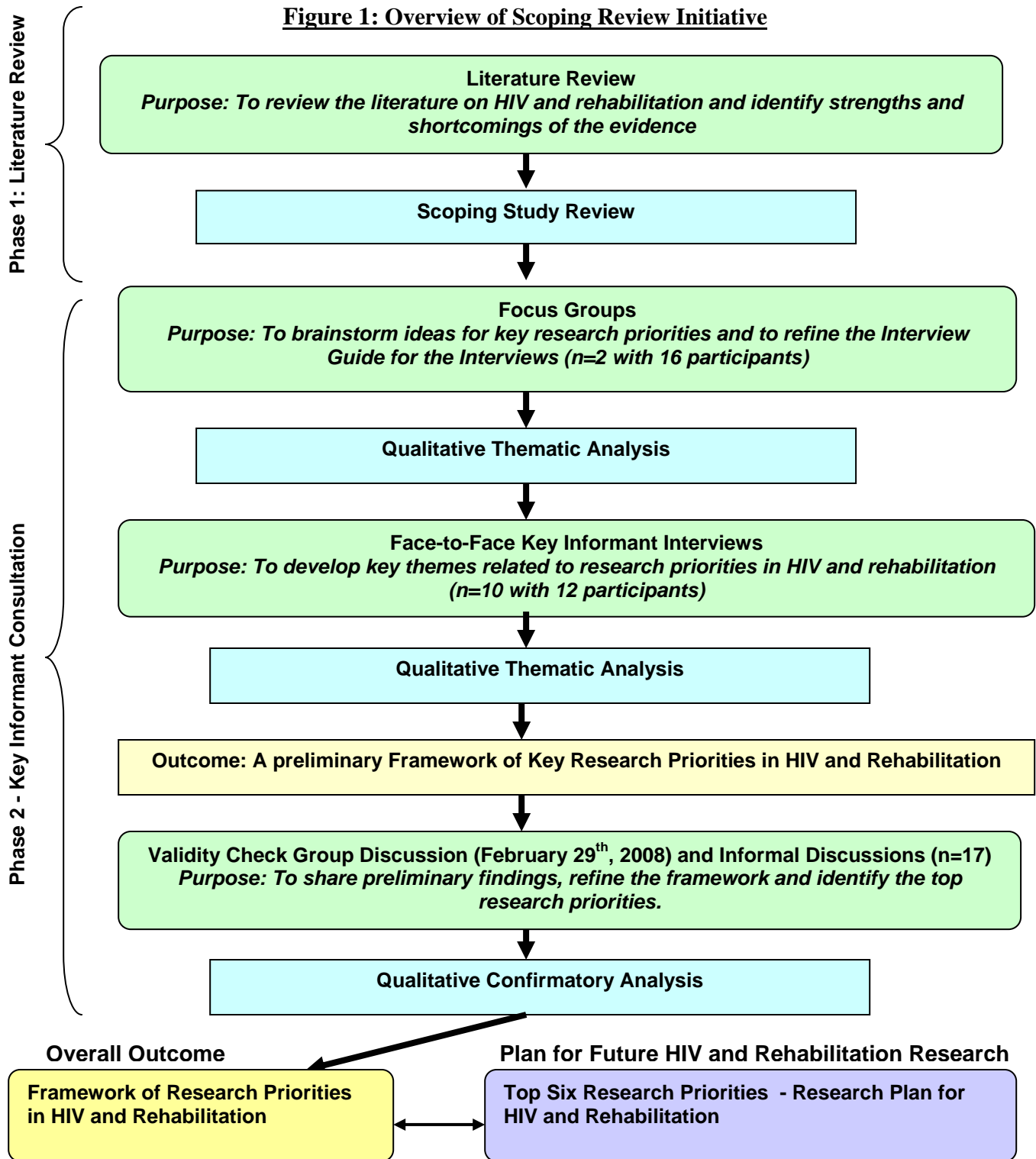
Scoping studies aim to map key concepts underpinning a research area and the main sources and types of evidence available. Scoping studies may be used to a) examine the extent, range and nature of research activity, b) determine the value of undertaking a full systematic review c) summarize and disseminate research findings, or d) identify research gaps in the existing literature (11). We obtained ethics approval of this initiative from McMaster University, Hamilton, Ontario.

This scoping review included two major phases: 1) literature review followed by 2) a series of focus groups and key informant interviews. This method was appropriate for bringing a new understanding to a phenomenon by focusing on identifying the experiences, meanings, and views of individuals of interest, allowing in-depth exploration of concepts (12). Because of the close links between research priorities and clinical practice guidelines, this initiative was conducted in tandem with another that identified guiding principles and themes for the development of best practices guidelines for HIV and rehabilitation.

An overview of this initiative is presented in Figure 1. We conducted a review of existing literature on HIV research followed by a series of focus groups, key informant interviews and informal consultations. The purpose of the literature review was to identify potential gaps in existing HIV and rehabilitation research. We then used a multi-method approach of inquiry consisting of focus groups, face-to-face semi-structured interviews, followed by a validity check group consultation. The purpose of the focus group and interviews was to gather data to establish key research priorities for rehabilitation in the context of HIV. The purpose of the validity check group consultation was to increase credibility by enhancing and refining emerging research priorities with new and returning key informants. Based on results from these approaches, recommendations were established on key

research priorities that should be addressed in the field of HIV and rehabilitation to advance policy and practice.

Figure 1: Overview of Scoping Review Initiative



Phase #1: Literature Review

We conducted a literature review of published and grey literature to explore: *What is known about the existing literature on HIV and rehabilitation for people living with HIV?* We specifically sought to identify strengths and gaps in HIV and rehabilitation research. The review was comprised of the following 4 phases:

- 1) Identifying relevant literature – We searched electronic databases including MEDLINE, CINAHL, EMBASE, PsychINFO, reference lists, existing networks, reports and position papers from relevant organizations and conferences published since 1980 to January 2007.
- 2) Literature selection – Two reviewers (KO and AW) reviewed abstracts and then full articles and documents to determine which studies ‘best fit’ with the research question. We reviewed the MEDLINE abstracts specifically and coded their content according to the *Episodic Disability Framework* which considers dimensions, contextual factors, and, triggers of disability (13).
- 3) Charting the data – We charted information obtained from the literature, sorting material according to key themes and issues. We extracted data from the included articles and entered these data onto a data charting form using Excel. Data extracted included author, year, study location, intervention type and comparator if any, duration of the intervention, study populations, aims of the study, methodology, outcome measures, important results, and important considerations for future research.
- 4) Summarizing and reporting the results – We summarized the results of the review and highlighted the strengths and gaps of the HIV and rehabilitation research field.

The next step of a scoping review is the consultation phase whereby stakeholders may further contribute to the information captured in the literature review. This phase was addressed by the qualitative phase of focus groups and interviews in phase 2.

Phase #2– Key Informant Consultation

We conducted a series of focus groups and key informant interviews with a range of national and international stakeholders including people living with HIV, researchers, educators, clinicians and policy makers with expertise in HIV and rehabilitation, research and/or best practices between June and October 2007. We asked individuals what they felt were important issues (research topics) in HIV and rehabilitation related to practice, research and policy. We audiotaped the consultations and took field notes throughout for later verbatim transcription and thematic analysis. We used a systematic set of procedures in which to identify key themes to develop an overall understanding of the concepts.

We used a constant comparative method of analysis whereby data collection and analysis occurred simultaneously. We categorized data from the focus groups and interviews and compared them systematically with new emerging categories, looking for any similarities or differences that may arise in the data. We devised a hypothetical compilation of research themes within a draft framework when all data from the interviews and focus groups were analyzed. This preliminary framework was refined within the validity check group discussion.

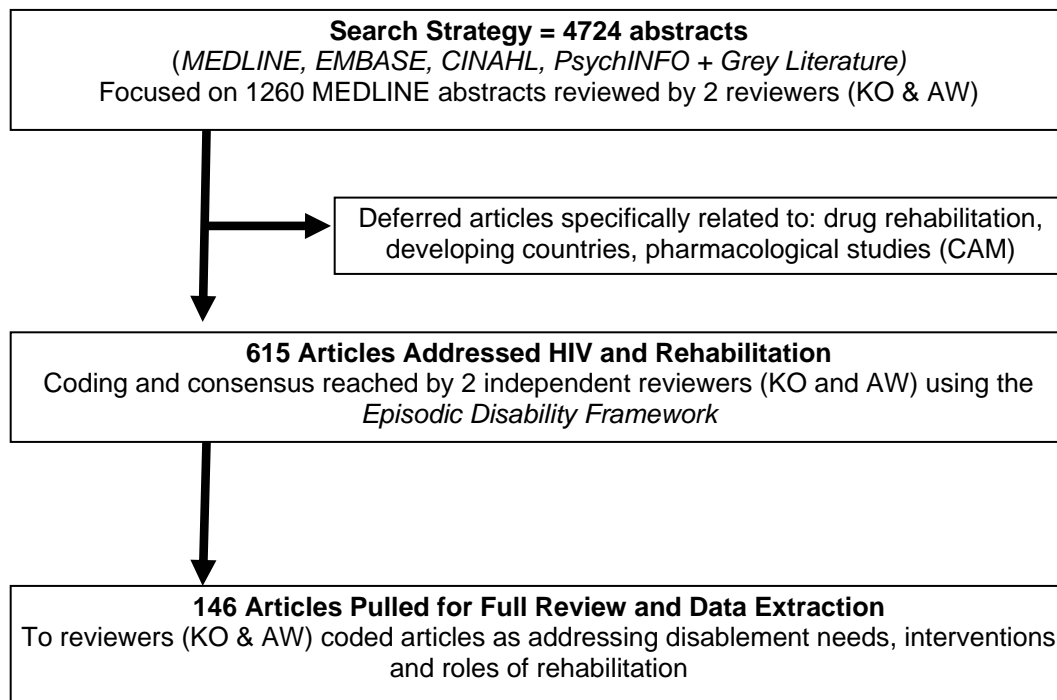
In addition, we conducted informal consultations throughout the data collection and analysis phase. A final validity check phase included reporting back to stakeholders and reworking of the results using an iterative consensus based approach (November 2007 to February 2008). A draft framework and identification of key research priorities were vetted in full day consultation workshop funded by

the Canadian Institutes of Health Research, held on February 29, 2008. Persons living with HIV, rehabilitation and other health professionals, HIV researchers, representatives from HIV research organizations, and other AIDS service organizations attended from across Canada including British Columbia, Alberta, Manitoba, Ontario, and Nova Scotia. Brief presentations were given on work to date followed by detailed group discussion to identify the top research priorities in HIV and rehabilitation and a plan for next steps.

