Final Report: Rehabilitation Services for People Living with HIV/AIDS: Development of a National Survey of Health Care Provider Groups

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Executive Summary

The aim of this research project was to develop a framework and draft questionnaire as the foundation for a national Canadian survey of health providers to investigate and document issues related to rehabilitation in the context of HIV/AIDS. A national advisory committee was established to help guide the development of the framework, survey questionnaire, and the implementation of the survey. A resource document was developed to provide the investigators and the advisory committee with an overview of the literature in the area of rehabilitation in the context of HIV/AIDS to help shape the development of a future conceptual rehabilitation framework. From this resource document, in consultation with the advisory committee, and with responses from thirteen key informant interviews of individuals with knowledge and expertise in the area of HIV/AIDS, an HIV/AIDS conceptual rehabilitation framework was developed. This framework provides a broad understanding of rehabilitation domains, services and issues in the context of HIV/AIDS. Based on this conceptual framework, and in collaboration with the advisory committee a questionnaire (survey instrument) was developed with the purpose to describe and compare the knowledge, attitudes, and practices of selected health care provider groups (HIV service providers and rehabilitation service specialists) concerning rehabilitation services for people living with HIV/AIDS (PHAs). A sampling frame was developed, and support and endorsement from the various targeted health care provider groups across Canada were sought. Lastly, several research proposals were developed and submitted to the Canadian Institutes for Health Research (CIHR) and the Ontario HIV Treatment Network (OHTN) to implement the survey in order to describe and compare the knowledge, attitudes and practices of selected health care provider groups concerning rehabilitation services for PHAs. The results of the proposed research will shape the development of HIV programs and policies.

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Introduction / Rationale for the Project

The course of diseases associated with HIV infection is continually changing. Since the introduction of highly active antiretroviral therapy (HAART), people living with HIV/AIDS (PHAs) are living longer.[1] HIV disease is increasingly viewed as a chronic, long-term condition rather than a terminal illness. This increased chronicity is mirrored by the increasing prevalence of disability among PHAs, and an increased role for rehabilitation. However, much is unknown about the field of rehabilitation in the context of HIV/AIDS.

In Canada, rehabilitation in the context of HIV disease is at a formative stage. It is critical that baseline information on the understandings and state of rehabilitation in the context of HIV be collected in order to foster cooperation across health care professional groups, HIV/AIDS organizations, PHAs, sectors of government and private industry, and academe. While there is a small core of individuals working to develop practice perspectives and provide education, activity tends to be fragmented and restricted to a few centres where there is high prevalence, such as Toronto and Vancouver. A pilot study to begin to document the prevalence of impairments, disabilities, and handicaps among PHAs in Canada has been conducted; however, no complementary work has been performed to investigate rehabilitation in the context of HIV from a service provider perspective.[2] To this point, little is known about the field of rehabilitation in the context of HIV/AIDS.

The current dilemma is that we have little knowledge about how rehabilitation is placed within the continuum of management of HIV disease. First, the level of knowledge, awareness, and attitudes toward rehabilitation in the context of HIV/AIDS among health care providers is not well understood. Second, current practices and rehabilitation services provided for PHAs are unclear (i.e., the extent to which HIV service specialists refer PHAs to rehabilitation service providers and the extent to which rehabilitation service providers treat PHAs). Third, the geographic and professional variations in clinical practice are not well understood. Fourth, little is known about the service inter-relationships among health care providers – specifically HIV service specialists and rehabilitation service providers, including community based organizations and complementary and alternative therapists. Finally, there appears to be a lack of a comprehensive theoretical framework to guide the development and inform practice in rehabilitation. In a position paper, The Canadian Working Group on HIV and Rehabilitation (CWGHR) identified the lack of knowledge about rehabilitation services provision for PHAs as a major gap in HIV health care.[3] With a framework to help guide rehabilitation practice in the context of HIV/AIDS, and a greater knowledge of rehabilitation service provision, we may more effectively develop the rehabilitation field for PHAs.

The aim of this research project was to develop a framework, draft questionnaire and a proposal for a national Canadian survey of health providers to investigate and document issues related to rehabilitation in the context of HIV/AIDS.

Methodology

Project Setup

Kelly O'Brien (BScPT, MSc(candidate)) was hired as a part time research officer for this research project. A meeting was held with investigators to review the overall timeline, goals and objectives of the project.

