



**Integrated models of rehabilitation available at the point of care:
Interviews with select programs**

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The purpose of this research has been to identify integrated models of rehabilitation within front line health care. Through the key informant interviews described in this report, we hope to increase awareness of possible collaborations and opportunities for partnerships between and among HIV programs and rehabilitation programs / care providers. Through sharing this report with other stakeholders in the HIV and rehabilitation communities, we hope to initiate conversations and potential partnerships that will improve access to rehabilitation care for people living with HIV.

1.0 Background:

Rehabilitation services available at the point of care are important for the treatment of complex, chronic diseases such as HIV. However, a number of studies point to an under-utilization of rehabilitation services for persons with complex chronic diseases by their health care providers, and an unmet need for rehabilitation services reported by people living with complex chronic diseases. There is no known cure for many of these diseases, and often other concurrent conditions may emerge (e.g. diabetes or osteoporosis secondary to HIV). Therefore it is important to ensure that people living with HIV receive support and treatment over the course of their disease. Rehabilitation professionals such as occupational therapists (OT), physical therapists (PT) and speech language pathologists (SLP) offer non-pharmacological interventions that have both a preventive and therapeutic role in the management of complex chronic diseases. However there are few examples of service delivery models that operationalize a rehabilitation approach to patient care whereby rehabilitation professionals are working with the client, as well as collaborating and communicating with the other members of the individual's health care team. Such models are needed to ensure that persons with complex chronic diseases receive rehabilitation interventions early in the disease process and that their needs and preferences are considered in the continuum of care. Explicit service delivery models would also ensure that rehabilitation services are integrated at the point of care, and that the role of rehabilitation is clearly defined in the continuum of care for complex chronic diseases.

Integrated models of rehabilitation available at the point of care have been recently examined from two perspectives: pan-disease access to rehabilitation services at the point of primary care (McColl et al 2006), and integrated models of care specifically for arthritis (Cott et al 2005, MacKay et al 2008). These Canadian projects included a detailed literature review and synthesis, as well as in-depth consultations with a wide range of stakeholders. The results of these recent Canadian studies provide insights into the successes and challenges of attempting to provide rehabilitation services available at the point of care to people living with HIV. To ensure these findings are applicable in the context of HIV, we sought to interview a small number of representatives from a range of services to determine the critical success factors and other factors involved in planning, running and maintaining rehabilitation services available at the point of care.

The programs discussed in the interviews were identified through a larger web-based search for a range of types and locations of programs and organizations across Canada that provide front line health and social care. Some programs include services for people living with HIV and some focus specifically on other diseases (e.g. arthritis or Multiple Sclerosis) where the model of integrated rehabilitation care could be adapted to services for people living with HIV.

2.0 Methods:

Semi-structured interviews were conducted with a small, purposive sample of key informants who represented various models of care and/or were known as opinion leaders in the provision of rehabilitation at the point of care. All worked within publicly-funded health care systems. Key informants were selected for representation of complex chronic diseases, practice sectors and geographic variation. Key informants were selected to represent various professions, practice sectors, and geographic areas (i.e. rural vs. urban). The interviews followed a semi-structured format. Participants were interviewed in March 2009. Potential participants were contacted by electronic mail to enquire about their interest in participating in the study. Participants completed a confidentiality agreement (Appendix A). The interview guide included open-ended questions about structures and processes in the model of care, strengths and challenges, and key components of the delivery of rehabilitation services at the point of care. Interview questions with sample probes are presented in Appendix B. Interviews were conducted face-to-face (n=2) or by telephone (n = 4). Interviews ranged from 30 to 60 minutes. Data were analyzed using content analysis and a constant comparative approach.

3.0 Key Findings:

The six participants included:

- [ID1] An OT / Program Manager from a provincially funded rehabilitation service linked to specialty a clinic. The clinic is the only location in the province. Clients attend the specialty clinic and are referred to multidisciplinary rehabilitation program as required. The rehabilitation program is staffed by PTs and OTs. There is also part-time funding for a nurse for bowel/bladder function), social worker, and psychologist to perform neurocognitive testing. The specialty rehabilitation service was established in 1991 as a pilot project and has received ongoing provincial funding ever since. There is no cost to service recipients.
- [ID2] A PT / Research Director for a provincially funded community rehabilitation service which services 95% of the province. PTs, OTs and social workers provide rehabilitation education and services to clients in their home or workplace, at community clinics, in physician's offices, etc. The program was first established in 1948 and is funded provincially. There is no cost to service recipients.
- [ID3] A family physician, formerly practicing at a Community Health Centre (CHC) which provides rehabilitation services (at no cost to clients), now practicing at a Family Health Team (FHT) without direct access to rehabilitation services.
- [ID4] An OT with a multidisciplinary HIV program (established in the 1990s as a hospital based program but then moved to community/out-patient based as people living with HIV began to live longer. The program is now located within a primary care family practice unit and provides provincially funded access to PT, OT, Pharmacist, dietician, nursing, as well as physicians.
- [ID5] A PT at a CHC providing rehabilitation services. The CHC includes a staff of OTs and PTs; kinesiology students help run the fitness program.
- [ID6] A hospice providing on-site and homecare for people living with HIV, including development of a day centre and exploring opportunities to integrate rehabilitation programs into the day program.

Key findings for critical success factors and other considerations could be classified using the system of McColl et al. (2006) who identified recommendations to integrate rehabilitation

services into primary care which can be considered at the clinical (micro-), organization (meso-) and system levels (macro-).

a) Micro-level factors:

team concept, interprofessional trust, communication (McColl et al. 2006)

- All participants had experience with an organization that supports interprofessional teams. In those services providing team rehabilitation services, rehabilitation specialists have a longer than usual work history with the organization and know their colleagues well; this allows programs to determine who the best person is to deal with what issue.
- The primary health care physician discussed the difference between working in a team environment where there was on-site access to rehabilitation services; there are clear benefits to clients from knowing the team and the people with whom they are working. The optimal provision of care is facilitated by the ability to walk down the hall and have a conversation with other professionals on the team.
- All participants cited the importance of trust – for clients and between providers – for all involved “you need to know who you are working with”.
- An added benefit of an onsite care team is that whoever knows the patient best can then intervene at times of crisis. In addition, providers can ask colleagues to monitor patients about whom they are concerned when they are away.
- Access to a longstanding health team may also encourage trust and disclosure especially regarding issues such as substance abuse.
- Client trust is also important in negotiating relationships when the health care provider has ‘control’ over communication with insurance etc.

Important adjunct resources

- All key informants noted the role for access to training and professionals to deal with psychosocial issues. Most often when clients are referred to rehabilitation services it is not only for physical impairments and challenges with participation but there is also an important psychosocial component often beyond the scope of a rehabilitation professional.
- When interdisciplinary program/resources are not available in primary care, the provider places increasing importance of OT versus PT because of the range of topics that OTs cover “because their broad objective is to get people doing what they want to do more easily”. The most helpful interventions in HIV include: OT for participation, PT for strengthening, and an OT led pain management program; acupuncture and massage therapy have also been helpful for some clients.

b) Meso-level factors:

Compensation (McColl et al. 2006)

- Key informants who were in the business of providing rehabilitation services suggested that a global funding strategy best suited the objective of optimal provision of services to clients (versus discipline specific, fee for service). Further, one organization negotiated with the provincial funder to allow classification as a generic ‘rehabilitation provider’ (versus individual head counts for PTs, OTs, etc) to ensure that the service was able to provide the best mix of resources for the current client population.
- Other key informants from primary care discussed the challenges of adding rehabilitation providers to the service when they had to specify number of positions for particular disciplines (e.g. CHC were unable to add to the original request for rehabilitation positions and use money from vacancies in other professionals to provide stop-gap

- funding for rehabilitation services; the FHT has never been able to add rehabilitation providers to funding requests).
- The primary care providers attempt to access specialty services (including rehabilitation) through other chronic disease management program funding models (e.g. healthy aging program or diabetes)
 - At the primary health care level, additional services are also provided by 'pilot' or 'research' funding; therefore these organizations are always trying to find funding opportunities. (e.g. pilot interdisciplinary pain program at FHT includes OT, social work, pharmacy, dietician)
 - There was consensus that trying to use a 'stop gap' measure by negotiating these types of creative practices to make up for funding shortfalls, could also backfire. In at least one situation, the funder suggested that since the organization could attain these services through other methods, funding was not required. From the perspective of the organizations, this lack of certainty in the ability to provide rehabilitation services as a component of optimal care, did negatively impact on service providers' perceived ability to provide the highest quality of care to their clients.

