Rehabilitation and HIV:
Exploring Intersections at the Global Level

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Executive Summary

Why a study exploring rehabilitation and HIV at the global level?

Recent political advances have created a climate whereby international non-governmental organizations and the United Nations are calling for improved *HIV care, treatment and support* for all people living with HIV in the world. Meanwhile, a separate approach called *community based rehabilitation* has evolved in parallel to address the widespread problem of disability in developing contexts.

The two evolving movements of community based rehabilitation (CBR) and HIV care, treatment and support appear to share similarities. For instance, they both locate people living with HIV and/or disabilities at the centre of program planning; both focus on community development; and both subscribe to an integrated, interdisciplinary approach. Despite these similarities, however, the two health care approaches have not been formally compared to date.

What was the purpose of this study?

The purpose of this study is to explore the lessons that can be learned by comparing and contrasting the two approaches of **community based rehabilitation** and **HIV care, treatment and support**, with respect to practice, policy and research.

What methods were used?

- Qualitative, interpretive analysis including literature review of the history, practice and funding of both CBR and HIV care, treatment and support. Sources included peer reviewed journals, websites, meeting reports, position papers, and the popular press.
- Key informant semi-structured interviews of a purposive sample of frontline workers, policy-makers, researchers, funders and individuals working in non-governmental organizations.
- Analysis of interviews and literature for emerging themes on the intersection of CBR and HIV care, treatment and support.

What were the lessons learned?

Lessons Learned
1. Community based rehabilitation and HIV care, treatment and support both subscribe to an interdisciplinary approach to care. However, a difference between theory and practice may exist in HIV care, treatment and support whereby program components operate in parallel to each other as opposed to the integrated interdisciplinary approach.
2. In HIV endemic regions, community based rehabilitation programs must take into account issues related to HIV when program planning.
3. A broader definition of rehabilitation, such as that put forth by the UN definition of community based rehabilitation (1994)[1], could enhance the role of rehabilitation in the context of HIV.
4. Stigma and discrimination are battles which are common for both people with disabilities and people living with HIV/AIDS. Discrimination against HIV or disability can compromise the success of programs.
5. With respect to resource allocation in developing countries, the concerns of people with disabilities and/or people living with HIV/AIDS may hold low priority in the context of broader social issues such as poverty and hunger.
6. Both community based rehabilitation and HIV care, treatment and support appear to benefit from a rights-based approach to advocacy and planning.
7. Political mobilization at community, governmental and global levels is key for initiating change for people living with HIV and people with disabilities.
8. Meaningful involvement of communities and commitment to using local and culturally appropriate resources are vital to program success for both people living with HIV and people with disabilities.
9. HIV and CBR programs share challenges with respect to the sustainability of funding. Funding criteria may be similar for both groups.

What were the conclusions?

This exploratory study revealed numerous similarities and tensions between **community based rehabilitation** and **HIV care, treatment and support**. We hope that these findings will spark dialogue among people working in these important fields regarding mutual lessons to be learned. Further exploration of the intersections between these two approaches is warranted in the hope of accelerating achievements in policy and practice for both people living with HIV and people with disabilities.

Introduction

HIV/AIDS: A Global Crisis

The global prevalence of human immunodeficiency virus (HIV), the precursor to acquired immune deficiency syndrome (AIDS), is a crisis with millions of people infected worldwide. Of the infected population, approximately 96% live in developing countries, the majority of whom live in sub-Saharan Africa.[2] The mid-1990's witnessed an extraordinary advance in the treatment of HIV, as it was the first time effectiveness was shown with the now gold standard treatment antiretroviral (ARV) therapy.

In the context of the developed world, although ARVs were not a cure, the progressive nature of the disease and the life expectancy of people living with HIV/AIDS dramatically improved. For people who can access and tolerate these drugs, the disease process has become cyclical and chronic in nature. Consequently, developed countries like Canada have recognized an expanded role for rehabilitation in general, and specifically physiotherapy, as this population's needs shift from survival to the management of impairments, activity limitations and participation restrictions related to HIV/AIDS (endnote for CWGHR).

With the introduction of effective treatments came a new challenge: access to drugs for all in need. The costs for ARVs are prohibitive and therefore only affordable by high-income countries. Of the 42 million infected people worldwide, only 230,000 people have access to the ARVs.[3] These figures represent a failure to mount a response matching the urgency of the HIV epidemic worldwide, despite recent scientific progress. Furthermore, access to medications is only one of the many sorely lacking elements necessary for tackling the HIV crisis.

What is "HIV Care, Treatment and Support"?

