



# Evaluation of a Community-Based Self-Management Program to Increase Access to Rehabilitation for People Living with HIV

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## Abstract

We qualitatively evaluated a novel educational program to help people living with HIV understand the role of rehabilitation, facilitate access to rehabilitation, and promote self-management of chronic disease in Canada. The program incorporated components of self-efficacy, client-centered care, peer education, and problem-based learning. Delivery of the community-engaged program was viewed as feasible and acceptable; however, a flexible delivery model was deemed important. Perceived learning was related to rehabilitation, advocacy, and taking responsibility for one's health. A co-leader model and access to online resources were strengths. Future work should assess the ability to apply advocacy knowledge and skills to access rehabilitation services.

## Keywords

educational intervention, self-management, patient activation, rehabilitation for HIV, people living with HIV

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## Introduction

In high-income countries such as Canada, HIV is increasingly recognized as a chronic illness in which those with access to antiretroviral treatment can live a near normal life span.<sup>1</sup> While virologic suppression is key, other strategies are required to support the long-term management of disability that may result from the effects of the virus, associated comorbidities, and the natural consequences of aging.<sup>2,3</sup> As of 2011, in Canada, an estimated 71,300 people were living with HIV and women accounted for 23.2% of the national total.<sup>4</sup> Although evidence increasingly supports the effectiveness of rehabilitation strategies in the management of HIV,<sup>5</sup> access to rehabilitation services in Canada remains a challenge.<sup>6</sup> This is due to several reasons including a lack of knowledge among people living with HIV (PLHIV) of how rehabilitation services could help them with health-related issues and how to access services.<sup>6</sup> Similarly, health professionals who are in a position to refer patients with HIV to rehabilitation services may be unfamiliar with the potential role of rehabilitation in the context of HIV.<sup>6</sup>

These findings underscore the need to increase awareness of the rehabilitation needs of PLHIV among health-care providers who possess both knowledge about HIV and the ability to refer to rehabilitation services. Targeting health-care providers directly with a knowledge translation intervention to build capacity is challenging, however, as they often lack time to access new knowledge and must keep informed of advances in multiple areas.<sup>7,8</sup> Alternatively, PLHIV are well positioned to advocate for rehabilitation services with their health-care

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### What Do We Already Know about This Topic?

Access to rehabilitation services in Canada is a challenge for many people living with HIV often due to the lack of knowledge of health providers, and people living with HIV, of the potential role and benefits of rehabilitation in the context of HIV.

### How Does Your Research Contribute to the Field?

Findings from this study support the acceptability, feasibility, and perceived value of a community-based self-management program designed to help people living with HIV become knowledgeable about, and advocate for, rehabilitation services.

### What Are Your Research's Implications toward Theory, Practice, or Policy?

Findings from this study support development of a self-management program, which builds skills to better communicate with health-care providers and to self-advocate for disability-related needs amenable to rehabilitation.

provider. Increasing knowledge of the diversity of disability experienced by PLHIV and the benefits of rehabilitation services could help PLHIV self-manage their condition and self-advocate for timely and appropriate rehabilitation services in the episodic trajectory of their condition.

Self-management is recognized as an important element of long-term strategies to manage chronic conditions, including HIV.<sup>9</sup> Although reviews of HIV-related self-management programs revealed insufficient evidence to support their long-term effectiveness, strong evidence supports short-term improvement in knowledge, physical, and psychosocial outcomes among PLHIV.<sup>10</sup> Common elements in self-management strategies exist across chronic conditions, though HIV has unique considerations, including a lack of direct self-monitoring of immune function and issues related to stigma and disclosure.<sup>11</sup> Increased access to health services and improved communication with health providers are common outcomes of self-management programs.<sup>9</sup> To achieve these favorable outcomes, PLHIV require training and support to effectively self-manage their health, communicate their potential needs to access rehabilitation services, and participate in shared decision-making with their health-care provider. Our purpose was to evaluate the acceptability, feasibility, and perceived learning of a novel, peer-supported, community-based self-management program designed to increase the capacity of PLHIV to advocate for rehabilitation services to address their health-related needs in the Canadian context.