Referral (McColl et al. 2006)

- Of the two specialty rehabilitation programs, one allowed self referral (> 50% of clients seen in 2006-2007); and the other allowed self-referral after the initial referral.
- The CHC accepts referrals for rehabilitation services for community members who are not CHC clients but this service is rarely used.
- The primary health care provider rarely refers to community rehabilitation because of concerns regarding quality of service.

Accountability and Governance (McColl et al. 2006)

- Accountability was discussed in the context of evaluation (section C below).
- Governance challenges included space and mandate. The university affiliated FHT is unable to accommodate rehabilitation students because space is very limited, and the primary objective of the organization is to train primary care physicians (versus rehabilitation professionals); the challenge at CHC was that primary objective is providing service not education so there was a tension between training health profession students and provision of care.
- Participants spoke of the importance of champions to advocate for continuation of services (e.g. specialist linked to multidisciplinary clinic).

c) Macro-level factors:

Population based approach (McColl et al. 2006)

- Several participants discussed that within their care model, rehabilitation professionals often had to provide care beyond professional scope. For example: crisis intervention, advocacy, physiotherapists doing splinting (primary therapist model).
- Specialty rehabilitation services provided telemedicine and other emerging models of care (e.g. allied health professionals in advanced clinical roles) to under-serviced or rural populations.
- An important component of successful specialty rehabilitation services was the emphasis on rehabilitation focused self-management programs; that said, these programs also allowed clients an ability to self-refer back to the program as required.
- From the perspective of the primary care physician – current models of OT and PT don't quite 'get it' when it comes to providing services to people living with HIV.

- From the perspective of the OT – rehabilitation professionals need to better understand alternative lifestyles and accept them without judgment. For example they must be able to discuss sexual practices and harm reduction; the diversity and cultural sensitivity piece is still not adequately addressed in pre-entry-to-practice training programs.
- Most participants felt that very few services provide adequate health services to the most disadvantaged populations.
- Another population challenge is the aging of therapists who are currently working in health service models that are funded at level of program; who will replace these professionals, many of whom have developed advanced expertise and have decades of experience? The compensation in some programs is not competitive to hospital based programs, private clinics or administrative positions.

Evaluation

- Rehabilitation programs that receive ongoing funding felt that building evaluation components into the service from its onset contributed to success in maintaining funding. Even the CHC collects some performance indicators around diseases of interest e.g. diabetes monitoring, asthma, success of the aging at home program by looking at hospitalizations pre- and post program.
- It was pointed out that program evaluation is important not only to funders but also to stakeholders.
- For those not actively evaluating their program it was felt that the move to an electronic chart may help capture quality of care indicators; but most institutions are still far from this.

d) *Emerging Themes*

Access to specialty services including rehabilitation

- The primary care providers attempt to access specialty services (including rehabilitation) for clients with HIV through chronic disease management program funding models (e.g. healthy aging program or diabetes)
- In a discussion regarding the challenge of accessing under-serviced populations such as women living with HIV, it was suggested that many women used to receive care through Sick Children's Hospital who would treat the children and ensure the family received care at the same time.

Components of integrated rehabilitation care for people living with HIV

- Ability to counsel (in a non-judgmental way) regarding harm reduction
- Working with the client to accept the diagnosis
- An evaluation of the client's current living situation. For example, provide functional assessment of persons living with HIV in their home – do they have the equipment they need; make it a part of routine care like monitoring CD4 counts; have regular follow-up; OT home visits are extremely important
- Advocacy – including working to ensure that there is a support network
- Self-management strategies
- PT specific physical interventions (e.g. strengthening)
- Equipment to live at home
- Management of comorbid conditions
- A team that knows each other and knows the patient

4.0 Conclusions:

Interprofessional teamwork is required to provide the best possible primary care to people with complex chronic diseases and is the best model for HIV. Factors that promote effective teamwork, such as interprofessional understanding and trust, clear accountabilities, effective and efficient communications on a number of levels, harmonized compensation methods and a population based approach are key critical success factors for the integration of rehabilitation services at the point of care (McCull et al 2006).