RESULTS - Phase 1 –Literature Review

The search strategy yielded 4724 abstracts, of which 1260 from MEDLINE were comprehensively reviewed. While the other databases also may have contributed relevant information to this review, we felt that the MEDLINE search provided an adequate picture of the current literature on HIV and rehabilitation allowing us to inform the consultation. Abstracts from the other databases (n=3464), and those relating to drug rehabilitation, developing countries and pharmacologic interventions ,including complementary or alternative medications (CAM), were deferred for future consideration. We identified 615 relevant abstracts and coded their content according to the *Episodic Disability Framework* which considers dimensions, contextual factors, and triggers of disability (13). Of these, 146 articles were identified to ‘best fit’ the HIV and rehabilitation question, were pulled for full review, and classified as addressing: disablement needs, effectiveness of interventions and, roles of rehabilitation professionals.

Figure 2: Overview of Scoping Review Search Strategy Results



Overview of the Literature

Of the 146 articles pulled for inclusion and data extraction in the review, 91 were published after triple combination antiretroviral therapy became standard in Canada (1997 onwards) and 55 were published prior to this era.

Fifty eight of the articles were classified as having described the disablement needs experienced by adults living with HIV. Main types of disablement documented included physical impairments and activity limitations experienced by people living with HIV, some of which were associated with opportunistic infections and resultant hospitalizations. Sixty-three articles described interventions that may be used to address HIV-related disablement. Most of these (86%) were published after triple combination antiretroviral therapy became standard in Canada and the majority documented the effect of aerobic, resistive or combined aerobic and resistive exercise on health outcomes for adults living with HIV. Twenty-five articles described the roles of rehabilitation professionals in the care and treatment of people living with HIV. The majority of these articles (68%) was published prior to 1997 and discussed the role of rehabilitation professionals primarily in acute or palliative care settings. Many of these articles described the benefits of an interprofessional rehabilitation team or program in the care and treatment of people living with HIV.

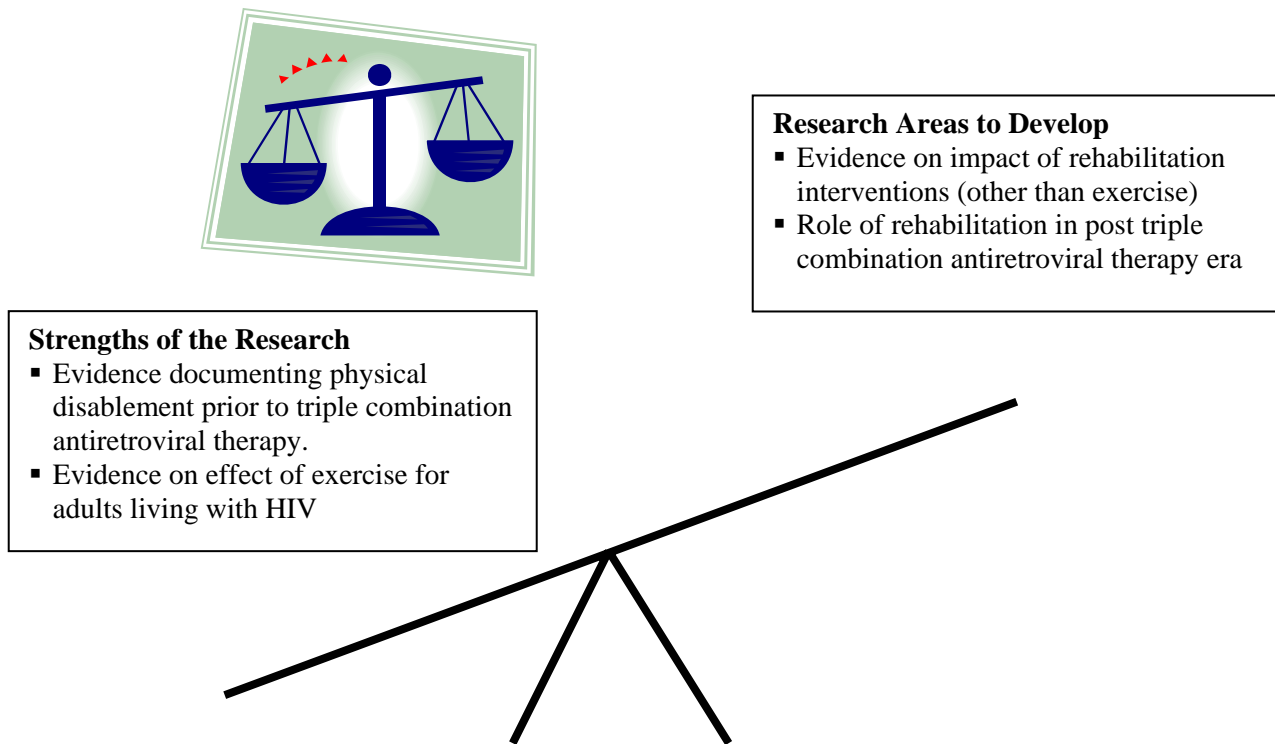
Most of the articles (66%) included men participants living with HIV, as opposed to women only, children, or aging individuals living with HIV. Given our inclusion criteria, most articles reported on studies carried out in the United States or Canada (60%) whereas others were carried out in Europe (10%) or were review articles and/or did not report a specific geographical region (30%).

Strengths and Shortcomings of the HIV and Rehabilitation Literature

Strengths of the HIV and rehabilitation literature include increasing evidence on rehabilitation interventions in the post combination antiretroviral era. However, the majority of this research is on the effect of exercise, with little evidence on the impact of other rehabilitation interventions. Another strength of the literature was the call for rehabilitation early in the epidemic, highlighting the important role for rehabilitation in the care and treatment of people living with HIV. However, much of this literature was primarily within the acute and palliative care context, and little evidence exists exploring the role of rehabilitation in health promotion or prevention since the introduction of triple combination antiretroviral therapy. Finally, much of the disability literature was focused on physical impairments experienced with HIV associated with opportunistic infections, rather than considering the broad spectrum of disablement including social inclusion and uncertainty.

Overall, there was an imbalance of evidence in the HIV and rehabilitation literature. Areas in which to develop research include exploring the impact of rehabilitation interventions (other than exercise) for people living with HIV, discussing the range of disablement experienced by those living with HIV (beyond physical impairments), addressing the impact of aging and emerging concurrent health conditions, and the role of rehabilitation in the care and treatment of people living with HIV in the post-combination antiretroviral therapy era.

Figure 3: Imbalance of HIV and Rehabilitation Literature



RESULTS - Phase 2 – Key Informant Consultation

We conducted two focus groups in June 2007 and August 2007 with a total of 16 participants. We also conducted 10 individual key informant interviews (either face-to-face or telephone) between July and October 2007 with a total of 12 participants (1 interview consisted of 3 key informants). Participants included people living with HIV, researchers, educators, clinicians and policy makers with expertise in HIV and rehabilitation research and represented a range of geographical areas from across Canada and internationally. We asked key informants their thoughts on the important topics in HIV and rehabilitation (Appendix B).

Framework of Research Priorities in HIV and Rehabilitation

Based on gaps in the evidence identified in the literature review and themes that emerged from the key informant consultation, we formulated the *Framework of Research Priorities in HIV and Rehabilitation* (Figure 4). This framework included three main overlapping research priority areas to consider in future HIV and rehabilitation research:

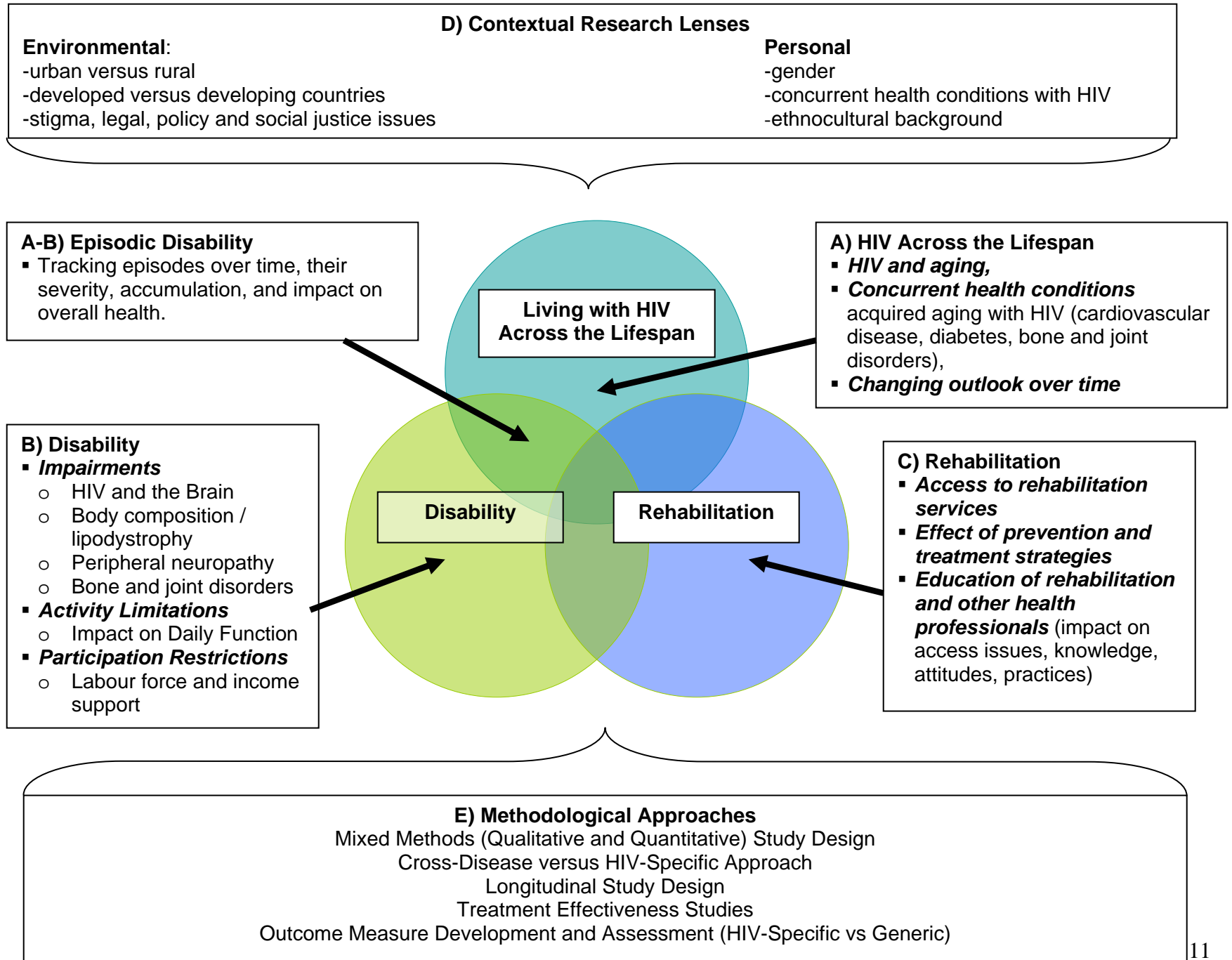
- HIV across the Lifespan** (e.g. HIV and aging, concurrent health conditions living with HIV, and changing outlook over time) (Figure 4, Box A),
- Disability** [impairments (e.g. HIV and the brain, body composition / lipodystrophy, peripheral neuropathy, and bone and joint disorders), activity limitations (e.g. challenges in daily function), and participation restrictions (e.g. labourforce and income support)] (Figure 4, Box B), and

C) **Rehabilitation in the context of HIV** (e.g. access to services by people living with HIV, effect of rehabilitation interventions on the health of people living with HIV, impact of HIV rehabilitation education with future and current health professionals) (Figure 4, Box C).

These research priorities may be explored through a variety of **environmental contextual lenses** (e.g. urban versus rural, developing versus developed countries, and stigma, legal, policy and social justice issues) and/or **personal contextual lenses** (e.g. gender, ethnocultural backgrounds) (Figure 4, Box D). Further, **methodological considerations** for conducting HIV and rehabilitation research included: adopting mixed methods study designs (qualitative and quantitative), considering HIV-specific versus cross-disease approaches, incorporating longitudinal study design (to explore disability over time), increasing the number of rehabilitation treatment effectiveness studies (to explore the impact of interventions), and establishing validated measurement tools in HIV disability and rehabilitation (Figure 4, Box E).

Each of the framework components is described in further detail with supportive quotes from the data, and followed by examples of research questions. Additional data supporting the development of this framework and the research questions are provided in Appendix A.

Figure 4: Framework of Research Priorities in HIV and Rehabilitation



1) Research Priority Themes

A) HIV Across the Lifespan

Key informants described three main research priorities that related to living with HIV Across the Lifespan: a) HIV and aging, b) concurrent health conditions experienced with HIV, and c) changing outlook over time living with HIV.

HIV and Aging

Key informants described the uncertainty related to living with HIV from birth to older adulthood. For those who were diagnosed with HIV at birth, they may be living with various types of disablement as they enter adolescence and adulthood. For those diagnosed prior to the advent of HAART and living with HIV for over 15 years, individuals might be unsure whether their disablement is attributed to HIV, its associated conditions, adverse effects of treatment, or whether it involves a combination. Informants also spoke of the potential to learn from the broader field of research on aging and apply it to HIV:

“In places like Canada we have people getting infected at various agesthere is this group of people like myself, younger generations and older generations that will be facing getting old with HIV which is actually going to be more common... what I’m trying to say here is this is going to be across the board....we will all be getting older and living longer... So ... the research on HIV and aging....needs to be hand in hand with research on aging period.”(INT6)

Example Research Question: What is the physical, social and psychological impact of aging with HIV over the lifespan?

Concurrent Health Conditions Experienced with HIV

As individuals live longer with HIV in developed countries, many may experience concurrent illnesses while aging with HIV. Early onset osteoporosis, osteoarthritis, heart disease, diabetes, increased cholesterol, metabolic disorders, obesity versus wasting, inflammatory arthritis, stroke, transplants, multiple sclerosis and bone and joint disorders were examples of concurrent health conditions identified by key informants. Research should consider the physical, social and psychological impact of living with HIV, concurrent health conditions, and the added complexity and disablement that may arise from these conditions as they may accrue over time living with HIV.

“The new challenges are... the intersection of other chronic diseases” (INT-10)

“we know that we’re going to be seeing more joint and bone issues. We know that osteopenia-related and osteoporosis related metabolic issues are going to be high on the rise. We’re going to be looking at joint replacements for people living with HIV who’ve been on antiretroviral for decades and as the population ages.”(INT5)

Example Research Questions: What types of concurrent health conditions do people living with HIV experience? What are added types of disablement experienced by individuals living with concurrent health conditions with HIV? What are the prevalence and incidence and types of impairments associated with bone and joint disorders in people living with HIV?

Changing Outlook over Time

Key informants described the importance of exploring how one's outlook living with HIV changes over time. The experience of having to 're-invent' oneself from planning for imminent death upon initial diagnosis prior to the advent of HAART, to now faced with planning for the future such as returning to work is important to consider, and to explore how this change in outlook impacts the overall health of individuals.

“Reinventing ourselves ... what are the psychological changes that occur when somebody moves away from the fatalism of waiting to die with HIV into the thinking that ah ... I'm tired of waiting to die from HIV so I want to live again and refocus my life back towards setting goals and priorities that are for a future date... the psychological change and the... personality changes that have occurred ..the way we feel about ourselves and our hope for the future.” (FG1-P5)

Example Research Question: What is the experience of individuals living with HIV for an extended number of years in relation to their disability, rehabilitation and long term outlook over time?

B) Disability

Key informants described a range of research priorities that related to exploring the impairments, activity limitations and participation restrictions that people living with HIV experience.

Impairments and Activity Limitations

Four main areas to explore impairments and activity limitations were identified as research priorities:

- a) Lipodystrophy including the extent and impact of body composition changes, body image issues the impact of wasting versus obesity among people living with HIV, and metabolic issues;
- b) HIV and the brain including the importance of exploring the neurocognitive impairments of HIV and its medical treatments, the impact these might have on functional capacity, and the impact of rehabilitation cognitive treatment interventions for people living with HIV. Areas to explore included types of disablement associated with mild to moderate memory and concentration problems, minor cognitive motor disorder, and HIV dementia;
- c) Peripheral neuropathy; and,
- d) Bone and joint disorders including the impact of osteopenia, osteoporosis, joint replacement, and arthritis.

“I would like to see ... some of the things which are more subtle perhaps sequelae of HIV disease more particularly patients who have been positive for a long period of time ... the mild to moderate memory concentration problems and mild to moderate kind of upper limb problems peripheral neuropathies and I suppose lower limb as well. ...I think there isn't a lot around how do we assess and more importantly what treatment strategies are there for someone with minor sort of minor particularly cognitive changes...” (INT3-R1)

Key informants highlighted the need to explore the nature and extent of disablement experienced with these impairments, the impact these impairments had on daily function (activity limitations), and the types of cognitive or physical rehabilitation interventions that may reduce or prevent these impairments for people living with HIV.

Example Research Questions: What are the prevalence and incidence of cognitive impairments among people living with HIV in Canada? What rehabilitation interventions exist that may prevent or reduce cognitive impairments experienced by people living with HIV (what is their effectiveness)? What other rehabilitation interventions exist that may prevent or reduce physical impairments related to living with HIV? To what extent are these interventions effective (see also “effectiveness of rehabilitation interventions” below)

Participation Restrictions

Labour force and income support, and other social participation issues emerged as specific research priorities that related to participation restrictions. Key informants described the need to explore workplace accommodation for those who would like to return or remain in the workforce, and the need to evaluate a flexible labour force and income support model with people living with HIV. Recommendations also were raised for research to investigate the ‘success stories’ and learn from existing return-to/stay-at-work and income support programs in other jurisdictions across Canada and internationally. Finally, the importance of exploring the differences between barriers and facilitators to work in urban versus rural environments was also highlighted.

“It would be really nice to do some research on HIV positive people who are on medication who haven’t left the workforce. How do they do it?” (FG1-P3)

“It would be useful to research policy models in other jurisdictions about how they set up income security programs, social assistance programs, disability insurance whether private or public to see ... whether those programs and the way they work together actually work better with PHAs than some of the inflexibilities that are found in some of the programs in Canada.” (INT2)

“Identifying some of the most common kinds of disabilities or impairments experienced by people living with HIV in the workplace and then trying to delve deeper and find out well what kind of accommodations have been offered by their employers to deal with whether it’s fatigue or time off for medical appointments or whether it’s allowing people to sort of cycle on and off for you know weeks or months at a time in and out of the workplace.”(INT2)

Example Research Questions: What are the predictors of a successful return to (or stay at) work strategy for people living with HIV? What is the impact of a flexible disability income support program on the health and economic outcomes of people living with HIV, employers, insurers, and government in Canada? How many people living with HIV are experiencing barriers to labour force participation in Canada? What are the primary barriers that people are experiencing? What kinds of rehabilitation / how can rehabilitation mitigate (the impacts of) these barriers?.

Key informants also identified other areas of participation that required further exploration in HIV and rehabilitation research. Social networks, housing, income support, and availability of/access to health and social services were examples of areas highlighted in need of further exploration. Key informants identified the need to establish a better understanding of the extent to which people living with HIV are participating in society, barriers and facilitators to participation, and recommendations of how service delivery could be improved to enhance participation.