Resource Document: A literature search was conducted in the following areas: HIV, rehabilitation in the context of HIV, marginalized populations, complementary and alternative therapies, frameworks, quality of life, quality of life instruments, knowledge and attitudes of practice in the area of HIV/AIDS, and previous surveys of rehabilitation professionals. A resource document was developed to provide investigators and advisory committee members with a background and overview of the literature in this area and to identify key points of consideration for the future development of a rehabilitation framework and a future survey instrument.

Advisory Committee: An advisory committee was formed to help guide the development of the rehabilitation framework and survey instrument. Membership included the following six members from across Canada:

Arlis McQuarrie (School of Physical Therapy, Saskatoon, Saskachewan),
Chris Sulway (PT, St. Michael's Hospital, Toronto, Ontario),
Evan Collins (MD, University Health Network, Toronto, Ontario),
Barney Hickey (RN, Vancouver, British Columbia),
Louis-Marie Gagnon (Maison Plein Coeur, Montreal, Quebec) and
Jim Marianchuk (RN, Toronto, Ontario)

Rehabilitation Framework Development

Key Informant Interviews: The investigators determined that it would be beneficial, because of geographical and professional diversity, to gain a broader consultation regarding the development of a rehabilitation framework beyond the advisory committee. We approached the Ethics committee at the University of Toronto regarding the potential to pursue key informant interviews and gain a broader consultation from individuals with knowledge and expertise in this area. After ethics approval, thirteen key informant interviews were conducted over the telephone with health care professionals working in the area of HIV/AIDS across Canada. Responses from these interviews were used as a basis for discussion at the first advisory committee meeting with respect to framework development, and to help with the content of the survey instrument and writing of the proposal.

Rehabilitation Framework Development: Advisory Committee Meeting #1: A meeting was held in Toronto with advisory committee members and study investigators on May 2nd, 2002. An overview of the study, progress to date and terms of reference for the advisory committee were discussed. The majority of the meeting included discussions on development of the rehabilitation framework that would later facilitate the development of a survey instrument. Discussions regarding the rehabilitation framework and survey included: definition and scope of rehabilitation to be used for the purposes of the survey, purpose of the survey, emerging and current issues to be addressed in the survey, domains to be included in the survey, targeted populations of the survey, goals of the survey, potential research questions to be answered, and potential survey item questions, survey methods and analytic methods were discussed. From these discussions, a rehabilitation framework was developed.

Survey Instrument Development
Draft Survey Development: A draft version of the survey instrument was developed from the framework in consultation with the advisory committee, using responses from key informant interviews, and resources of previous survey instruments such as the Community Pharmacy survey. Questions in the instrument were devised based on the survey goal and objectives. The investigative team reviewed, refined and revised the draft survey instrument, which was then distributed to the advisory committee for their review.

Survey Content Validation and Target Population Consultation
Survey Pre-Test - Advisory Committee Meeting #2: A second advisory committee meeting was held on June 26th, 2002 to discuss the draft survey instrument. Investigators and advisory committee members located in Toronto met at the HIV Studies Unit and others not located in Toronto participated in this meeting via conference call. Advisory committee members provided feedback on the content, comprehensiveness, question wording, response categories, and order of the items of the instrument. Furthermore, potential target populations were discussed including potential professional organizations and contact persons in which to seek support for the survey.
Revision of the Survey: Revisions were made to the survey instrument after consultation with the advisory committee
Re-test the revised survey instrument - Advisory Committee Meeting #3: A third advisory committee meeting was held on August 14th, 2002. Investigators and advisory committee members located in Toronto attended this meeting in Toronto at the HIV Studies Unit and others not located in Toronto participated via conference call. The advisory committee reviewed the revised survey instrument. Further revisions to the survey instrument were made based on the feedback from the advisory committee at this meeting and a final draft survey instrument developed.

Organizational / Professional Group Endorsement / Sampling Frame Development
Sampling Frame: National, provincial and territorial professional organizations and regulatory bodies were contacted for all targeted health care provider groups across Canada to seek support and endorsement of the survey. A sampling frame was developed to establish the professional group support, endorsement, and agreement to participate in the survey for the two targeted health care provider groups: *1) HIV Service Specialists:* HIV physicians (general practitioners, psychiatrists, ID specialists), nurses, dieticians, social workers, psychologists, pharmacists, and 2) *Rehabilitation Service Providers*: occupational therapists, physical therapists, speech language pathologists and physiatrists that may or may not work in the area of HIV/AIDS.