Recent political advances have created a climate whereby international non-governmental organizations (NGOs) and the United Nations (UN) are calling for improved "*HIV care, treatment and support*" for all people living with HIV in the world. HIV care, treatment and support may be thought of as a package of services providing comprehensive care to people living with HIV. According to The Joint United Nations Programme on HIV/AIDS (UNAIDS), this includes:

> …accessible voluntary counseling and testing services; prevention and treatment of HIV related illnesses; palliative care; prevention and treatment of sexually transmitted infections; prevention of further HIV transmission; family planning; good nutrition: social, spiritual, psychological and peer support; respect for human rights; and reducing the stigma associated with HIV/AIDS. Central to these features is the holistic integration of prevention, treatment planning and intervention.[4]

The global care demands of HIV far exceed current international and domestic efforts; the majority of the infected population receives insufficient services. However, changes in the political and social climate have led to pressure for increased access to HIV care, treatment and support worldwide.

In response to this challenge, new efforts have been launched, such as an initiative called *Accelerating Access* in May 2000, in which five UN organizations entered into a partnership with five major pharmaceutical companies. Accelerating Access led to some countries accessing ARVs for as low as US$295 for a year's treatment.[5]

Although some progress was achieved, the cost for the drugs remained too high for many developing countries. In June 2001, at the UN General Assembly Special Session on HIV/AIDS (UNGASS), the unprecedented *Declaration of Commitment* was endorsed by 189 nations around the world. For the first time, treatment and care, including access to ARVs, were specifically recognized as essential elements of the response to the global HIV/AIDS pandemic.[6]

In addition, the *Global Fund to Fight AIDS, Tuberculosis and Malaria*, a public-private partnership intended to reduce the global impact of these three diseases, has prompted further high level political commitment to address the urgent global crisis of HIV/AIDS.[7]

Disability: Another Global Pandemic

Disability affects one in ten people in the world.[8] The response to this staggering health problem has evolved over time. Up to and following World War II, institutionalized rehabilitation was the care strategy used for people living with disabilities. Stigma was an enormous issue for people living with disabilities secondary to physically debilitating diseases such as leprosy.[9] Moreover, in developing countries few rehabilitation services were available at all.

In the early 1970s, "*community based rehabilitation*" (CBR) was developed as a UN initiative to address disabilities at the community level. The main objectives of CBR include development of interdisciplinary programs that rely on local communities as units of action. People living with disabilities are assured equal access to services and enhanced quality of life, through community integration and promotion of human rights.

In 1978, the *Declaration of Alma-Ata*[10] was established which promoted health care as a fundamental human right for all individuals, including those with disabilities. The UN then declared the *Decade of the Disabled (1983 to 1992)*, which led to the adoption of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* in 1993 by the UN General Assembly.[11]

As a result of these declarations and international policies, global awareness was enhanced and an increased number of programs targeting the prevention and treatment of disability were initiated.

What is "Community Based Rehabilitation"?

In 1994, the *UN Joint Position Paper on Community Based Rehabilitation* defined CBR as:

> A strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. [Community based rehabilitation] is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.[1]

Community based rehabilitation programs have been operating successfully for many years. Some examples include the "War Victims Rehabilitation Project"[12] (1996-2001) for persons disabled by war in Bosnia-Herzegovina, Kosovo and Albania.

Another project in Guatemala (1999-2001) was designed to address the rehabilitation needs of landmine survivors and persons disabled by war. This project helped in increasing awareness through education and training programs, which facilitated social and economic integration of people living with disabilities into their communities.[13]

Meanwhile, an African NGO, Comprehensive Community Based Rehabilitation Tanzania (CCBRT), aims to provide inclusive rehabilitation services for people living with disabilities and people living with HIV. However, in the HIV context, this program has encountered several barriers, including having to cope with the debilitating nature of the HIV disease though reduced workforce, decreased funding and discrimination.[14]

Intersections of Community Based Rehabilitation and HIV Care, Treatment and Support

The two evolving movements of CBR and HIV care, treatment and support appear to share similarities. For instance, they both locate people living with HIV and/or disabilities at the centre of program planning and implementation. They both focus on community development and are both concerned with an integrated, interdisciplinary approach.

Despite these similarities, however, the two health care approaches have not been formally compared to date. In fact, the intersection of these two movements is only now beginning to be considered on the global stage.

It has now become a global priority to address the HIV/AIDS crisis. Accordingly, there is potentially an immense role for rehabilitation worldwide, throughout all stages of the HIV disease process. Similarly, the CBR field could benefit from fresh ideas from the HIV world. Hence, comparing these two models may offer innovative ideas for the people working in these fields.

Purpose

The purpose of this study is to explore the lessons that can be learned by comparing and contrasting the two approaches of CBR and HIV care, treatment and support, with respect to practice, policy and research.

Methods

A literature review was conducted of peer reviewed journals, web based materials, meeting reports, position papers from various international health related organizations and articles from the popular press. The formal search strategy included Political Science Abstracts and Medline (from 1996 to present), with key words such as: HIV; AIDS; CBR; HIV care, treatment and support; politics; and antiretrovirals.

The second phase of data collection involved key informant interviews, either independently or in pairs. Key informants with expertise in CBR and/or HIV care, treatment and support were chosen using a purposive sampling strategy. Participants were sought from the following five stakeholder groups: NGOs, frontline workers, policy makers, researchers/academics and funders (see Appendix A).