“I think the issues have to be better described ...an obvious thing to do would be a survey of PHAs around their key issues in terms of living with HIV ... around social participation but in a variety of arenas. So work... social networks, housing, income supports and on and on it goes. ... move onto understanding how those services are being delivered...where are their service needs and then evaluating both the effectiveness and the accessibility and the availability of those services...” (INT9)

Example Research Questions: What are the key social participation issues / challenges experienced by people living with HIV in Canada? How are services being delivered to address these social participation needs? Are they accessible? Are they effective?

C) Rehabilitation in the Context of HIV

Three main research priorities emerged under the rehabilitation theme:

- a) Knowledge of and access to rehabilitation among people living with HIV,
- b) Effect of rehabilitation prevention and treatment strategies, and
- c) Impact of education of current and future rehabilitation professionals and other health providers on HIV and rehabilitation.

Knowledge of and Access to Rehabilitation

Key informants described the gaps in need and access to rehabilitation services. Given the overwhelming prevalence and diverse nature of disablement experienced by people living with HIV, key informants felt it was important for research to explore the knowledge of rehabilitation among people living with HIV. One priority was to explore the rehabilitation services available to people living with HIV in Canada so that we may establish a map that practically outlines the rehabilitation services available to this population in different jurisdictions across Canada:

“I think one of the important issues is to create all kinds of subway maps. Very flattened, very clear for people to understand. ... I think in terms of rehabilitation we require a bunch of maps so people really see at a glance like when I go and take the subway or the sky train that I see at a glance a number of stations that I have to follow to say get insurance that will protect me throughout my episodic disability ... t or to see how to negotiate my job conditions with a human resources person....the idea of mapping the field is very important.” (INT6)

While a national survey was done in 2004 to explore rehabilitation services from the perspective of rehabilitation professionals and HIV specialist health providers, the extent to which people living with HIV understand and access rehabilitation is less clear (5). Another research priority identified was to explore how many people living with HIV in Canada are accessing rehabilitation, their reasons for accessing these services, and any success these interventions may have in reducing disability experienced by this population, In addition, it will be important to explore barriers to accessing rehabilitation services and the potential impact these barriers (and lack of access to rehabilitation) are having on people’s health and quality of life..

“Now that we know the role for rehab professionals in HIV care, we need to determine whether we are actually delivering it.”(INT8)

“Because ...of the way the epidemic started a world of HIV specialization was created. ... there’s this perception that if it’s HIV you go to the HIV doctor or someone that has HIV in their title and...”

there's this whole rehabilitation system out there that was never created with HIV in mind. How much of that is being accessed... "(FG2-P1)

Example Research Questions: What is the understanding among people living with HIV of rehabilitation in the context of HIV? How many people living with HIV are accessing (or have accessed) rehabilitation services in Canada? What are the barriers and facilitators to accessing rehabilitation services from the perspective of people living with HIV?

Effect of Rehabilitation Prevention and Treatment Strategies

A second research priority was determining the effect of various rehabilitation strategies to prevent or reduce disability. This was also a gap identified in the scoping review as little evidence has documented the effectiveness of varying rehabilitation interventions.

"I think... there are some untapped or under tapped opportunities within rehabilitation as prevention. Prevention of side effects of treatment, especially long-term treatment with antiretroviral therapy as well as the complications of HIV...talking about prevention of Osteopenia and exercise for somebody who's on long-term antiretrovirals. So those preventative interventions... but it's some of the preventative pieces that are... that's a harder sell.... It's less obvious... "(INT5)

Example Research Question: What is the effect of various rehabilitation interventions in preventing or reducing impairments, activity limitations and participation restrictions for people living with HIV in Canada?

Impact of Education on of Health and Rehabilitation Professionals

The third research priority related to rehabilitation included exploring the impact that educating current and future rehabilitation and other health professionals may have for people living with HIV. While there exist curricula and courses that teach about HIV related rehabilitation, very few have been formally evaluated (14). Key informants articulated the importance of evaluating the impact education has on the knowledge, attitudes and practices of these health professionals, and whether this education may translate into enhanced access and delivery of rehabilitation services for people living with HIV.

"I think we have a golden opportunity with Gillian's course that's been developed for health care professionals to be thinking about some research, to be doing some outcome measurement before and after the course, a year after the course, two years after the course like let's design kind of a good little piece of research to follow the participants that take that continuing education course to see what impacts it might have and that wouldn't have to cost a lot but it would need a little bit of thought and hurry up before we start launching it all over the place and actually think ... about how we're going to track our changes and so forth." (FG1-P2)

Furthermore, education research should go beyond audiences of traditional rehabilitation professionals and attempt to engage referring professionals (e.g. physicians, social workers, AIDS Service Organizations) on the roles of rehabilitation to further enhance access to rehabilitation.

"I think the work that's been done thus far within the rehab professionals needs to expand outwards because our gatekeepers are physicians and other health professionals that now need to be able to

recognize... have the back-up support there that they can actually get people to the rehab professionals for the services that they need ...I can't say this enough that will rely upon policy change as well because physicians and other health care professionals will have to be supported monetarily and with other carrots to get them to do the right things to get people to the rehabilitation professionals.” (INT1)

Example Research Questions: What is the impact of HIV education (interprofessional and uniprofessional) on the knowledge, attitudes and practices of current and future rehabilitation professionals and other health providers in Canada? What is the long-term impact of the CWGHR interprofessional learning course?

Overlapping Components

A-B) Episodic Disability

The two overlapping components of disability and living with HIV across the lifespan produced a new research priority termed episodic disability. Key informants described the need to track the major and minor episodes of disability that occur over time, explore the etiology of episodic disability, and the long term impact of these episodes over time.

“How do these impairments play out long-term? Do they play out the same way?” (FG2-P3)

“We haven't done any work on the etiology of the disability. In other words what's causing it? ... I'm thinking about environment issues and things like that that may have an impact on episodic disabilities.” (INT4)

Example Research Questions: What is the nature of episodic disability experienced by PHAs (tracking the episodic nature)? What is the long term outcome of living with episodic but ongoing disability for PHAs? What is the etiology (source) of different types of episodic disability? (this may help to better choose or identify rehabilitation interventions to address it). What are the long term implications of living with multiple episodes over time with HIV?

2) Contextual Research Lenses

In addition to the content-related themes of research, key informants described the different lenses in which a research question could be explored. These lenses were classified as environmental and personal and provide ways in which research questions related to the above content areas could be addressed.

Environmental Contextual Lenses

Three environmental contextual lenses emerged including urban versus rural, developed versus developing countries, and stigma, legal, policy and social justice issues (poverty, multiple vulnerabilities).

Urban versus Rural

Key informants described the differences of rehabilitation and disability issues that may exist for persons living in rural versus urban areas of Canada. Each of the above questions may be explored from both a rural and urban perspective to highlight similarities and differences in experiences:

“Perhaps there’s a different in the rate of episodic disabilities amongst the urban population versus rural.” (INT4)

Example Research Questions: Do differences exist in labour force and income support issues in rural versus urban environments? If yes, what are the similarities and differences?

Developed versus Developing Countries

Key informants described the increasing evidence published about disability and rehabilitation in developing countries. Research conducted in the developing world context may have applicability to people living with HIV in Canada. Future research may explore where disability and rehabilitation similarities and differences exist among people living with HIV across these different environments.

“There also seems to be ... I think... a collapsing of ... the division that’s been ... that sometimes in place about what’s relevant to people in rich countries and what’s relevant to people in poor countries. There are dramatically different contexts and experiences that set the stage for people’s experience with disability and HIV but there’s all kinds of similarities too and so while being respectful of the differences I think we maybe haven’t paid enough attention to where the similarities are too. And so ... yeah I think there could be in terms of the research I think there’s going to be more learning back and forth.” (INT7)

Example Research Question: What are the similarities and differences in disability and rehabilitation for PHAs in developed versus developing countries?

Stigma, Legal, Policy and Social Justice Issues

Stigma, legal, policy and social justice issues emerged as environmental barriers that continue to prevent people living with HIV from fully participating in society. Future research may explore how HIV-related stigma affects access, implementation, success of rehabilitation interventions, or returning to the labour force.

“We have almost no research in Canada on the extent to which discrimination is encountered as a barrier in those kinds of contexts like people living with HIV. There are a few ... small scale studies with maybe a few dozen participants in a few communities across the country but there’s no systematic kind of way of trying to track discrimination as a barrier.” (INT2)

Key informants also highlighted the legal, policy and social justice issues faced by people living with HIV, particularly among persons living in poverty or with multiple vulnerabilities. These environmental barriers may pose challenges to accessing rehabilitation services, maintaining financial independence, or returning to the labour force.

“There are legal and policy barriers or enablers for people getting access to rehab services broadly understood and there are legal and policy barriers or enablers to people actually getting “rehabilitated” in the sense of for example returning to work or continuing with their educational pursuits or engagement in other activities that they want to be involved in...” (INT2)

Example Research Questions: What are the nature and extent of stigma experienced by people living with HIV in the context of rehabilitation? What legal, policy and social justice barriers exist that prevent access to rehabilitation services for people living with HIV?

Personal Contextual Lenses

Three personal contextual lenses emerged from which disability and rehabilitation research may be explored, including: gender, concurrent health conditions living with HIV and ethnocultural backgrounds.

Gender

Key informants described the imbalance of research performed with men compared to women. Informants emphasized the need to explore the disability and rehabilitation experience specific to women, including the potential differences related to life roles and effectiveness of rehabilitation interventions.

“One of the things that became quite startling apparently to me is that there’s very little research being done in the realm of women and how they experience HIV and you touched upon that as well. Womenhave different issues and different roles in the community and how we prescribe exercise... there should be some relevance to ... women’s lived experience with HIV and how we can ...help facilitate rehabilitation and looking at the research around impacts that it will have on women...” (FG2-P4)

Example Research Question: Is the disability experience different for men versus women living with HIV? If yes, how is it different?