Proposal Development
Canadian Institutes for Health Research (CIHR): A research proposal was developed and submitted to CIHR on September 15th, 2002 and March 17th, 2003 to obtain funds to conduct the national survey of health care provider groups on services for people living with HIV/AIDS. The proposal requested funds for pilot testing and finalization of the survey instrument, implementation of the survey, analysis of results focusing on inter-group as well as regional / provincial comparisons, and dissemination of results to a wide range of professional and HIV research audiences.

The Ontario HIV Treatment Network (OHTN): A second proposal was developed and submitted to the Ontario HIV Treatment Network on October 4th, 2002 requesting funds to conduct a provincial survey of health care provider groups on service for people living with HIV/AIDS. Using the draft survey instrument developed, the proposal requested funds to pilot test and finalize the survey instrument, implement the survey to the targeted health care provider groups via mail and follow-up telephone interviews, analyze results focusing on inter-group as well as regional comparisons, and disseminate results to a wide range of professional and research audiences. Audiences would include: scientific meetings, CWGHR, and the various professional and organizational groups that participated in the survey.

Results

1) Resource Document: A resource document was created by the research team. It summarizes current information on HIV disease, rehabilitation, quality of life, knowledge and attitudes in practice, complementary and alternative therapies, and marginalized population. It was developed to assist the investigators and advisory committee members in the development of an HIV/AIDS conceptual rehabilitation framework.

2) HIV/AIDS Conceptual Rehabilitation Framework: The framework development was based on an extensive review of the literature, consultations with the six members of the Advisory Committee, and interviews with thirteen key informants from across Canada who have knowledge and expertise in the area of rehabilitation in the context of HIV/AIDS. This framework was deliberately constructed with an extensive scope to allow the research team to conceptualize services for PHAs in new and innovative ways. The surveys based on the framework were intended to allow exploration of a wide range of attitudes and perceptions of health service provider groups. The framework includes two intersecting components: first, from the perspective of those living with HIV/AIDS, are issues and disabilities associated with living with HIV. Second, from the service provision perspective, is the concept of rehabilitation, rehabilitation services, and their potential place within the context of HIV/AIDS. At the centre of the model the concepts of rehabilitation and disability meet. Each of these domains will be outlined in the following sections.

Living with HIV/AIDS – Unique Features

HIV may have an impact on many life domains – from the physical to the social and vocational. HIV infection is multi-systemic. It affects multiple body systems, including the musculoskeletal, neurological, and cardiorespiratory systems.[4 5] HAART and other antiretroviral therapies complicate the impact of HIV infection. HIV has become characterized by unpredictable cycles of wellness and illness; therefore, responses to coping with these cycles requires continual adaptation to HIV.[6 7] HAART or other antiretroviral therapies often cause unwanted side effects which impact lifestyle and day-to-day activities. Morbidity resulting from HIV and related treatments varies from individual to individual and may include a variety of *disabilities* identified on several levels: *body impairments* (at the level of the body part or function, e.g., pain), *activity limitations* (limitations at the level of the individual, e.g. ability to walk) and *participation*

restrictions (limitations of an individual's ability to interact with society, e.g., ability to work).[8] It has been found that people living with HIV/AIDS (even prior to progression to AIDS) have greater levels of disability than the general population. This may be seen in areas such as grocery shopping, employment, and social interaction.[9] Participation restrictions such as employment, attending school, and shopping appear to be more prevalent than activity limitations, such as the ability to carry out day-to-day activities.[6 10 11]

Psychological impacts of living with HIV include the stress related to being diagnosed with a life threatening chronic illness with no cure.[12] Furthermore, the unpredictable and unknown course of the illness results in fear.[13] Increased stress is associated with greater depression, greater distress and ultimately to increased HIV symptomology.[12 13] However, emotional and psychological impacts of living with HIV are not all negative: Friedland and colleagues found overall quality of life scores among PHAs to be more positive than predicted.[14] Areas of positive impact include increased commitment to partner, affirmation of identity, and personal growth. Another study found no difference in quality of life in a comparison of HIV positive and negative men.[15]

There are many social and environmental issues faced by those living with HIV/AIDS. Since the long-term effects of antiretroviral therapy are unknown, planning return to work is difficult. In addition, there are issues concerning disability benefits, disclosure of HIV status, workplace discrimination, flexible employment to accommodate the unpredictable nature of the illness, and having to address gaps in work history.[16] In particular, there are return to work issues for those who are living with antiretroviral therapies.