Informants were invited to participate via electronic mail. All participants were given a list of interview questions (see Appendix B), a consent form (see Appendix C) and a standardized background information sheet (see Appendix D).

In total, 18 key informants were contacted. 14 subjects accepted, three declined and one did not respond to our initial contact. Of the 14 subjects who accepted, 11 key informants completed the study. Consent forms were obtained via fax, in person or via electronic communication.

Given the global scope of the participants, interviews were conducted face-to-face and electronically. Participants were asked to answer a structured set of open-ended questions, and to provide any extra relevant information. With the participants' consent, the face-to-face interviews were tape recorded and transcribed, and the electronic mail interviews were printed.

During analysis, the research team met for 12 meetings, of two to three hours each. Qualitative analysis was used to identify emerging themes from the 11 interviews. All transcripts were coded[15] for evident themes by all group members individually. Ideas and key words were named and categorized to specific themes through a group effort. Thematic analysis of the data was based on overlaps and differences between CBR and HIV care, treatment and support resulting in lessons to be learned regarding future directions for this field.

Electronic communication may have allowed for a greater risk of subjects not responding, since electronic mail may be lost or unanswered. Additionally, misinterpretation of the questions posed and answers given was found using electronic communication.

Time and financial constraints also limited the scope of this study in terms of number of people interviewed and number of interviews with each participant. As such, this study should be viewed as a first step, designed to spark discussion as opposed to an exhaustive analysis of the study question.

Results

A variety of themes emerged from the analysis of perspectives and experiences of the key informants from the worlds of CBR and HIV care, treatment and support. This section discusses nine key themes and the lessons that may be learned.

Theme 1 - Interdisciplinary Approach: Theory versus Practice

HIV care, treatment and support and CBR share similar ideologies, yet appear to differ in practice with respect to a cohesive and interdisciplinary approach. There was agreement among experts of both CBR and HIV care, treatment and support that an interdisciplinary strategy is necessary to ultimately achieve their goals. For example, as a physiotherapist working in HIV remarked:

> [HIV] involves family care, good nutrition, physical, spiritual and… It's not just the drugs, although that is an important part of it and not just prevention…. It's far more reaching – it's about communities, it's about following the needs the people identify themselves and that struck me as similar to [CBR] in a lot of ways. So I think some of the philosophies underpinning them are quite similar, even though the language might be different.

Community based rehabilitation informants used key words such as "community involvement" and "integrated" to describe their model. They defined the CBR strategy as a cohesive and holistic approach, which aims to improve the quality of life of all people living with disabilities, regardless of diagnosis.

In contrast, as identified by HIV frontline workers, the practice of HIV care, treatment and support tends to exist in segregated components. For instance, prevention efforts and medication delivery often run in parallel to each other instead of as one interdisciplinary unit. As a CBR physiotherapist working in Kenya and Botswana stated:

"Lack of a cohesive, multidisciplinary approach."

> When you look at the activities involved in HIV care, treatment and support, from prevention, counseling, testing, treatment, care and support and many other aspects, it is a huge task involving varied teams of professionals. It may be difficult to have well coordinated activities. Each aspect of the program seems to be working independent of the other.

Therefore, the intended cohesiveness of HIV care, treatment and support, as described in the Declaration of Commitment on HIV/AIDS[16], may differ in theory and practice.

Lesson 1: *Community based rehabilitation and HIV care, treatment and support both subscribe to an interdisciplinary approach to care. However, a difference between theory and practice may exist in HIV care, treatment and support whereby program components operate in parallel to each other as opposed to the integrated interdisciplinary approach.*

Theme 2 - HIV Mainstreaming

HIV/AIDS affects the most productive sector of society in Africa, with enormous socioeconomic consequences. The risk factor of poverty severely affects both disability and HIV.[17] As such, HIV care, treatment and support and CBR experts emphasize that where HIV is prevalent, CBR services provided must take into account the complex issues related to HIV.

"All CBR programs in HIV endemic areas need to have an integrated HIV component."

The head of an African CBR organization stated that, in HIV endemic areas, "no rehabilitation strategy is possible without addressing the specific problems imposed by HIV/AIDS." Likewise, several HIV experts concur that, "where HIV is endemic, everything in those societies needs to incorporate HIV."

Another physiotherapist working in HIV care warned that up to 40% of the trained staff may die of AIDS in HIV endemic areas prior to effective strategy implementation. Correspondingly, a CBR expert in Tanzania stated that his organization is increasingly unable to achieve their main objectives since 27% of their workers have already died from the disease.

He also stated that: "Our rehabilitation programs for disabled people need to recognize and incorporate the specific challenges imposed by HIV/AIDS; otherwise they cannot achieve the objective of 'rehabilitation'."

Lesson 2: *In HIV endemic regions, community based rehabilitation programs must take into account issues related to HIV when program planning.*

Theme 3 – Is HIV Ready for Rehab?

Some key informants suggested that people living with HIV in a developing context will not be at a rehabilitation stage until access to medications and improvement in life expectancy are addressed. For example, an expert in CBR viewed the role for rehabilitation as linked to longevity: "many people living with disabilities live a long time … whereas that's not true for people living with HIV/AIDS."