Concurrent Health Conditions Living with HIV

Given individuals are living with HIV longer, many may be living with a multitude of concurrent health conditions. This may result in increased health-related challenges for people living with HIV. Key informants stressed the need to better understand the types of concurrent health conditions people living with HIV experience, the types of disablement associated with these conditions, and strategies used to address their sequelae:

“You might want to ... look at the burden of illness... especially around comorbidities and to try to grapple with the two or three comorbidities that we should really spend a little more time on in defining efficacious interventions.” (INT1)

Example Research Question: What are the common concurrent health conditions that people living with HIV experience? What is the impact of living with these concurrent health conditions for people living with HIV?

Ethnocultural Backgrounds

Key informants also highlighted the potential differences in disability and rehabilitation across different ethnocultural backgrounds. Future research may explore any of the above research questions through an ethnocultural lens.

“What are the implications for HIV within different cultural groups and what are the implications for rehab in those groups because they’re different...” (FG2-P2)

Example Research Question: Is disability experienced differently by PHAs across different cultural groups? If yes, how is it different?

3) Methodological Approaches

In addition to the above research priority areas and contextual lenses from which to explore them, key informants described methodological considerations for embarking upon this new program of research. These included: a) adopting mixed methods (qualitative and quantitative) study designs, b) considering an HIV-specific versus cross-disease approach, c) incorporating longitudinal study designs (to explore disability over time), d) increasing the number of rehabilitation treatment effectiveness studies (to explore the impact of interventions), and e) establishing validated measurement tools in HIV disability and rehabilitation.

Key informants emphasized the strength of the Canadian Working Group on HIV and Rehabilitation in approaching research from both a cross-illness or cross-disability perspective, depending on the question. This approach (taken primarily within the labour force and income support realm) has provided a ‘strength in numbers’ approach so that findings from any research may have broader implications for those living with episodic illnesses (not just specifically HIV):

“I also think that there’s probably applicability of work in rehabilitation roles, education, capacity building from other fields of episodic disabilities or other chronic illnesses that could be applied or could be, could be repeated or paralleled with the HIV population that hasn’t been fully explored.” (INT5)

Key informants particularly highlighted the paucity of literature pertaining to treatment strategies and the need to document the effect of different rehabilitation interventions for people living with HIV. Research is needed to document evidence on the ability of rehabilitation to reduce or prevent disability for people living with HIV and may provide evidence to support the need for increased access to rehabilitation for this population.

“I think that we are missing some ... significant research and data in rehabilitation as a whole around the success of intervention and the successes of intervention in HIV and working with people with HIV/AIDS...” (INT5)

Another methodological priority highlighted by informants was the need to identify or develop measurement tools to adequately describe disability experienced by people living with the HIV. Further, it is important for measurement properties of these tools to be determined (e.g. validity, reliability and responsiveness) so that we may be able to accurately and reliably document the impact of different interventions:

*“I think a real priority for research is actually having some outcome measures that we can use.”
(INT3-R1)*

Example Research Questions: What are the similarities and differences of rehabilitation and disability issues experienced across persons living with different types of episodic illnesses? [HIV specific versus cross-illness approach] How is disability experienced over time with people living with HIV? [cohort study design approach] What is the effect of a [rehabilitation intervention] on the impairments, activity limitations and participation restrictions for people living with HIV? [treatment effectiveness study] What measures exist (HIV-specific or generic) that accurately and reliably describe disability experienced by people living with HIV? [outcome measure development].

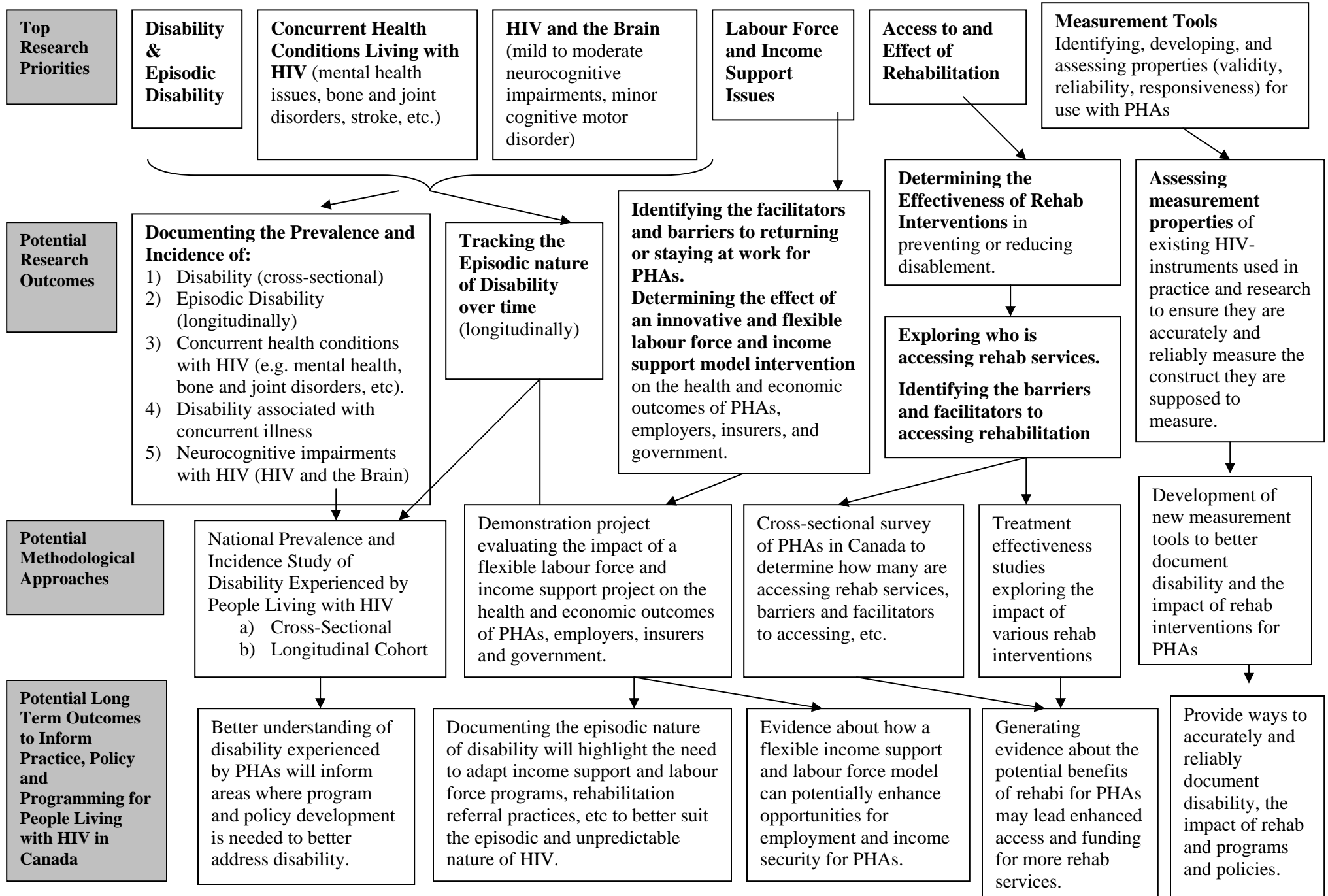
Summary and Recommendations for Next Steps – Top Research Priorities

The *Framework of Research Priorities in HIV and Rehabilitation* (Figure 4) outlines the various areas in which HIV and rehabilitation research is needed. While all of the above areas are important to consider, for the purposes of establishing next steps, we sought to identify the top research priorities that may translate into a plan for future research. Six top research priorities were identified among participants in a one day validity check consultation workshop on February 29, 2008. Results from this consultation are summarized in the *Research Plan for HIV and Rehabilitation* (Figure 5).

- 1) Disability and Episodic Disability
- 2) Concurrent Health Conditions Living with HIV
- 3) HIV and the Brain
- 4) Labour Force and Income Support
- 5) Access to and Effect of Rehabilitation
- 6) Measurement Tool Identification, Development and Assessment

The *Research Plan for HIV and Rehabilitation* highlights the top six research priorities that may be addressed in HIV and rehabilitation research, methodological approaches that may be used to carry out this research and potential short and long term outcomes that may inform and enhance overall practice, policy and programming for persons living with HIV in Canada. Many areas of overlap exist within this plan, and the outcomes and approaches presented are by no means all inclusive. This plan primarily provides an example of areas and ways stakeholders may wish to pursue future HIV and rehabilitation research to address identified gaps in the field.

Figure 5: Research Plan for HIV and Rehabilitation



CONCLUSIONS

In conclusion, this scoping review yielded the *Framework of Research Priorities in HIV and Rehabilitation*. This framework included three main overlapping areas to consider in future HIV and rehabilitation research: A) Living with HIV Across the Lifespan (e.g. aging with HIV, concurrent health conditions, changing outlook over time), B) Disability (e.g. impairments, activity limitations and participation restrictions), and C) Rehabilitation (e.g. access to services, effect of rehabilitation interventions, and impact of education of health care providers on HIV and rehabilitation). These research priorities may be explored through a variety of environmental contextual lenses (e.g. urban versus rural, developing versus developed countries, stigma, legal, policy and social justice issues) and/or personal contextual lenses (e.g. gender, ethnocultural backgrounds), using different methodological approaches (e.g. using a mixed methods study design, considering cross-disease versus HIV-specific approaches, incorporating longitudinal study designs (to explore disability over time), increasing the number of treatment effectiveness studies (to explore the impact of interventions), and pursuing outcome measure development).

Additional consultation identified six top key research priorities from this framework to advance the HIV and rehabilitation field which included:

1. Disability and Episodic Disability,
2. Concurrent Health Conditions Living with HIV (e.g. mental health, bone and joint disorders, cardiovascular disease),
3. HIV and the Brain (e.g. mild to moderate memory and concentration problems, minor cognitive motor disorder),
4. Labour Force and Income Support,
5. Access to and Effect of Rehabilitation, and
6. Measurement Tool Identification, Development and Assessment.