Populations affected by HIV/AIDS are often culturally or financially marginalized. Initially in Canada and the United States, homosexual men were the primary group affected by HIV/AIDS. However, the profile of those impacted by the disease has expanded to include women, intravenous drug users, heterosexuals, aboriginals, and youth.[17] Each population faces different needs, experiences, and health care access issues. A factor that contributes to the marginalization of PHAs is the geographic area in which people live. Little has been written on this in Canada. In the United States, PHAs in rural communities were reported to have difficulty because of access to health services (i.e., traveling to see health care professionals), lack of employment opportunities, and unsupportive work environments.[18 19]
In one American study, access to health care was shown to be a greater issue for people living with HIV/AIDS than those with other chronic illnesses.[20] Limited access to health care services has been shown to adversely affect health-related quality of life for people living with HIV/AIDS.[18 20]

Again, in the United States, women and intravenous drug users were reported to have specific issues, including lower quality of life, greater reductions in energy, more pain, and more difficulties with daily activities.[18 21] Several groups have unique characteristics that may contribute to their marginalization, including seniors living with HIV/AIDS,[22 23 24] and youth.[25 26] These individuals may face a variety of underlying physical, psychosocial, and quality of life issues related to their life stage including disease process, sexuality, discrimination, and issues of chemical dependence. However, women were among the first to report using rehabilitation in the form of exercise as a strategy to maintain their health.[27]

Despite increased medical knowledge, misperceptions still exist in the public at large, resulting in stigmatization and discrimination of people living with HIV/AIDS in Canada.[28 29] Stigmatization and discrimination are experienced in many forms and

issues vary depending on the population (e.g. homosexual men, prisoners, women, aboriginals, sex trade workers, intravenous drug users, youth, or ethno-cultural communities). Discrimination may be experienced at both a personal and social level.[28] Personal stigmatization and discrimination may lead to stress and isolation that may affect the individual as well as family and friends. At a societal level, stigmatization and discrimination may lead to denied employment, insurance, and housing resulting in a social handicap which can make it difficult for people living with HIV/AIDS to assume roles within their community.[5]

Thus, there are distinct physiological, emotional, and societal features that set HIV infection apart from other illnesses. Characteristics such as the unpredictable course and widespread multisystemic infection, complex antiretroviral therapy, stress related to the unpredictable course of infection, return to work issues, marginalization and geographical location, stigma and discrimination are all features that contribute to the distinctive character of HIV disease. Given the changes in treatments and outcomes, PHAs face a bewildering range of life issues as they cope with the demands of HIV. There is a pressing need to investigate the impact and potential challenges these unique features have on the access to, and delivery of rehabilitation services for, PHAs in order to understand how rehabilitation may contribute to the management of HIV.

Rehabilitation in the Context of HIV/AIDS

A. Defining Rehabilitation

The term rehabilitation may have a variety of definitions depending upon the context. Within health care, the term is broadly defined as *the development of a person to the fullest physical, psychological, social, vocational, avocational, and educational potential consistent with his or her physiological or anatomical impairment and environmental limitations*.[30] This definition captures the many life domains as well as the medical conditions and environmental constraints that may affect these domains for any individual. Specific to the HIV context, rehabilitation has been defined as *a range of techniques or interventions that can be applied to maintain, restore, or enhance aspects of health and quality of life.*[3] This definition originates from the service provider perspective with a focus on the potential service activities. Like the previous definition, it frames rehabilitation activities to include many activities directed at improving all aspects of life or well-being of those living with medical conditions. The definition of rehabilitation adopted for the purposes of this study is *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.* This definition is similar to the CWGHR definition, but includes prevention within the range of activities that may be performed, and links rehabilitation activities and services directly to body impairments, activity limitations, and participation restrictions in order to connect the functions of rehabilitation to various service dimensions (Appendix B).