Cott et al (2005) identified the following ten components as important in any model of care for arthritis: collaborative, multidisciplinary teams; provider skill, education, and awareness and client education / awareness; stable and predictable funding; continuity of care across the continuum; regulation to support rehabilitation professionals in the management of arthritis; conceptual approaches or frameworks such as self-management and client-centredness; primary and secondary prevention strategies; timely access to services early in the disease process; community action and development initiatives; and, methods for evaluation. Information derived from the key informants interviewed for this project confirm that these themes are also relevant for the optimal provision of rehabilitation at the point of care for people living with HIV.

5.0 Next steps:

CWGHR will disseminate and discuss the findings of these interviews with our multi-sector and multi-disciplinary stakeholders to determine opportunities for development of new partnerships to promote integration of rehabilitation services into front line care for people living with HIV.

References:

Cott C, et al. A client-centred health service model of primary health care and rehabilitation for arthritis. Working Report 2005-04. Arthritis Community Research and Evaluation Unit, April 2005.

MacKay C, et al. Characteristics of evolving models of care for arthritis: a key informant study. BMC Health Services Research 2008;8:147.

McColl MA, et al. Models for integrating rehabilitation and primary care. Final report. Queen's University, 30 June 2006.

Appendix A. Confidentiality Agreement

**Integrated models of rehabilitation available at the point of care:
interviews with select programs**

CWGHR Confidentiality Agreement

Background: Through web based research and consultation with colleagues, CWGHR has identified a range of organizations or programs that include accessible rehabilitation services for people living with HIV/AIDS (PHAs) and other diseases.

Objective: To interview staff and clients (where possible) in a range of services to identify the range of factors involved in planning, running and maintaining rehabilitation services available at the point of care.

Methods: Interviews will be held with program staff and/or PHAs involved in identified programs to determine how these programs were developed, their structure and operational features, results of evaluations to determine their impact on PHAs and/or adaptability to people living with HIV (i.e. in the case of other disability groups such as multiple sclerosis and arthritis).

Deliverables: A summary of interview results will be developed including key components of integrated models to promote adaptability of these models in other settings.

Funded by: The Public Health Agency of Canada

Terms of agreement: All participants in the *Integrated models of rehabilitation available at the point of care: interviews with select programs* are asked to confirm their understanding of CWGHR's use of anonymized comments or other data. Your organization may be described by some publicly available descriptors (e.g.a primary care clinic providing front line care to persons living with HIV). HOWEVER, direct quotes from participants will be anonymized so they cannot be linked back to a person or organization. CWGHR recognizes that the opinions expressed by individuals do not necessarily represent the opinions of their organization or institution.

I agree to the terms of agreement:

Printed Name: _____ Signature: _____

Date: _____

For CWGHR office use only:

Your organization: _____

Mailing address: _____

Telephone: _____ Email: _____

PLEASE COMPLETE AND FAX TO THE CWGHR CONFIDENTIAL FAX LINE:
1 416 595 0094

Appendix B. Interview Guide

For the purposes of this discussion, when we talk about a wide range of rehabilitation services; we include physiotherapy, OT, SLP, vocational rehabilitation services as well as other regulated health professions such as chiropractic and massage therapy.

Here is the list of questions we hope to cover:

1. Briefly describe your position and experience with the organization. sample probes: Role, setting (e.g. community vs. hospital), years of experience
2. Please describe your organization as to the provision of services or programs for HIV care (scope of care if not HIV specific e.g. primary care including family physicians, nurse practitioners, chiropracist, pharmacist, etc...) Sample probes: Who is target population (stage of disease, age)?
3. What rehabilitation interventions/services are provided/available? Who delivers the services/ interventions? Describe the eligibility and referral processes. Describe the communication processes.
4. How are rehabilitation services funded / What is the pay structure for rehabilitation services ? e.g publicly funded, private insurance, direct pay by patient, other?)
5. How did this approach to programming originate (ie. included in original design of the program or added as needs emerged)
6. Please describe the strengths of this model of care.
7. In your experience, what are the challenges or barriers in this model of care?
8. Have you evaluated the impact of the provision of rehabilitation services in your program? If yes, how?
9. Do you have any challenges in sustaining rehabilitation services within your program?
10. Please describe your perspective on ideal elements for increased access to rehabilitation at the point of care for people living with HIV/AIDS. (e.g. characteristics, structures and processes, eligibility / access to services)
11. Do you know of other programs / settings where publicly funded, accessible rehabilitation services are integrated into front line care for people with HIV? For people with other health conditions?