These priorities, potential methodological approaches to address them, and potential short and long term outcomes from this research are summarized in the *Research Plan for HIV and Rehabilitation* (Figure 5). This plan may be used by students, researchers and funding organizations as a way to highlight the current gaps in HIV and rehabilitation research, and suggest future areas in which to pursue research in this area in order to enhance the care, treatment and support of persons living with HIV in Canada.

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Appendix A - Research Priority Themes Expanded Elaboration of the 3 Bubble Themes

Research Priorities	Sub-Categories	Supportive Quotes	Example Research Question(s)
<p>A) HIV Across the Lifespan</p>	<p>HIV and Aging (birth to older adulthood)</p> <p>Concurrent Health Conditions experienced living with HIV (in relation to HIV and potential long term effects of HAART). Examples include:</p> <ul style="list-style-type: none"> -osteoporosis - osteoarthritis - heart disease - diabetes, - increased cholesterol - metabolic disorders - obesity versus wasting - inflammatory arthritis - stroke - multiple sclerosis <p>Consider the physical, social and psychological impact of living with HIV across the lifespan..... the added effect of comorbidities PHAs may have aging with over time.</p> <p>Consider the changing outlook over time living with HIV -re-inventing oneself living with HIV – what it means expecting to die with HIV to now living with a chronic illness.</p>	<p>“Aging with HIV and what we’re going to do with that I think that’s an exceedingly useful thing to research ‘cus who knows what happens 30 years after HIV infection. How chronic management is. Nobody’s been there.... So perhaps that’s something to think about in how we’re going to deal with that. How are you going to deal with an elderly population with those new comorbidities...” (FG1-P5)</p> <p>“In places like Canada we have people getting infected at various agesthere is this group of people like myself, younger generations and older generations that will be facing getting old with HIV which is actually going to be more common... what I’m trying to say here is this is going to be across the board....we will all be getting older and living longer... So ... the research on HIV and aging....needs to be hand in hand with research on aging period.”(INT6)</p> <p>“The new challenges are... the intersection of other chronic diseases” (INT-10)</p> <p>“Reinventing ourselves ... what are the psychological changes that occur when somebody moves away from the fatalism of waiting to die with HIV into the thinking that ah ... I’m tired of waiting to die from HIV so I want to live again and refocus my life back towards setting goals and priorities that are for a future date... and to have that hope for the future... the psychological change and the... personality changes that have occurred ..the way we feel about ourselves and our hope for the future.” (FG1-P5)</p> <p>“Remapping out your life” (FG1-P4)</p>	<p>What are the types of disablement experienced among persons aging with HIV?</p> <p>What is the physical, social and psychological impact of aging with HIV?</p> <p>What types of comorbidities do persons aging with HIV experience in relation to the disease and its treatments (e.g. long term effects of HAART)?</p> <p>What are the added rehabilitation complexities of these comorbidities (osteoporosis, diabetes, etc)?</p> <p>What are the implications for access to health and rehabilitation services for people aging with HIV?</p> <p>What are the similarities and differences of aging with HIV in comparison with other episodic illnesses (e.g. diabetes, multiple sclerosis, Parkinson’s, etc)?</p> <p>What are the similarities and differences in relation to the time of HIV diagnosis? (pre versus post HAART, etc)</p>

Research Priorities	Sub-Categories	Supportive Quotes	Example Research Question(s)
<p>B) Disability</p>	<p>1) Impairments and Activity Limitations</p> <p>Lipodystrophy - body composition changes, body image issues, wasting versus obesity</p> <p>HIV and the Brain -Neurocognitive impact of HIV and its medications and what impact these have on functional ability? - Mild-moderate memory and concentration problems -Minor cognitive motor disorder versus HIV encephalopathy versus dementia - HIV dementia (and how it relates to aging with HIV) - Cognitive rehabilitation interventions?</p> <p>Peripheral neuropathy -pain with peripheral neuropathy and intervention studies (building on the acupuncture work)</p> <p>Bone and Joint disorders and transplants -osteopenia, osteoporosis, joint replacement, metabolic issues, arthritis, organ transplants</p>	<p>“I was talking about minor cognitive changes, weight loss, weight gain, lipo... peripheral neuropathy those sorts of things I’m not sure that we’re as good as we could be at sitting down and saying well what’s important to you... we haven’t perhaps researched enough what’s important for people.” (INT3-R1)</p> <p>“I would like to see ... some of the things which are more subtle perhaps sequelae of HIV disease more particularly patients who have been positive for a long period of time ... the mild to moderate memory concentration problems and mild to moderate kind of upper limb problems peripheral neuropathies and I suppose lower limb as well. ...I think there isn’t a lot around how do we assess and more importantly what treatment strategies are there for someone with minor sort of minor particularly cognitive changes...” (INT3-R1)</p> <p>“... peripheral neuropathies...students are always asking how are we going to treat this and there’s not a lot of research that’s being done from a rehab perspective on how to actually broach those.” (FG2-P4)</p> <p>“we know that we’re going to be seeing more joint and bone issues. We know that osteopenia-related and osteoporosis related metabolic issues is going to be high on the rise. We’re going to be looking at joint replacements for people living with HIV who’ve been on antiretroviral for decades and as the population ages.”(INT5)</p>	<p>What is the impact of cognitive impairments related to HIV and its treatments on functional activities? Engaging in life roles?</p> <p>How do we best assess and treat PHAs with minor cognitive and motor changes? What are some prevention strategies to prevent further deterioration? What are rehabilitation approaches to ensure adequate adherence, nutrition, etc.?</p> <p>What is the incidence of HIV dementia among PHAs? Among PHAs who are aging?</p> <p>What elements of cognitive impairments are attributed to HIV versus age-related dementia?</p> <p>What types of cognitive rehabilitation interventions may be useful for persons with cognitive impairments? What are their effectiveness?</p> <p>What are the effects of treatment interventions for peripheral neuropathy?</p>

Research Priorities	Sub-Categories	Supportive Quotes	Example Research Question(s)
<p>B) Disability (continued)</p>	<p>2) Participation Restrictions</p> <p>Labour force and Income Support</p> <ul style="list-style-type: none"> - Learning from the ‘success stories’ - Exploring workplace accommodation needs for PHAs and the extent to which PHAs are accommodated. - Research other jurisdictions – what is going on in other existing income security programs (how do they work and are they successful? Why or why not?) - Return to work programs - Urban versus rural barriers and facilitators to employment for PHAs. - Returning to school <p>Other Social Participation issues of Living with HIV</p>	<p>“It would be really nice to do some research on HIV positive people who are on medication who haven’t left the workforce. How do they do it?” (FG1-P3)</p> <p>“Some way of showing the benefits and the costs savings of doing a concerted program and then doing a comparison with another program. ...”. (FG1-P8)</p> <p>“It would be useful to research policy models in other jurisdictions about how they set up income security programs, social assistance programs, disability insurance whether private or public to see ... whether those programs and the way they work together actually work better with PHAs than some of the inflexibilities that are found in some of the programs in Canada.” (INT2)</p> <p>“Identifying some of the most common kinds of disabilities or impairments experienced by people living with HIV in the workplace and then trying to delve deeper and find out well what kind of accommodations have been offered by their employers to deal with whether it’s fatigue or time off for medical appointments or whether it’s allowing people to sort of cycle on and off for you know weeks or months at a time in and out of the workplace.”(INT2)</p> <p>“I think the issues have to be better described ...an obvious thing to do would be a survey of PHAs around their key issues in terms of living with HIV around social participation but in a variety of arenas. So work... social networks, housing, income supports and on and on it goes. ... move onto understanding how those services are being delivered...where are their service needs and then evaluating both the effectiveness and the accessibility and the availability of those services...” (INT9)</p>	<p>What is the impact of a flexible disability income support program on the health and economic outcomes of PHAs, employers, insurers, government in Canada?</p> <p>What are the predictors of a successful RTW or stay at work strategy?</p> <p>What kinds of accommodation are needed by PHAs in the workplace? What currently exists in the workplace for accommodation? Is it adequate? Why or why not?</p> <p>What policy models exist in labour force, income support and workplace accommodation in other jurisdictions?</p> <p>How many PHAs with episodic disability are experiencing barriers to employment in Canada?</p> <p>What are the key social participation issues experienced by PHAs in Canada?</p> <p>How are services being delivered to address social participation needs? Are they accessible / available? Are they effective?</p>

Research Priorities	Sub-Categories	Supportive Quotes	Example Research Question(s)
<p>A-B) Episodic Disability</p>	<p>Tracking major and minor episodes over time</p> <p>Etiology of episodic disability. What is the source and can we develop strategies to address that source?</p> <p>Explore the long-term impact of episodes over time.</p>	<p>“How do these impairments play out long-term? Do they play out the same way?” (FG2-P3)</p> <p>“We haven’t done any work on the etiology of the disability. In other words what’s causing it? ... I’m thinking about environment issues and things like that that may have an impact on episodic disabilities. “ (INT4)</p>	<p>What is the nature of Episodic Disability experienced by PHAs?</p> <p>What is the long term outcome of living with episodic but ongoing and chronic disability for PHAs?</p> <p>What is the importance of episodic disability to PHAs living in rural versus urban environments.</p> <p>What is the etiology (source) of different types of episodic disability? (this may help to better chose or identify rehab interventions to address it)</p> <p>What is the impact of the environment on episodic disability experienced by PHAs in Canada?</p> <p>What are the long term disability impacts of HAART for PHAs?</p>