## Methods

We developed an evidence-informed educational program focused on increasing the capacity of PLHIV to effectively identify and communicate their rehabilitation needs to their health-care provider(s) to facilitate access to rehabilitation services. Consequently, this program aimed to increase the capacity of PLHIV to self-manage their health challenges.

This was a 3-phase project guided by an advisory committee comprised of 3 PLHIV purposefully recruited based on their community-based research expertise and lived experience with HIV and disability. We recognized that for PLHIV to be able to advocate for rehabilitation services, they needed to be familiar with the goals of rehabilitation and the roles of rehabilitation professionals. Thus, in the first phase, we developed materials that would serve as educational resources for PLHIV. We interviewed 16 PLHIV and 26 rehabilitation clinicians with expertise in managing HIV to advise on the adaptation of an online interprofessional clinical guide to HIV rehabilitation to a PLHIV audience.<sup>12</sup> This qualitative study yielded 10 recommendations for adapting the clinical guide and development of case scenarios.<sup>12</sup> The result was a stand-alone online module on evidence-informed rehabilitation that would serve as an accessible resource to PLHIV throughout the project.

In the second phase, we developed a novel program to help PLHIV to understand the role of rehabilitation in managing disability, facilitate access to rehabilitation, and promote self-management. Using the social cognitive theory of self-regulation,<sup>13</sup> the program was designed to be delivered in the community by 2 co-leaders, an HIV community agency worker and a peer facilitator living with HIV, in four, 1-hour weekly sessions. We incorporated evidence-informed pedagogical features including client-centered care,<sup>14</sup> peer education,<sup>15</sup> and problem-based learning<sup>16</sup> Content included an introduction to rehabilitation and self-management, common challenges of living with HIV, and how to access and work with rehabilitation professionals. The written materials that accompanied the program included links to the online module throughout (for access to materials that accompany the program, go to [<http://www.realizecanada.org/wp-content/uploads/e-module-December-1.pdf>]). Additional details of the program are available elsewhere.<sup>17</sup>

In the third phase, we evaluated the feasibility, acceptability, and perceived learning of the program from the perspectives of PLHIV and the peer leaders. We partnered with 3 HIV community agencies in 3 cities (Toronto, Ottawa, and Kamloops) located in 2 provinces (Ontario and British Columbia) during this phase that identified 1 agency worker and 1 agency client living with HIV to take the role of workshop co-leaders. Co-leaders participated in a 2-day experiential training program and were provided with a manual to support their learning. The "facilitator" manual included techniques on how to be an effective facilitator, how to address common challenges, tips on how to prepare for and run a workshop, and suggested activities and time allocations. Each agency recruited 6 to 8 participants for their workshops from their clientele through

flyers on site and e-mail invitations. Agencies also approached individuals who they felt would benefit from participation in the program. Each agency delivered the program on 2 occasions. Program participants received an honorarium upon completion.

### Data Collection

Prior to delivery, participants completed a paper-based questionnaire to provide demographic information and identify their primary goals for the program. Within 3 weeks of completing the program, an experienced research associate interviewed a sample of 12 participants (4 randomly chosen from each site) by phone or in person. Interviews were semistructured and explored questions related to participants' motivation for enrolling in the program, learning that occurred, usefulness of resources, perceived strengths and limitations of the program, and any recommendations for future delivery. In addition, we interviewed all co-leaders ( $n = 6$ ) for their perceptions of positive experiences, any challenges, and their views on important learning that occurred. Interviews ranged from 6 to 42 minutes in length.

### Analyses

All participant and co-leader interviews were audio recorded and transcribed verbatim. Two authors (*PS and NG*) conducted a qualitative directed content analysis.<sup>18</sup> Participant goals related to a specific theme were grouped together. Following this, an open coding technique was used to independently code the transcripts line by line. After the initial coding, all codes were compared and grouped into broader concepts or themes. NVivo 10<sup>19</sup> was used to facilitate coding and data management.