However, in parts of the world where people can access treatments, people with HIV are living longer lives. A Canada-based HIV expert described a greater shift towards a rehabilitation focus in Canada where there is access to treatment and medication:

> …Well I guess the limitation is trying to get people to see rehabilitation as a potential role in a care model because the way HIV has evolved…was more of a fatal disease and now …it's turned more to what they call this chronic cyclical disease and it hadn't been until then that there's now a role for rehabilitation.

Others suggested that the role of rehabilitation is not linked to longevity, but rather must be redefined according to the needs of the people of the region There can be various interpretations whereby rehabilitation plays a role at all stages of the HIV prevention and care continuum. Some HIV experts see rehabilitation as purely physical; others see it as a holistic, all-inclusive approach.

"The real question is no more whether or not rehab programs in Africa should get involved. The real question is how and to what extent…"

A physiotherapist working in Botswana with an HIV population said: "Most clinicians still view rehabilitation as an unnecessary luxury, hence it is only thought of as a last resort when everything else has failed in their treatment plan."

Other informants suggested a new and innovative role for rehabilitation. For example, a representative of a community based organization in Tanzania that works with a HIV population argued that if rehabilitation is to occur within Africa, then problems specific to the nature of the disease must be addressed.

> … Problems imposed by HIV/AIDS: overall poverty, hunger, lack of medical care, orphans and lack of legal assistance. We need to redefine 'rehabilitation' in the African context according to how AIDS affects the lives of the people…

Thus, some experts advocate for an expanded view of rehabilitation that would enhance its usefulness within a HIV context.

Lesson 3: *A broader definition of rehabilitation, such as that put forth by the UN definition of community based rehabilitation (1994)[1], could enhance the role of rehabilitation in the context of HIV.*

Theme 4 - Stigma and Discrimination

Stigma and discrimination are common battles for both people living with disabilities and people living with HIV. A frontline CBR worker situated in Tanzania described the theme as follows:

> [Society] finds restrictions due to physical impairments disturbing, strange, they don't know what to do with it and those attitudes are the core reason why people with disabilities are discriminated.

Discrimination against HIV or disability can compromise program success and prevent acceptance of the problem in the community. For instance, a physiotherapist working in rehabilitation programs in Botswana stated:

> A community can only fully dedicate itself to a project they understand well and have no fears to associate with. There are also some cultural beliefs and myths some people already have about HIV/AIDS, which makes maximum participation of people in many communities difficult.

"Attitudes of others disable, not just physical restrictions."

In the eyes of one HIV expert, the layers of stigma and discrimination pertaining to HIV care, treatment and support and CBR differ. This NGO representative voiced concern that if people living with HIV were treated within a CBR approach, then the community at large might begin to view HIV as a disability, adding another layer of discrimination to pre-existing stigma.

Both HIV care, treatment and support and CBR approaches identify the need to address stigma and discrimination, regardless of the population being treated (i.e. disability or HIV/AIDS). Key informants from both sides agreed that program success relies on changing the attitudes of society by meaningfully involving people living with disabilities and people living with HIV in the community.

Lesson 4: *Stigma and discrimination are battles which are common for both people with disabilities and people living with HIV/AIDS. Discrimination against HIV or disability can compromise the success of programs.*

Theme 5 – The Bottom of the Ladder

"People living with disabilities are vulnerable and sit at the bottom

Another theme that emerged was the concept that both disability and HIV in developing countries are viewed as low priorities within a daunting list of social issues. As two CBR experts have indicated, in developing countries people living with disabilities "sit at the bottom of the priority list."

When faced with national problems, such as poverty and hunger, rehabilitation and community integration of people living with disabilities may not be seen as high priorities for resource allocation.

Similarly, a physiotherapist involved in global HIV policy found that despite the global concern of HIV/AIDS, there continues to be "denial from the countries themselves and disinterest from the West", thereby putting people living with HIV at the bottom rung of the priority ladder.

She spoke of extraordinary disparities between the standard of care available to people in the developed versus developing world. Thus, people with HIV and disabilities in developing contexts may be considered amongst the lowest priority groups, despite potential for treatment and increased quality of life.

Lesson 5: *With respect to resource allocation in developing countries, the concerns of people with disabilities and/or people living with HIV/AIDS may hold low priority in the context of broader social issues such as poverty and hunger.*

Theme 6 - A Rights-Based Approach

CBR and HIV care, treatment and support may both benefit from a rights-based approach to advocacy and planning. Informants argued that people living with disabilities and people living with HIV deserve full access to health care and full opportunities within society, because it is their right as human beings.

"The concept of human rights is really the key underlying driver."

An activist who examines legal policies in relation to HIV from a human rights position argued that human rights are much broader than equality or non-discrimination for people living with disabilities or people living with HIV:

> You can protect people all you want from discrimination, but if there are no medications to be handed out, no access to rehabilitation services and community supports then you will not be successful with getting care, treatment and support or CBR.