Research Priorities	Sub-Categories	Supportive Quotes	Example Research Question(s)
<p>C) Rehabilitation</p>	<p>Knowledge of and Access to Rehabilitation</p> <p>Mapping the field of resources available to PHAs.</p> <p>Access and delivery issues related to social participation, housing, work, stigma and discrimination, isolation, etc.</p>	<p>“That I think is important information for people with HIV to have in an accessible format because it helps them navigate especially if they’re trying to make informed decisions ...it would be useful to pull that kind of information together and keep it updated for people.” (INT2)</p> <p>“I think one of the important issues is to create all kinds of subway maps. Very flattened, very clear for people to understand. ... I think in terms of rehabilitation we require a bunch of maps so people really see at a glance like when I go and take the subway or the sky train that I see at a glance a number of stations that I have to follow to say get insurance that will protect me throughout my episodic disability ... t or to see how to negotiate my job conditions with a human resources person....the idea of mapping the field is very important.” (INT6)</p> <p>“Now that we know the role for rehab professionals in HIV care, we need to determine whether we are actually delivering it.”(INT8)</p> <p>“Because ... of the way the epidemic started a world of HIV specialization was created. ... there’s this perception that if it’s HIV you go to the HIV doctor or someone that has HIV in their title and... there’s this whole rehabilitation system out there that was never created with HIV in mind. How much of that is being accessed...” (FG2-P1)</p>	<p>What is PHAs’ understanding of rehabilitation in the context of HIV?</p> <p>What are the barriers and facilitators to accessing rehabilitation for PHAs?</p> <p>How many PHAs are currently accessing rehabilitation?</p> <p>What are ASOs’ understanding and knowledge of rehabilitation in the context of HIV? – do they know how to refer? Do they know the cost of rehab services for their clients?</p> <p>Are PHAs accessing rehabilitation care? – If not, what are the barriers?</p> <p>What is the knowledge and understanding of rehabilitation among hospital staff?</p> <p>What is the current level of education and knowledge among PHAs? Employers? Insurers? Etc. about barriers or the role of policy in Labour Force and Employment?</p>

<p>C) Rehabilitation (continued)</p>	<p>Effect of prevention and treatment strategies -Potential for rehabilitation to reduce or prevent adverse effects from HIV or its medications.</p> <p>Education of rehabilitation professionals (effect on access issues, knowledge, attitudes, practices)</p>	<p>“I think... there are some untapped or under tapped opportunities within rehabilitation as prevention. Prevention of side effects of treatment, especially long-term treatment with antiretroviral therapy as well as the complications of HIV....talking about prevention of Osteopenia and exercise for somebody who’s on long-term antiretrovirals. So those preventative interventions... but it’s some of the preventative pieces that are... that’s a harder sell.... It’s less obvious...” (INT5)</p> <p>“I think we have a golden opportunity with Gillian’s course that’s been developed for health care professionals to be thinking about some research, to be doing some outcome measurement before and after the course, a year after the course, two years after the course like let’s design kind of a good little piece of research to follow the participants that take that continuing education course to see what impacts it might have and that wouldn’t have to cost a lot but it would need a little bit of thought and hurry up before we start launching it all over the place and actually think ... about how we’re going to track our changes [changes] and so forth.” (FG1-P2)</p> <p>“I think the work that’s been done thus far within the rehab professionals needs to expand outwards because our gatekeepers are physicians and other health professionals that now need to be able to recognize... have the back-up support there that they can actually get people to the rehab professionals for the services that they need ...I can’t say this enough that will rely upon policy change as well because physicians and other health care professionals will have to be supported monetarily and with other carrots to get them to do the right things to get people to the rehabilitation professionals.” (INT1)</p>	<p>What are prevention strategies and their impact in HIV and rehabilitation?</p> <p>What is the impact of HIV education (IPL and uni-professional) among current and future rehabilitation professionals and other health care providers in Canada?</p> <p>What is the long term impact of the IPL course? Pre-post measurement of knowledge, attitudes and practices?</p>
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Contextual Research Lenses	Sub-Categories	Supportive Quotes	Example Research Question(s)
Environmental Contextual Lenses	<p data-bbox="415 261 783 326">Urban versus Rural Environments</p> <p data-bbox="415 431 783 496">Developed versus Developing Countries</p> <p data-bbox="415 870 783 1032">Stigma - how HIV-related stigma affects access, implementation, success of rehabilitation interventions, returning to work, etc.</p> <p data-bbox="415 1138 783 1235">Legal, Policy and Social Justice Issues (poverty, multiple vulnerabilities)</p>	<p data-bbox="798 261 1499 358">Perhaps there's a difference in the rate of episodic disabilities amongst the urban population versus rural. (INT4)</p> <p data-bbox="798 431 1499 829">There also seems to be ... I think... a collapsing of ... the division that's been ... that sometimes in place about what's relevant to people in rich countries and what's relevant to people in poor countries. There are dramatically different contexts and experiences that set the stage for people's experience with disability and HIV but there's all kinds of similarities too and so while being respectful of the differences I think we maybe haven't paid enough attention to where the similarities are too. And so ... yeah I think there could be in terms of the research I think there's going to be more learning back and forth. (INT7)</p> <p data-bbox="798 870 1499 1097">We have almost no research in Canada on the extent to which discrimination is encountered as a barrier in those kinds of contexts like people living with HIV. There are a few ... small scale studies with maybe a few dozen participants in a few communities across the country but there's no systematic kind of way of trying to track discrimination as a barrier. (INT2)</p> <p data-bbox="798 1138 1499 1365">There are legal and policy barriers or enablers for people getting access to rehab services broadly understood and there are legal and policy barriers or enablers to people actually getting "rehabilitated" in the sense of for example returning to work or continuing with their educational pursuits or engagement in other activities that they want to be involved in... (INT2)</p>	<p data-bbox="1514 261 1919 423">Do differences exist in labour force and income support issues in rural versus urban environments? If yes, what are the similarities and differences?</p> <p data-bbox="1514 464 1919 691">What are the similarities and differences in episodic disablement among PHAs in developed and developing countries? Rehabilitation service delivery? Access issues? Effect of treatment?</p> <p data-bbox="1514 870 1919 1000">What is the nature and extent of stigma experienced by PHAs in the context of rehabilitation? Work? School?</p> <p data-bbox="1514 1138 1919 1268">What legal, policy and social justice issues exist that impact access to rehabilitation services for persons living with HIV?</p>

Contextual Research Lenses	Sub-Categories	Supportive Quotes	Example Research Question(s)
Personal Contextual Lenses	<p data-bbox="415 264 779 529">Gender and Roles Differences in women versus men in relation to exercise, social participation, interpersonal relationships, different roles (parental roles, work roles, sex trade workers, incarcerated women, etc),</p> <p data-bbox="415 1003 779 1166">Concurrent Illnesses Living with HIV (exploring burden of living with concurrent illnesses with (e.g. depression, stroke, etc.)</p> <p data-bbox="415 1203 779 1235">Ethnocultural Backgrounds</p>	<p data-bbox="804 264 1488 561">One of the things that became quite startling apparently to me is that there's very little research being done in the realm of women and how they're experience HIV and you touched upon that as well. Women ...have different issues and different roles in the community and how we prescribe exercise... there should be some relevance to ... women's lived experience with HIV and how we can ...help facilitate rehabilitation and looking at the research around impacts that it will have on women... (FG2-P4)</p> <p data-bbox="804 599 1488 967">Although I think we're getting better at thinking about women I think we still are living in a time when ... women are still marginalized... We have these women who are ... not valued, we don't think about doing research with them and then we have women who are marginalized in terms of income and then we have people who maybe are you know intravenous drug users, sex trade workers ... there are many, many levels of discrimination I think that happens among the women who are living with HIV and I think we've done a lot of work and there's been a lot of research done ...(INT8)</p> <p data-bbox="804 1005 1488 1167">You might want to ... look at the burden of illness... especially around comorbidities and to try to grapple with the two or three comorbidities that we should really spend a little more time on in defining efficacious interventions. (INT1)</p> <p data-bbox="804 1205 1488 1302">What are the implications for HIV within different cultural groups and what are the implications for rehab in those groups because they're different... (FG2-P2)</p>	<p data-bbox="1520 264 1908 394">Are there different disability and rehabilitation experiences for men versus women living with HIV?</p> <p data-bbox="1520 431 1908 529">What is the impact of exercise for men versus women living with HIV?</p> <p data-bbox="1520 566 1908 761">What impact does the role of being a parent have on the health of women versus men living with HIV? What is the impact of caring for children in the lives of PHAs?</p> <p data-bbox="1520 1005 1908 1167">What are the common concurrent illnesses in which people living with HIV experience? What is the impact of living with these concurrent illnesses with HIV?</p> <p data-bbox="1520 1205 1908 1334">Are there differences in disability and rehabilitation experiences for PHAs in different cultural groups?</p>

Methodological Approaches & Considerations	Sub-Categories	Supportive Quotes	Example Research Question(s)
Mixed Methods Approach	Qualitative and Quantitative Study Design	We've got a lot of ... anecdotal information and qualitative information which I think is very useful but I think we now need to expand on that and put a little face to the scientific rigour of certain interventions and certain conditions for people living with HIV. (INT1)	Not applicable.
Cross-Disease versus HIV-Specific Approach	<p>Research on Episodic Disability using a Cross-Disease Approach</p> <p>Evaluating impact of interventions or policy changes for persons with episodic illness</p> <p>Exploring similar and different rehabilitation and disability issues across different episodic illnesses.</p>	People who live with MS do have similar kinds of unpredictability they can wake up one morning and they can't see. The next morning they can see again. They can wake up one morning and they can't walk to the bathroom but they could yesterday like so I'm not saying it's the same but in some episodic conditions there are striking similarities in that wild unpredictability thing that's so bizarre, so random. (FG1-P5)	What are the similarities and differences of rehab and disability issues experienced across persons living with different types of episodic illnesses?
Longitudinal Cohort Study Design	Using Cohort Study Databases (e.g. OHTN Cohort Study) to document the episodic nature of disability with HIV over time.	I think the other question I think might be of interest is what role would CWGHR play in trying to stimulate an expansion of any work that's going on in these cohorts. To either ask additional questions, to do sub studies because all of this is possible now. All of this is being thought of. So if they did for example next year a series on rehabilitation maybe that would be the focus is to send out surveys to individuals in Ontario. Maybe we can get collaboration of other cohorts as well and get a common set of data that can be used to study individuals and maybe look at interventions they've had and the outcomes they've had and the outcomes that they've had at various times. (INT1)	How is disability experienced over time with people living with HIV?