### Ethics Approval and Informed Consent

Ethics approval was received by McMaster University (Hamilton Integrated Research Ethics Board, Project # 14-544) and University of Toronto (HIV Ethics Board, Protocol # 30678). All participants provided written informed consent.

### Results

Thirty-six PLHIV volunteered and attended the first program session and 26 (72%) completed all 4 sessions. Men comprised most of the participants (80%). Mean (standard deviation) age of participants was 52.0 (11.3) years and the mean (standard deviation) number of years living with HIV was 17.3 (9.3) years. Six programs were conducted, each with 4 to 8 participants. Six co-leaders were involved in the program delivery. Demographic data on the program co-leaders are not included due to the small numbers and need for anonymity.

We had intended that each community organization would modify their presentation style and approach based on their strengths and assessment of the group needs. This resulted in a variety of program processes. At one organization, the group prepared extensively for their sessions and developed supporting power points and handouts. Another organization took a

more informal approach with the peer leader describing the session as "a lot of sitting down and talking and really explaining how everything works." In the third organization, the leaders stated they were "nervous" and reverted to a more didactic approach in which they read directly from the manual. One group experienced challenges related to the open discussions that occurred as participants sought attention during the programs and had difficulty staying on topic.

### Participant Goals

Participant goals were categorized into 6 areas. The most common goal for attending the program was to gain general knowledge related to HIV (30%), followed by gaining knowledge in self-management and self-care (23%) and in rehabilitation (15%), provision of social support (18%), and developing return to work strategies (8%).

### Feasibility and Acceptability

*Who benefits?* Through the interviews, the co-leaders and participants expressed their views on who should be targeted to attend the programs. There were divergent views with some indicating that there should be a screening for the most suitable participants. There were suggestions that for some, rehabilitation was not a priority until they dealt with more urgent life struggles and were ready to engage in their own health care. An example of this was expressed by this co-leader, who noted that many in his group were "very health conscious" and concerned about nutrition and stated that "food was the very least of my worries." At another site, one participant spoke of how the co-leaders had a "really good eye for those who are ready to participate and engage in this type of thing."

Although most participants were recruited through flyers or e-mail at the community agencies, 3 participants stated that they were encouraged to attend by agency staff or volunteers. For example, one participant noted that he attended the program for his worker as he wanted to do "something for him." These participants appeared to be not as engaged and had difficulty articulating any meaningful learning. One participant spoke of needing to choose PLHIV who are not "doing it for the money." Some mentioned that this type of program is a "commitment" and suggested there be a stringent process to be accepted into the program.

Another participant noted that there were some immigrants in his group in which English was not their first language and who struggled to understand the content. In contrast, he spoke of how one participant who was a new immigrant had challenges getting what he or she needed from the health-care system and how the program would be very beneficial in helping him or her learn to navigate the system.

Others expressed concerns about combining long-term survivors living with HIV and those who were more recently diagnosed in the same program. One participant spoke of a sense of knowing most of the material as he had been living with HIV for many years. Another commented,

It's difficult to say how you put people who have been with the disease for a year or two years [together with] people who have been with the disease for 10 or 20 years. They have different focuses and different outlooks on life. (Man, 58 years, 8 years living with HIV)

**Value of resources.** We intentionally included access to an online module and a list of resources as part of the program to reinforce learning and encourage and support participants to take responsibility for managing their health.

We asked participants for their perceptions on the usefulness of the program materials including the online module. Participants were positive about the online module and appreciated the links to various resources. Some planned to use it on an as-needed basis when questions and issues arose or to share with others.