A CBR expert, who has worked in administration and training in programs internationally, explained that in countries with a national poverty crisis, all citizens may not receive equal access to care, particularly people living with disabilities. However, from a CBR perspective: "It is a right of people living with disabilities to be part of the system, to contribute, to make mistakes, shifting them to another level of interdependence within the community."

Likewise, an HIV activist argued that social and economic rights are intertwined with health care rights. He commented that poverty must be addressed as a human rights issue. Poverty leads to lack of access (including affordable medication) and to lack of the right to be a contributing member of the community. He also suggested that "the concept of human rights is often limited on the part of legislators, politicians and policy makers."

In a similar vein, a project manager of CBR programs in Eastern Europe described the philosophy of CBR as broad and inclusive of all people living with disabilities, regardless of diagnosis. Thus, the strategy understands people with HIV or disabilities to be equal participating citizens.

Similar perspectives were brought to light by people involved in HIV care, treatment and support. Thus, addressing human rights issues is a strong component of CBR and HIV care, treatment and support.

"What to do is no longer the challenge – we know exactly what to do and how to do it. What is missing is money and political will."

Lesson 6: *Both community based rehabilitation and HIV care, treatment and support appear to benefit from a rights-based approach to advocacy and planning.*

Theme 7 - Political Mobilization

Informants from the worlds of CBR and HIV care, treatment and support identified the need for advocacy for and by people living with disabilities or people living with HIV to affect change at the government level and improve access to services.

Political mobilization refers to the involvement of community citizens in bringing attention to relevant issues and thereby pressuring the government to initiate legislative and resource allocation changes. For example, a physiotherapist working in HIV in Canada pointed out that the availability of funding and resources may be a result of politicizing HIV/AIDS:

> It's interesting now that HIV rates [in Canada] are significantly dropping and stabilizing…so it'll be interesting in the next 5 years to see whether they can keep the same kind of political pressure to receive the care they need.

An informant from an HIV NGO also addressed the need to change policy in order to improve access: "there needs to be political mobilization from the community and it needs to be backed up by social movements." He believed that:

> Law must be used to try to force governments when they are resisting to actually taking the steps necessary to get drugs to people at an affordable price and to make sure health care services are properly funded.

Similarly, a CBR informant identified the need to involve community citizens to drive social mobilization:

> People with disabilities can be powerful agents of change and if you have a good spokesperson, they could influence government and leaders….people will learn to be self advocates.

Therefore, both groups identify the need for community citizens to be active agents of political mobilization to pressure the government for improved access to health care services.

Lesson 7: *Political mobilization at community, governmental and global levels is key for initiating change for people living with HIV and people with disabilities.*

Theme 8 - Community: The Unit of Action

Experts in both HIV and CBR voiced that effectiveness of programs is highly dependent on involvement at the community level. In HIV/AIDS, this philosophy is characterized by "the GIPA Principle", which stands for Greater Involvement of People with AIDS.[18] This perspective is mirrored in disability communities by the mantra, "nothing about us without us".[19]

"Both [approaches] involve active participation of the community in the care of the patient; both make it possible for the family and community to learn, share and appreciate the HIV/AIDS situation in their communities."

A HIV representative described a South African term *ubuntu* which represents the spirit of giving and sharing in the community context regardless of the reason. This philosophy is integral to both frameworks and emphasizes the need for a community to recognize and own the problems of its members.

Also, it allows communities to define their needs and identify the objectives of rehabilitation programs, which would result in a change of attitudes and empower these individuals to become the drivers of this shift in thinking. Finally, it is important for these communities to become self-sustaining and maintain the success of programs by utilizing culturally specific resources that are available within the community.

Sentiments that community involvement is a key requirement for successful implementation of programs were echoed by a frontline CBR clinician working with an HIV population. He stated:

> As the disabled person becomes more and more active, some of the attitudes of the people around get adjusted and they are willing to get engaged in contributing to giving it a chance…

Similarly, a representative from a NGO focusing on HIV said:

> [We] need to insist on community being at the table, because in particular, people with HIV/AIDS, are people who know the best what their needs are.

Additionally, a member of a NGO for CBR commented that to achieve satisfactory results "culturally appropriate and indigenous" solutions must be embraced to meet the needs of the community. One HIV frontline worker believed that an advantage of CBR was in that it "employs the use of locally available resources and appropriate technology", thus making it inexpensive to operate.

Conversely, he appeared sceptical as to how HIV care, treatment and support could achieve the same strategy, since one of the crucial requirements, ARVs, may only be minimally available in disadvantaged countries, posing a considerable obstruction to the goal of program-sustainability.

Lesson 8: *Meaningful involvement of communities and commitment to using local and culturally-appropriate resources are vital to program success for both people living with HIV and people with disabilities.*

Theme 9 – Challenges in Funding

Program funding criteria, as described by both HIV and disability funders appeared to be strikingly similar. Necessary elements included:

- identifiable groups in which human rights or ethical issues need to be addressed
- community driven programs to ensure sustainability
- incorporation of the target groups into their respective societies
- and quantifiable outcomes.