B. Principles

Extracting from the literature, we identified several commonly accepted principles and components that are appropriate to rehabilitation in the context of HIV/AIDS. First, rehabilitation should be *goal oriented*,[31] focused on the achievement of preset goals based on the needs and desires of an individual and the environment. Goals of rehabilitation may be to improve overall health and quality of life through the maintenance, enhancement or restoration of physical, social, functional, psychological and vocational well-being. Second, rehabilitation should be *client centred*.[31] Optimally,

the client is actively involved in all aspects of their rehabilitation including assessment, implementation and evaluation of services. Client-centred care requires that professionals and programs be flexible and that service delivery be organized in a way to best meet diverse client needs and wishes. The extent to which services for PHAs have adopted these goal-oriented and client-centred approaches to rehabilitation is unknown.

C. Cycle of Rehabilitation

Rehabilitation may be viewed as an on-going cycle of assessment, intervention and re-assessment. From this perspective, the initial assessment includes a discussion of the individual's expressed goals for rehabilitation. The rehabilitation professional or team may provide options, or interventions to assist an individual to meet their goals. As an individual's needs may change, it is important to have ongoing monitoring to ensure optimal progress and ensure the individual's needs are being met.[31] As in the case of the principles of rehabilitation discussed above, there is no clear understanding about the extent to which these components are applied in light of the characteristic chronic and cyclical illness of HIV infection.

D. Rehabilitation Services

In the field of HIV/AIDS, many health and social service providers may be considered rehabilitation professionals. These include traditional providers such as occupational therapists, physical therapist, social workers, and speech language pathologists, and as well other providers such as individuals working in AIDS service organizations or complementary and alternative therapists. [5 31 32 33 34 35] In some geographic areas an extensive network of resources has been constructed to meet the needs of people living with HIV/AIDS. The emergence of AIDS-service organizations (ASOs) has had a unique role in the empowerment of people living with HIV/AIDS – ASOs have adopted key roles in advocacy, education, and ensuring that a strong network of support is available for PHAs.[36] Also distinct among HIV populations is the way individuals have sought out innovative alternative and complementary health care. Complementary and alternative therapies refer to therapies other than conventional Western medicine.[31] The forms of complementary and alternative therapies listed in the literature vary widely, and range from herbal remedies, to hands-on body therapies to mind-body interactions. Reports show that nearly 80% of the HIV population in Ontario have used some form of complementary or alternative therapy at some point.[37] Reasons given for uptake of complementary and alternative therapies may be to maintain health, to diminish side-effects associated with medications, to maximize quality of life, as an alternative to Western medicine, or as survival mechanisms.[38] In addition to complementary and alternative therapies, families, caregivers and the overall social network of an individual may have strong rehabilitative roles for PHAs. In this broader context, members of an individual's family or caregivers may also be considered rehabilitation service providers. Despite the numerous provider groups and informal supports that may be involved in the rehabilitation of PHAs, the knowledge and skills these providers possess, the services they provide, their respective roles, and the extent to which they overlap is unclear and needs to be documented.

E. Rehabilitation Settings

Rehabilitation professionals may work in a variety of settings. Traditional health service providers such as physical therapists, occupational therapists and physicians

may be found in traditional settings such as hospitals. However, this may be changing as there is increased emphasis in some jurisdictions towards the privatization of these professional services. Traditional and non-traditional therapists, such as complementary and alternative therapists, social support groups, community workers and legal counselors, may be accessed beyond the traditional health care setting in community centres, or even in the client's home.[39]

F. Rehabilitation Partnerships and Roles

Current health care practice emphasizes the importance of a collaborative partnership between an individual and members of a rehabilitative team. Communication and the coordination of care among professionals and others working with the client are seen as key components to rehabilitative success.[39] An inter-professional approach may include providers from a variety of disciplines. In addition, the nature of the relationship between an individual client and a health care provider may vary. For example, a client's involvement in decision-making may depend on the client as well as provider preferences. Urowitz and colleagues examined preferences of decision-making among PHAs and found that contrary to expectations this population would prefer a shared decision-making role with their health care providers.[40] This relates to individual medical decision-making specifically; however, it is not known how decision-making occurs around social aspects that may be dealt with by rehabilitation professionals.