<p>Treatment Effectiveness Studies</p>	<p>Evaluating effects of different rehabilitation interventions on neurological, musculoskeletal and cardiorespiratory impairments or sequelae of PHAs.</p> <p>Evaluating effect of return to work policy interventions</p>	<p>I think that we are missing some ... significant research and data in rehabilitation as a whole around the success of intervention and the successes of intervention in HIV and working with people with HIV/AIDS.... (INT5)</p> <p>Even if we get just some basic straight forward pragmatic trials of common rehab interventions in HIV that would be wonderful. I'm not sure it needs to aerobic or PRE because I think we've got those bases but all the other things that we talked about ...building the evidence-base for vocational rehab in this group for cognitive stuff in this group for..... all the HIV specific stuff would be very useful... Lipodystrophy rehab ... where's the evidence for that? (INT10)</p>	<p>What is the effect of a [rehabilitation intervention] on the impairments, activity limitations and participation restrictions for people living with HIV?</p>
<p>Outcome Measures</p>	<p>Outcome measure development and property testing. Need to establish adequate HIV-specific outcome measures for rehabilitation.</p> <p>HIV-Specific Versus Generic Measures: Specific measures around lipodystrophy, peripheral neuropathy, quality of life, etc. Consider language and culture and socioeconomic status – applicability of any newly developed questionnaires</p>	<p>I think a real priority for research is actually having some outcome measures that we can use. Because obviously we need to be able to show that our services are effective and I'm thinking particularly from a professionals point of view and to enable us to be able to go to our health authority and say we know that this service is going to be effective because we can look at your patient population, extrapolate it from another population and say we used this outcome measure with these interventions and this was the outcome at the end. The difficulty is the complexity of our patients ... perhaps a lot of the existing tools you've got out there are fine but it would just be nice to have a piece of work that said that it's okay to select from a toolbox or that there is always work to be done but actually do we need something that is specifically for HIV or actually do we need to look at a whole broad range of scales just based on upon the impairments and disabilities that we see... it would be nice to develop some of those specific tools. (INT3-R1).</p>	<p>What measures exist (HIV-specific or generic) that accurately and reliably describe disability experienced by persons living with HIV?</p>

Appendix B – Interview and Focus Group Discussion Guide

Draft Focus Group / Interview Discussion Guide

(Date Last Revised: May 23, 2007)

Introduction (5 minutes)

Thank you for agreeing to participate in this study. As you know, I am (we are) meeting with you to obtain your perspectives and opinions on research priorities and best practices on HIV and rehabilitation. Rehabilitation in the context of this research is defined broadly as all services and activities that address or prevent impairments, activity limitations and participation restrictions experienced by an individual. Impairments include things going on at the level of a body part such as pain or weakness; activity limitations include problems carrying out a daily task such as walking, and participation restrictions include difficulties with life situations such as the ability to work. These may be attributed to HIV or its associated treatments. I am (we are) interested in hearing about what you think are the priorities in HIV rehabilitation research that might advance policy and practice in the field, and what you think should be the guiding principles for the development of best practice guidelines targeted to the unique challenges of rehabilitation in the context of HIV. These are 2 different yet related issues that collectively will be used to advance program and policy in the field of rehabilitation and HIV. We would like to obtain your perceptions and opinions on these 2 topics over the course of this discussion.

A few points about confidentiality for the focus group discussion...

- We have asked you here today to talk about your own opinions regarding these issues; you are not representing your institution.
- That said, we may find that some of you have differing opinions and ones which may not be in keeping with the philosophy of your institution.
- We would like to ask you not to reveal the content of this discussion outside of this setting.
- We also ask that you not reveal identities of the other individuals in the focus group outside of this setting.
- At the end of the study you will receive a study summary.
- You may want to discuss some of the findings. We will make every effort to facilitate this, perhaps by getting the group together again to discuss in a follow-up focus group discussion.
- Having made these requests we can not guarantee that the request will be honoured by everyone in the room. Therefore, we are asking you to make only those comments that you would be comfortable making in a public setting; and to refrain from comments that you would not say in public.

Underlying assumptions and notes for facilitators:

- *This discussion should last for approximately 60-90 minutes.*
- *The focus groups will contain no more than 8 participants*
- *Participants represent various stakeholders in the field of HIV and rehabilitation including those living with HIV, CWGHR Board Members, researchers, educators, clinicians and policy makers in the field.*
- *Focus groups are conducted by two members of study team; one will facilitate group and the other will time-keep and record conversation and group behaviour.*
- *Reminder about when/how they'll receive the gift certificate*

Outline of Focus Group Discussion (for facilitators)

- *introduction & terms of the group*
- *pose open ended question*
- *ask for opinion*
- *ask for alternatives*
- *last 15 minutes: get help to divide into themes*
- *ask if anything else*
- *thank participants*

General Questions on Participant Knowledge and Background in HIV and Rehabilitation

What has been your involvement or role in the area of HIV and rehabilitation?

Objective #1: To Identify Research Priorities and Policy Issues in HIV and Rehabilitation (40 minutes)

What are your **overall thoughts** on the current state of research in the area of HIV and rehabilitation? ... **OR** What do you think are the **important issues** in HIV and rehabilitation?

What do you feel are **strengths** of this research field?

Do you feel are any **potential gaps / weaknesses** in this research field?

If yes, can you expand?

What do you think are important topics for rehabilitation research? Please describe.

Areas of **clinical practice** in HIV rehabilitation? [*may need to provide example*]

Areas of **education** in HIV rehabilitation? [*may need to provide example*]

Areas of **policy and programs** in HIV rehabilitation? [*may need to provide example*]

Are there any other areas of HIV and rehabilitation research that should be explored?

Are any of these areas of research **more important or a greater priority** than others?
If yes, can you explain why?

How might these research priorities be best addressed?

- a) Is there an **order** in which these research priorities should be addressed?
- b) By **whom** should they be addressed by? / Who should be the players involved in carrying out this research? CWGHR? Researchers? Community? Collaborative Team?
- c) What **funding agencies** might be best to apply for funding for this research?
- d) How might this research be best **shared with people living with HIV?**
Researchers? Educators? ASOs? Health care providers?

How can CWGHR use this research knowledge to advance future policy and practice changes in rehabilitation in HIV?

Objective #2: To identify guiding principles that should be considered in the development of best practices for rehabilitation in the context of HIV. (30 minutes)

In recent years, "**best practices**" have been used in sectors such as business, government and health care to provide the highest quality products or services to the public. In health care, best practices may include strategies, activities or approaches which have been shown [through research and other inputs] to be effective at achieving a goal. This goal may be the prevention, care or treatment of a disease or condition. **Clinical Practice Guidelines** or **Best Practice Guidelines** have been defined as "Systematically developed statements (based on best available evidence) to assist practitioner and patient decisions about appropriate health care for specific clinical (practice) circumstances". For example the field of arthritis and other diseases have established best practice guidelines to provide recommendations to address the needs of persons including rehabilitation and self-care.

Before these guidelines (or recommendations) can be developed, there first needs to be a set of guiding principles that will help to guide the development of these recommendations.

Guiding principles are recommendations or considerations which should be taken into account when developing best practices. For example, a guiding principle for a comprehensive approach to HIV prevention may recommend that people living with HIV should be actively engaged in all stages of the development, implementation and evaluation of HIV prevention policies and programs or that programs to reduce stigma and discrimination must be integral to all aspects of HIV prevention strategies.¹

Today we would like to talk to you about your ideas for guiding principles that should be considered in the development of best practices for rehabilitation in the context of

HIV. For this discussion we define **rehabilitation** (as mentioned earlier) as a dynamic process, including all prevention and/or treatment activities and/or services that address body impairments, activity limitations and participation restrictions for an individual.² Rehabilitation is an important component of care now that persons with HIV are surviving the disease. Rehabilitation interventions like occupational therapy and physical therapy are considered important components of optimal care, alongside medications, for the treatment of many chronic diseases such as arthritis and heart disease.

We/I'd like to ask you about your perceptions of the guiding principles which should inform the development of best practice guidelines for rehabilitation in HIV

Questions:

What is your **experience with, or general knowledge of**, the development or use of best practice guidelines?

In your view, what **considerations should be taken into account** when developing best practices for rehabilitation in the context of HIV?

How might best practice guidelines in HIV and rehabilitation be used? (what might their overall purpose be?, how could they advance practice and policy?)

Who should be involved in the process of developing best practice guidelines for rehabilitation in the context of HIV?

Who could use these guidelines? (e.g. rehabilitation professionals?, policy makers, educators?), **How** might they use them?

Review (15 minutes)

Let's take a few minutes to walk through what we've discussed so far. We've identified some of the key research priorities in HIV and rehabilitation and we've also identified some important guiding principles for the development of best practice guidelines in the field of HIV and rehabilitation.

Summary

Do you have anything else you wish to say about research priorities or best practice guidelines in the area of HIV rehabilitation?

Do you have anything else you wish to say about research or best practice guidelines generally as it relates to your experience working in the field of HIV rehabilitation?

Is there anyone else you think we should talk to about these issues?

For CWGHR AGM Only:

Do you have any thoughts on the types of questions that were asked in this focus group discussion today? What were the important questions asked? Were there any questions missing that we should add to the discussion guide?

Do you have any thoughts or tips for us (Annette and Kelly) on the way we facilitated the discussion today? What did we do well? Is there anything we can do to improve our facilitation of future focus groups and interviews?

What do you think about the order of the 2 topics (research priorities versus guiding principles for practice guidelines). Did you think the order of topics flowed? Do you think it would be best to start with the practice guidelines and move to the research priorities?

Thank you very much for participating in this interview/focus group today. Your responses will help to provide better overview on the important research and practice initiatives in the field and be used for CWGHR to help advance policy and practice in the field of HIV and rehabilitation.

¹ EngenderHealth's Guiding principles for a Comprehensive Approach to HIV/AIDS Prevention, Care and Treatment

¹ Worthington et al 2005, based on ICF Framework, WHO 2001