"They're not going to say you want to make the world a better place? So here's a million dollars."

Experts from both HIV care, treatment and support and CBR stressed that meeting program funding criteria is vital in ensuring the success and sustainability of their programs. As a frontline HIV worker observed:

> One of the successes [in HIV] is that they have politicized it and they turned it into an issue that everyone recognizes and they have managed to get funding because of that.

Community based rehabilitation representatives consider that it may be difficult to 'sell' the idea of CBR to funders because it is such a broad approach that is all-inclusive. It was also reflected that funders may find it more difficult to support CBR because they cannot attribute their contribution to one identifiable diagnostic.

As a CBR frontline worker stated concerning past methods used to obtain funds: "usually its one organization, well established, things have gone well in the past – then you can get funding."

A difference in funding sources may be found when comparing the frameworks. Community based rehabilitation experts described most of their funding sources as coming from the public sector, whereas HIV care, treatment and support respondents expressed a variety of private and foundation sources. Thus, HIV and community based rehabilitation programs share challenges with respect to the sustainability of funding.

Lesson 9: *HIV and CBR programs share challenges with respect to the sustainability of funding. Funding criteria may be similar for both groups.*

Discussion

Exploring the intersection between HIV care treatment and support and community based rehabilitation with respect to practice, policy and research has created a novel platform for discussion regarding the two approaches. Table 1 summarizes key lessons around similarities and differences, which could serve as a starting point for discussion.

For instance, people living with HIV and people living with disabilities share similar challenges with respect to their status within their communities. Both groups are subject to stigma and discrimination, thereby limiting their opportunities within society as a whole. The concerns of both populations have been described as low priority in the context of bigger problems in society, such as hunger and poverty.

Involvement of people living with disabilities and people living with HIV in program delivery may serve to facilitate acceptance and attitude change at a societal level. This involvement is seen as necessary in order for communities to determine their own needs and to help administer effective programs using indigenous resources.

Another similarity in the philosophies that drive CBR and HIV care, treatment and support is the notion of equal access to all health care services as a human right. This requires movement beyond non-discrimination to ensuring a rights-based approach to health. To this end, informants indicated that both groups should be encouraged to advocate for political and legal change, at community, national and global levels. Furthermore, informants stressed that CBR programs in HIV endemic areas have a responsibility to incorporate issues related to HIV into their work.

Poverty has been shown to be a significant hindrance in providing quality care to disability and HIV groups. As the head of a CBR organization in Tanzania explained, the status of living with a disability not only occurs in poverty-stricken regions, but also predisposes these individuals to a situation of poverty. Poverty may be understood as a perpetuator of both disability and HIV in some developing countries. For this reason, programs should take poverty into account if there is to be any success in alleviating the turmoil of both people living with disabilities and people living with HIV.

Informants in both areas described similar criteria for program funding. These criteria included program sustainability and clearly defined measures of program success. Interestingly, it became clear that although CBR programs seem to be funded largely by the public sector, those providing HIV services reported strong ties to private funding sources. Thus, there could be an opportunity for a wider pool of resources with further dialogue between providers of CBR and HIV care, treatment and support, especially in HIV endemic areas.

HIV care, treatment and support and CBR experts shared a common vision of holistic service delivery. However, various HIV experts voiced different perspectives of rehabilitation. Contrary to the suggestion that rehabilitation can only follow the delivery of medication, some informants stressed a broader, more innovative understanding of rehabilitation that is applicable in all stages of the HIV prevention and care continuum.

Community based rehabilitation is a strategy that has been successfully established with people living with disabilities for over two decades. HIV programs could learn from and work with networks created by existing CBR programs in the region, such as accessing local leaders and using existing educational strategies that have proven successful in those environments.

Likewise, the disability community could learn from the exceptional strategies used by HIV advocates to raise global awareness and rally for international support. Therefore, it is evident that experts in both areas could benefit from continued dialogue to enhance their practice and policy.

Table 1 - Lessons Learned for *Community Based Rehabilitation* and *HIV Care, Treatment and Support*

1. Community based rehabilitation and HIV care, treatment and support both subscribe to an interdisciplinary approach to care. However, a difference between theory and practice may exist in HIV care, treatment and support whereby program components operate in parallel to each other as opposed to the integrated interdisciplinary approach.
2. In HIV endemic regions, community based rehabilitation programs must take into account issues related to HIV when program planning.
3. A broader definition of rehabilitation, such as that put forth by the UN definition of community based rehabilitation (1994)[1], could enhance the role of rehabilitation in the context of HIV.
4. Stigma and discrimination are battles which are common for both people with disabilities and people living with HIV/AIDS. Discrimination against HIV or disability can compromise the success of programs.
5. With respect to resource allocation in developing countries, the concerns of people with disabilities and/or people living with HIV/AIDS may hold low priority in the context of broader social issues such as poverty and hunger.
6. Both community based rehabilitation and HIV care, treatment and support appear to benefit from a rights-based approach to advocacy and planning.
7. Political mobilization at community, governmental and global levels is key for initiating change for people living with HIV and people with disabilities.
8. Meaningful involvement of communities and commitment to using local and culturally appropriate resources are vital to program success for both people living with HIV and people with disabilities.
9. HIV and CBR programs share challenges with respect to the sustainability of funding. Funding criteria may be similar for both groups.