Given the range of life domains in which rehabilitation professionals and others may influence the rehabilitation of a PHA, there are many non-traditional areas where rehabilitation professionals have a potential role. An expanded role for rehabilitation professionals exists in the field of HIV/AIDS in areas of education, clinical practice, research and policy.[41] First, rehabilitation professionals working with PHAs may have a strong role as educators of current and future health care providers, members of the HIV community, caregivers and the general public. For example, education in health promotion programs and return to work issues may play a key part in rehabilitation management. Second, in the area of clinical practice, rehabilitation professionals are in a strategic position to become case managers for PHAs. Case managers have been associated with enhancing quality of life and survival for PHAs.[42] In a case management position, through the development of partnerships rehabilitation professionals may be responsible for client advocacy and coordination of appropriate services. Research and policy-making are other areas in which it is felt that rehabilitation professionals have a role to play in services development for PHAs.[43] The extent to which rehabilitation professionals engage in these activities is unknown.

In summary, rehabilitation providers appear to have a great deal to offer those living with HIV/AIDS as they cope with the multiple demands and ongoing life decisions required by HIV. However, there is much that has not been documented in the area of rehabilitation services in the context of HIV/AIDS. There is little understanding of the members that comprise the rehabilitative health care team for PHAs, their level of knowledge, the roles they perform, the environments in which they practice, and the nature of the relationships among health care providers and between health care providers and PHAs. As well, in the light of the expanded role for rehabilitation, the extent to which health care providers are currently involved in practice, education and research in the context of HIV/AIDS is unknown. The knowledge, awareness and extent of involvement of rehabilitation professionals in the area of HIV/AIDS urgently needs to be explored. Similarly, the extent to which HIV service specialists, such as HIV

physicians, are aware of rehabilitation and refer clients to rehabilitation is unknown. There is a pressing need for a survey to examine these questions.

3) Survey Instrument

The HIV/AIDS conceptual rehabilitation framework provided the structure upon which to base the survey. The range of issues identified through the framework were used to design a draft survey instrument to address rehabilitation service provision issues for PHAs. The survey was developed from the framework in consultation with the advisory committee, using responses from key informant interviews, and resources of previous survey instruments such as the Community Pharmacy Survey.[44] It was determined that for the purposes of this survey, two groups of professionals would be targeted, including rehabilitation service providers and HIV service specialists. While many other aspects of rehabilitation service provision, such as complementary and alternative therapy and community based organization involvement, were also of interest, it was decided that at this early stage of investigation it would be premature to include these groups. (However, it was determined that questions about these groups' involvement would be posed on the survey.) Questions in the instrument were devised based on the specific survey goal and objectives identified by investigators and the advisory committee as knowledge gaps in the area of rehabilitation in the context of HIV/AIDS.

4) Sampling Frame

A sampling frame was developed based on organizations of the targeted health care provider groups of the survey to seek professional group support and endorsement for the survey study. National, provincial and territorial professional organizations and regulatory bodies were contacted for all targeted health care provider groups across Canada. Targeted health care provider groups included:

1) *HIV Service Specialists* (HIV physicians (general practitioners, psychiatrists, ID specialists), nurses, dieticians, social workers, psychologists, pharmacists),
2) *Rehabilitation Service Providers* (OT, PT, SLP) and physiatrists that may or may not work in the area of HIV/AIDS.

The inclusion of people living with HIV/AIDS in the sample was discussed at the advisory committee meeting. While all advisory committee members acknowledged the importance of the perceptions of rehabilitation by people living with HIV/AIDS, it was decided that this was not the stated purpose of the project and was beyond the scope of this project. However, the conceptual framework that was developed may be used by a variety of groups including people living with HIV/AIDS.

5) Proposal to CIHR and the OHTN: Research Plan to Implement the Survey

A research proposal was developed and submitted to CIHR on September 15th, 2002 and March 17th, 2003 to request funds to conduct the national survey, and submitted to the Ontario HIV Treatment Network on October 4th, 2002 to obtain funds to conduct a provincial survey of health care provider groups on services for people living with HIV/AIDS. The purpose of the proposed research was to describe and compare the knowledge, attitudes, and practices of selected health care provider groups concerning rehabilitation services for PHAs, by collecting information through a national survey. The proposal requested funds to pilot test and finalize the survey instrument, implement the survey to the targeted health care provider groups via mail and follow-up telephone interviews, analyze results focusing on inter-group as well as regional / provincial

comparisons, and disseminate results to a wide range of professional and research audiences such as scientific meetings, CWGHR, and the various professional and organizational groups that participated in the survey.