[the online module] is well put together. . . if I could get [other people living with HIV] to read it, it gives them the first step in, wow, I have to be more active in my own health. (Man, 58 years, 8 years living with HIV)

Participants appreciated the extensive list of resources included in the online module. Having written materials to refer to and enhance learning was important. Participants referred to memory issues which necessitated the availability of written materials. One noted that he was presently doing well however stated, "in the future if I needed to refer to this I feel confident I would be able to find the information I needed." (Man, 33 years, 10 years living with HIV). One participant summarized the value of the online module,

I still feel that it's more about getting help and how to go about getting that help. And when to ask for help and how to go about asking for help. (Woman, 57 years, 16 years living with HIV)

Four participants spoke of challenges with written materials and/or difficulties accessing information online. They described "not being computer literate," "not being much of a reader," and difficulty "reading stuff." One spoke of retention and reading problems. Another mentioned that his only online access was through his cell phone and it was too difficult to read on a small screen. A co-leader supported the belief that the online module was at a high reading level, however reinforced with her group that the materials were useful resources not intended to be read and memorized, "we talked about searching. You do a search in the document and you can find things. And if you can't find it, talk to one of us." (Co-leader 4)

**Program process.** The co-leader model was perceived as a strength of the program, in particular the inclusion of a person living with HIV from the community. For the co-leaders, a cofacilitation model provided the opportunity to have a second person to "be there picking up, redirecting, managing behaviors." The participants appreciated that each leader brought varied strengths to the table,

One [of the co-leaders] could see one perspective and the other one a different perspective. And then you just take what each of them say. (Woman, 69 years, 21 years living with HIV)

Participants had varied views on the length of the program. There were pragmatic considerations, for example, in one area participants had travelled a considerable distance and thus preferred an all-day program to minimize travel. The co-leaders recognized the value in sharing personal experiences and suggested that this may not be feasible in the 1-hour format for each component. This co-leader spoke of the need for conversation,

[The program was] a trigger for conversation. This is something that people don't talk about and don't have the option of accessing that much. (Co-leader 4)

Group sharing and support were also perceived as a positive feature of the program. One participant, who admitted that he had a hard time to "stand up for myself" when talking with health-care providers, noted how 2 of the group members offered to attend his doctor's appointment to help him with his advocacy skills. Others enjoyed the social aspect of the group and felt the program promoted "teamwork." Participants enjoyed learning from others' experiences. One participant noted, "You bring people together to talk. And that talking educates." (Man, 58 years, 8 years living with HIV)

### Perceived Learning

Co-leaders and participants identified many areas of learning, some of which were specific to their own learning needs and illness context. Three themes reflected important perceived learning across participants: importance of advocacy, expanding and reinforcing rehabilitation learning, and learning to take responsibility for health.

**Importance of advocacy.** Through their involvement in the program, participants came to appreciate the importance of advocacy. Many expressed the importance of learning how to navigate the health-care system and advocate for their needs, not necessarily related to rehabilitation. As stated by this participant,

I think the most important thing, which partly I was aware of, is advocating for yourself. And then asking for something when you need it. (Woman, age 57, 16 years living with HIV)

This perspective was reinforced by the co-leaders. They spoke of the confidence that participants gained to ask questions of health-care providers. Several participants and co-leaders referred to the learning as "empowering." This co-leader reflected on one of his groups, "[Group 1] was more focused on empowerment and 'language with my doctors and preparing for my doctors.'" (Co-leader 4)

Advocacy meant different things to different participants. While many applied learning around advocacy to their personal

situations, others considered broader applications. For example, one group had more collective experience with advocacy and their discussions focused on how to help others advocate as expressed by this co-leader,

[The group] had no problems advocating for themselves. It became a conversation about not only advocating for yourself but teaching other people how to do it. And supporting other people in how to do it. And like the importance of it, looking at it as a community rather than an individual. (Co-leader 4)

**Expanding and reinforcing rehabilitation learning.** When asked about important learning related to rehabilitation, participants often spoke of how the program “reinforced their learning” or was a “refresher.” While some were able to articulate knowledge gained, other were challenged to identify specific knowledge and spoke in generalities. However, participants endorsed that they would recommend the workshop to others living with HIV. Knowledge of how to access resources was viewed as an important component of learning as stated by this participant,

I would tell [PLHIV] how [the program] reaffirmed a lot of the things I’m learning and how empowered it makes me feel to know that I have access to all of these resources. (Man, 47 years, 19 years living with HIV)

This co-leader felt that general awareness of rehabilitation as a management strategy was important learning,

[The program] brought rehabilitation or rehab services to the forefront in people’s mind. So they were like, “oh my god, that’s right. I don’t necessarily take drugs for that. There is another option.” (Co-leader 3)

One long-term survivor with HIV who felt knowledgeable about HIV management was surprised at the learning that had occurred.