Conclusion

The two approaches of HIV care, treatment and support and community based rehabilitation are strategies that have been implemented globally to address HIV/AIDS and disability respectively. In this study, literature was reviewed and informants with expertise in HIV and/or disability were interviewed to glean mutual lessons for practice, policy and research.

Numerous themes emerged which illustrated similarities and tensions between the two movements. We hope that the findings of this study will spark dialogue between the two schools of thought. Further exploration of the intersections between these two approaches is warranted in that hope of accelerating achievements in policy and practice for both people living with HIV and people with disabilities.

Endnotes

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Appendices

APPENDIX A

Key Informant Characteristics

Area of Expertise	Accepted/ Declined	Interview Format
Frontline Worker	Accepted	E-mail interview
Frontline Worker (HIV)	Accepted	Face to face interview in pairs
Frontline Worker / NGO (HIV)	Accepted	E-mail interview
Frontline Worker (CBR)	Accepted	No response to questions (lost to follow up)
Frontline Worker (CBR)	Accepted	No response to questions (lost to follow up)
Frontline Worker (CBR)	Accepted	Face to face interview in pairs
Research/Academic	Declined	
Research/Academic (HIV)	Accepted	Face to face interview in pairs
Research/Academic (CBR)	Declined	
Research/Academic (CBR)	Declined	
Non-Governmental Organization (HIV)	Accepted	Face to face interview
Non-Governmental Organization (HIV)	Accepted	Face to face interview
Non-Governmental Organization (CBR)	Accepted	Face to face interview in pairs
Policy (HIV)	Accepted	E-mail interview
Policy (HIV)	Accepted	E-mail interview
Funder	No Response	
Funder (HIV)	Accepted	Face to face interview
Funder (CBR)	Accepted	No response to questions (lost to follow up)

APPENDIX B

Interview Questions

1. Can you tell me about your experience in CBR and/or HIV care, treatment and support?
   PROBE:
   - What is your role?
   - How long have you been involved?
   - With whom are you involved?
   - What are the limitations/challenges/barriers you have experienced in your work?
   - What has been successful? (Why do you think it worked?)

2. Have you thought about the overlap between CBR and HIV care, treatment and support before?
   PROBE:
   - If YES: What are the similarities and differences that you have found?
   - If NO: Let me tell you a little bit about CBR/HIV HIV care, treatment and support (USE STANDARDIZED BACKGROUND INFORMATION SHEET – SEE ATTACHED). What similarities and/or differences between the two philosophies can you recognize?
   - Do you see lessons from one applying to the other?
   - What comparisons can be made, with respect to practice/policy/research lessons, from CBR and HIV care, treatment and support?

3. What do you think the lessons to be learned from CBR and/or HIV care, treatment and support are?

4. FUNDER ONLY:
   - How did you get involved in the funding of CBR/ HIV care, treatment and support?
   - In what ways do you see your agency/corporation/foundation affecting advances in CBR/ HIV care, treatment and support?
   - In order for you to fund an organization, what are the necessary program criteria?
   - What are your expectations from these organizations?

   OR
   - Have you ever applied for funding for CBR/ HIV care, treatment and support Projects?
   - What kinds of agencies/organizations funded these projects?
   - What were the necessary program criteria that allowed you to get funding successfully?

5. Is there anything that we have not already discussed that you would like to add?

6. Is there anyone else that you know of that we should be talking to as well?

7. Would you like to be identified within the report or would you like us to change your name?

APPENDIX C

Rehabilitation and HIV: Exploring Intersections at the Global Level

Brief Background and Purpose of the Project

HIV is a global epidemic. By the end of the year 2000, HIV had affected 36.1 million people with 90% of the population living in developing countries and 75% in Africa (UNAIDS at Barcelona) [1]. *HIV Care, Treatment and Support* is an approach to providing care to people living with HIV. However, few of these people actually receive HIV Care, Treatment and Support in its fullest form. Due to recent political and social changes, international non-governmental organizations and the United Nations have recognized the need to provide HIV Care, Treatment and Support for all people living with HIV in the world. A separate philosophy, called *Community Based Rehabilitation*, has been developed to address the widespread problem of disability in developing countries. The rehabilitation programs are used in the community to give individuals with disabilities equal opportunities and the means to contribute to society.

HIV Care, Treatment and Support and Community Based Rehabilitation have faced similar challenges with respect to practice, policy and research, and yet the two approaches have not been compared to determine the lessons that can be learned from each. The goal of this study is to compare these two approaches to caring for people living with HIV and/or disabilities in developing settings, in the hope of identifying ways to improve approaches to HIV Care, Treatment and Support and Community Based Rehabilitation.