Evaluation

The proposal stated that the following criteria would be used to evaluate the success of this project: 1) the completion of proposed outcomes of the project (results) and 2) the degree of interdisciplinary, inter-professional, and community (PHAs) collaboration achieved throughout the project.

1) There were five specific outcomes that were produced throughout the course of this project and these fulfill the objectives outlined in the proposal. The outcomes were as follows:

- First, the resource document represents a comprehensive review of the literature in the area of rehabilitation in the context of HIV/AIDS.
- Second, the HIV/AIDS conceptual rehabilitation framework provides a broader understanding of rehabilitation services and issues for PHAs while serving as a basis for the development of the future survey instrument.
- Third, the survey instrument that was rigorously developed, pre-tested and modified by investigators and advisory committee members.
- Fourth, the sampling frame which included a comprehensive national review of the support and endorsement from the targeted health care provider groups of the survey.
- Finally, the development of three research proposals that outline a research plan for national and provincial surveys of selected health care provider groups on rehabilitation practice and service issues in the context of HIV/AIDS.

2) All processes and outcomes of this research project were a result of extensive collaboration and consultation with the advisory committee of this project. The advisory committee was key in shaping the development of the HIV/AIDS conceptual framework, the established goals and objectives of the survey instrument, development and pre-testing of the survey instrument, and the development of the methodology to carry out the survey implementation reflected in the research proposals. The advisory committee included representatives from various health care provider groups, people living with HIV/AIDS, and representatives from all regions of Canada. Due to financial limitations in size of the advisory committee, additional and broader consultation was sought with thirteen additional key health care providers that possessed knowledge and expertise in the area of rehabilitation in the context of HIV/AIDS to further shape and provide input into the various stages of this project.

Thus, the completion of the five outlined results, as well as the extensive consultation and collaboration with representatives from the various health care provider groups and HIV community demonstrate the overall highly successful completion of this project.

How This Project Meets CWGHR Priorities

The proposed research project directly addresses priorities identified by the Canadian Working Group on HIV and Rehabilitation in their national environmental scan in 2001. The Canadian Working Group on HIV and Rehabilitation is a multisectoral, multidisciplinary group of experts in rehabilitation in the context of HIV, comprised of people living with HIV, representatives from AIDS service organizations, health care professionals, private industry, and government. The environmental scan sought to reveal emerging and unaddressed issues for people living with HIV in Canada with respect to rehabilitation, and included a literature review, key informant interviews and an extensive consultation process. This project directly addresses one of the priorities identified during this process.

This research project will provide a national response to, and advice on, rehabilitation in the context of HIV disease. The theoretical framework created as a component of this project will facilitate a broader understanding of the profile of rehabilitation services and issues in the context of HIV/AIDS. The rigorous development of the survey instrument and research plan in consultation with the national advisory committee has resulted in an instrument that has the potential to broaden the knowledge of rehabilitation service issues and practices in Canada. When implemented, the results of this survey will enhance knowledge and awareness about the state of health care rehabilitation practices with respect to HIV in Canada in the following areas: current practices, experiences and services provided; knowledge and attitudes of health care provider groups; potential education and training needs of health care providers; relationships between health care provider groups; provincial and regional practice variations; and emerging professional and service issues in the area of rehabilitation in the context of HIV/AIDS.

How To Ensure Others Will Benefit From This Project (Dissemination)

In order to ensure that others will benefit from the results and process of this research project, the results will be disseminated to various professional, organizational and community audiences. The research results will be disseminated in the form of publications in peer-reviewed journals and oral and/or poster presentations to audiences of current health care providers, researchers interested in the area of HIV/AIDS, and to community based organizations. Results were presented to the Canadian Working Group on HIV and Rehabilitation (CWGHR) at their national meeting in December 2002. Poster presentations based on the rehabilitation framework have been accepted for presentation at the Annual Canadian Conference on HIV/AIDS (CAHR) in April 2003, and the Canadian Public Health Association Meeting in May 2003. In addition, we are in the process of submitting a manuscript for publication in the peer-reviewed journal, *AIDS Patient Care and STDs*.

The proposal for the survey study includes extensive dissemination plans, including distribution of a report summarizing findings for all organizations that participate in the survey, presentations to academic and professional associations, and publication in peer-reviewed journals.

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