... occupational therapy ... I know much more about now. I have been involved in this for 30 years so for me, I learned and I am proud to say that I learned something because it was something that I wasn’t really completely familiar with. (Man, 58 years, 8 years living with HIV)

The co-leaders reflected on their perceptions of important learning that had occurred both personally and in the group. One talked about how he learned from the online module as it “broke down the specialties of each person involved in rehab.” He described a simple way to understand the difference between occupational therapy and physiotherapy articulated by another participant, “Physiotherapy is for inside my body, occupational therapy is for outside my body” (Co-leader 4).

Some of the participants had experienced physiotherapy or felt they had some knowledge about what it entailed. However, many were unfamiliar with the roles of other rehabilitation professionals in particular speech-language pathologists, occupational therapists, and physiatrists. This workshop leader described how the group learned through sharing their experiences,

Another fellow [spoke of] having trouble using the walker around the house. And the occupational therapist came in and moved the furniture. I don’t want to say the work is simple but the solutions are simple. (Co-leader 2)

Another co-leader spoke of how he was able to facilitate a broader knowledge of what various rehabilitation providers could offer.

Most of them, like me, have no idea about a number of things like what is a speech [pathologist] and what do they do. Or even what does a physiotherapist do? They didn’t know that. I gave them the width and breadth of what they do. So that was helpful. (Co-leader 5)

**Learning to take responsibility for health.** While participants appreciated the knowledge and skills they gained related to advocacy and rehabilitation, many also recognized that they needed to take the initiative to know more about the resources available and how to access these and learn to take responsibility for their health. Participants talked about needing to “participate in your health” and “becoming more involved in my own rehab care and treatment.”

One participant expressed the increased responsibility in the context of problem-solving, “you have to think logically for yourself, what fits your lifestyle, what fits your needs” (Man, 58 years, 8 years living with HIV).

Co-leaders reinforced this view. This co-leader reflected on how different groups learned different knowledge and skills, “Group 1 learned that they are responsible for their own health care” (Co-leader 4). Another described how participants were passive recipients of care and how they had learned to be more active,

A lot of these people, they didn’t ask questions [of their health care team]. They just didn’t know. They know now, like take a list, ask your Doctor as many questions as you want. (Co-leader 1)

## Discussion

This evaluation supports the acceptability, feasibility, and perceived value of a peer-supported community-based self-management program related to advocacy and rehabilitation in the context of HIV. Both co-leaders and participants noted the learning related to advocacy and how to take increased responsibility for one’s health. Although the emphasis was on having participants recognize the potential benefit of rehabilitation and how to advocate for referral with their primary health-care provider, participants felt the skills were important for managing other health issues.

Delivery of our program appears to be acceptable and feasible in a HIV service organization setting. The co-leader model was perceived as a strength, as was the access to supporting online resources. There were mixed feelings surrounding who would most benefit from the programs, with some suggesting that only PLHIV who were “ready to engage” in self-management interventions be selected. However, agencies

may not want to exclude interested clients and benefits may be highly variable; for example, while many participants valued the perspectives and skills related to advocacy, others were motivated by a need for social support. Others have noted that effective interactions among HIV peers may be dependent on the stage of HIV illness or subgroup identification.<sup>20</sup> Also, self-management programs may not be suitable for all, with some individuals less receptive to the approach or with varying learning styles.<sup>21</sup> These observations reinforce the importance of goal setting and the need for the agency to work with potential participants to understand whether the participant and program goals are congruent with one another. Participants should be assessed on their commitment as part of the learning relates to the discussion and role modelling of past experiences. Although in our project we recognize that the provision of an honorarium to participate in the evaluation components of the program may have been a motivator for some, this would not be a factor when delivered as a component of an agency's regular programming. Ultimately, the selection of clients will vary and should be the prerogative of the community agencies who best know their clients and their needs.