This study is being conducted by third year physical therapy students in collaboration with a faculty advisor from the University of Toronto. Completion of the project will fulfill the graduating requirements for a Bachelor of Science in Physical Therapy degree.

Consent Form

I, ______________________________, agree to take part in this project comparing the philosophies of Community Based Rehabilitation and HIV Care, Treatment and Support, with respect to practice, policy and research.

I understand that participation in the study will involve answering questions about:

- My experiences in Community Based Rehabilitation and/or HIV Care, Treatment and Support.
- The successes, limitations and challenges experienced in working with these philosophies of care.
- My ideas on the overlap between Community Based Rehabilitation and HIV Care, Treatment and Support.

- What I think the lessons to be learned from Community Based Rehabilitation and/or HIV Care, Treatment and Support are.
- How I think any policy, practice and research lessons learned from one can apply to the other.
- What determines my decisions to fund CBR or HIV Care, Treatment and Support programs? (If involved in funding).

I understand that I will participate in an interview/focus group led by up to 3 people in one sitting. This session will last approximately 1 hour. The interview/focus group will occur on the telephone, face to face or via electronic communication. I will be answering questions based on my experiences with Community Based Rehabilitation and/or HIV Care, Treatment and Support. I understand that by agreeing to participate in the study, I am also permitting the investigators to analyze my answers to develop general conclusions and recommendations for reports and presentations.

I understand that I will be asked at the onset of the face to face or telephone interview for my permission to be tape-recorded during the subsequent conversation. Given my consent, this will later be transcribed for analysis. Interview tapes will be locked in a secure place. Access will be limited to the 7 members of the study team.

I understand that I will be asked for permission at the onset of the interview, focus group or electronic communication whether I would like to be identified in reports and presentations that result from the study. I understand that if I decline, my name and any identifiable information will be changed on the transcription or printouts.

I understand that I may refuse to answer any questions or withdraw from the study. I understand that my specific answers will remain confidential.

I understand that if I wish, a summary of the study will be sent to me.

I understand what this study involves and agree to participate.

____
Date

________________________________	________________________________
Subject Name (please print)	Subject Signature
________________________________	________________________________
Witness Name (please print)	Witness Signature

If you have any questions or concerns, please do not hesitate to contact us at:
Stephanie Nixon, BScPT, MSc.PT Email: Stephanie.nixon@utoronto.ca

Students conducting the study are: Rosaleen Zobl, Maryann Sego, Amee Mehta, Uma Tharmaratnam, Saira Somji, Shelley Sharma

APPENDIX D

Standardized Background Information

Community Based Rehabilitation (CBR)

CBR is a derivative of United Nations initiatives that was developed in the early 1970s to address disabilities worldwide at the community level. In the 1994 Joint Position Paper on CBR, the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), and the World Health Organization (WHO) identified CBR as:

> "A strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services".

In this approach to CBR, the phrase "within general community development" is defined by the United Nations to be the following strategy:

> "…the utilization, (in an integrated programme), of approaches and techniques which rely on local communities as units of action and which attempt to combine outside assistance with organized local self-determination and effort, and which correspondingly seek to stimulate local initiative and leadership as the primary instrument of change".[1]

The main objective of CBR is to promote and protect the human rights of people with disabilities. CBR intends to achieve this by advocating for changes at the community level that will enable people with disabilities to have equal access to services and the opportunity to attain their maximum potential, in an attempt to enhance their quality of life and become more integrated into their own community.

HIV Care, treatment and support (HIV CT&S)

As seen by the increasing number of people infected with HIV/AIDS in low- and middle-income countries, prevention and treatment can no longer be viewed as unrelated strategies. The crux of the issue is to integrate prevention, treatment planning and intervention.

HIV CT&S is a concept that outlines comprehensive care for people living with HIV/AIDS. According to UNAIDS this includes available, accessible voluntary counseling and testing services; prevention and treatment of tuberculosis and other infections; prevention and treatment of HIV related illnesses; palliative care; prevention and treatment of sexually transmitted

[1] (2002) Retrieved on October 20, 2002 from www.unescap.org.

infections; prevention of further HIV transmission, through existing technologies and using future technologies; family planning; good nutrition, social, spiritual, psychological and peer support; respect for human rights; and reducing the stigma associated with HIV/AIDS.[2]

Currently, the delivery of HIV care, treatment and support is hindered by several factors. For example, diagnostic tests are not universally available; therefore, many people are unaware of their HIV/AIDS status. Also, there is a need for improved global access to antiretroviral drugs and funding to help low- and middle-income countries afford drug treatment. Health systems in such countries are also ill equipped to deliver effective treatment of HIV/AIDS and associated illnesses.

And finally, in places where these services are available, fear and stigma are still associated with HIV/AIDS and the abuse of human rights of infected individuals present the ongoing reluctance to come forward for testing and treatment. Therefore, HIV care, treatment and support needs to be administered on a community level and have a role within community organizations in order to promote social solidarity and to help protect these individuals against discrimination and violations of their rights.

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