Similarly, our findings support the need for flexible content and delivery to best meet the needs of PLHIV and agency resources. We intended the program to be delivered in 4 weekly program sessions to allow for learning to be reinforced between sessions, but this was not always practical. Also, group co-leaders had varying levels of experience and expertise. Although there was a prescribed curriculum, small group discussion allowed group members to share experiences and learn from others. Facilitating open group discussion requires a higher level of sophistication and understanding of how to deal with group dynamics. Although we provided training for the program leaders, this may be insufficient for some and a more directive, didactic approach to the sessions may be most comfortable for those with less experience with facilitation. Involvement of peer leaders in delivering self-management programs to PLHIV includes benefits such as engaging in health promoting behaviors, expansion of social networks, and increased knowledge and skills.<sup>22</sup> Thus, training and participation of peer leaders remains an important element of future initiatives.

We recognize that building skills to better communicate with health-care providers and to self-advocate for health-related needs is only one component of a comprehensive self-management program. The flexibility of our approach contrasts with popular standardized programs such as the Positive Self-Management Program, a 6-week standardized program for PLHIV,<sup>23</sup> although some fundamental components were incorporated into our sessions. Future work should examine whether shorter, more targeted educational approaches can result in improved communication with health providers and greater access to rehabilitation. Alternatively, knowledge of rehabilitation and how to access services could be integrated into standardized programs.

Our written resources were an important component of the self-management program. Learning needs to be reinforced; this

may be particularly important for those experiencing cognitive decline and memory issues related to HIV and aging.<sup>24</sup> The challenges related to literacy and access to a computer were important reminders of the need for resources targeted to a variety of educational levels and learning styles. In addition, due to accessibility or comfort levels, PLHIV may prefer alternatives to in-person delivery modes. Self-management programs have been accessed online, through tele-delivery and individually through mail services.<sup>21</sup> We support recommendations that endorse the consideration of preferences of implementation and delivery style of self-management programs in PLHIV.<sup>21</sup>

There is a cautionary note related to delivering self-management programs to vulnerable populations such as PLHIV. Gruman et al<sup>25</sup> identified the challenges of expecting vulnerable populations, who may be at increased risk for preventable illness as a result of their own inactions, to actively participate in their health care. As PLHIV may have fewer resources, less education, and lower health literacy, expectations that they manage their health may increase discrepancies in health outcomes.<sup>25</sup> Similarly, Marshall et al<sup>26</sup> found that patient activation levels were lower in PLHIV with lower levels of education. Hence a "one size fits all" approach to promoting self-management may not be feasible or advisable. Others have suggested that self-management groups be composed strategically by factors such as stage of illness, motivation and beliefs, and that readiness to participate be assessed prior to participation.<sup>21</sup>

This evaluation was limited in that it occurred in a high-income country. In low-income countries without well-developed rehabilitation services, self-management needs may be very different with medication adherence and HIV risk and prevention strategies more of a priority.<sup>27</sup> Additionally, we only measured perceived knowledge in a small number of participants who completed the programs. It is also important to emphasize that even with knowledge and skills to advocate, access to rehabilitation may be limited due to financial or geographical limitations. Fear of stigma and discrimination may also prevent PLHIV from seeking appropriate health-care supports or disclosing their status to health providers.<sup>9</sup>

As PLHIV continue to age and their care needs evolve, rehabilitation can play an increasingly important role in reducing disability and improving quality of life.<sup>21</sup> Further work is required to understand whether and how self-management interventions promoting access to rehabilitation can be adapted and tailored to subpopulations. Ultimately, the ability for PLHIV to apply their advocacy knowledge and skills and access rehabilitation needs to be evaluated over time.

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