BRIEF REPORTS

An Educational Intervention to Promote Access to Rehabilitation for People Living with HIV

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ABSTRACT

This paper describes the design and novel features of an evidence- and theory-informed client activation intervention to increase the capacity of people living with HIV to: 1) self-manage their health-related challenges using rehabilitation strategies, and 2) communicate their rehabilitation needs to their healthcare providers to improve access to rehabilitation.

Building on social-cognitive theory and evidence, the intervention is a community-based workshop to develop knowledge and skills of people living with HIV to advocate for rehabilitation services. Novel features include engagement of community-based organisations in a train-the-trainer delivery model, a problem-based learning design to promote problem-solving and application, and a focus on client-centred practice.

The intervention is flexible and adaptable. Health providers in other countries and contexts could use the pedagogical features to develop a workshop to meet their local needs. Given that most knowledge transfer interventions aim to change health provider behaviour, the focus on teaching people living with HIV to advocate for referral to rehabilitation is unique. The workshop model may be of interest to those in communities where access to rehabilitation for people living with HIV can be limited due to a lack of knowledge of the potential role of rehabilitation.

Key words: *Educational intervention, self-management, client activation, rehabilitation for HIV.*

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INTRODUCTION

For people living with HIV with access to antiretroviral therapy (ART), there has been a dramatic shift from an acutely fatal to a chronic illness. This increased longevity is often accompanied by health challenges or disability related to effects of the virus, side effects of medication and natural consequences of ageing (Worthington et al, 2005; O'Brien et al, 2008). Rehabilitation is broadly defined as any services and activities that address or prevent components of disability including impairments, activity limitations and participations restrictions (Rusch et al, 2004). It is multidisciplinary and can play a critical role in improving function and optimising health outcomes in people living with HIV. However, access to rehabilitation is often a challenge, with barriers related to lack of health provider knowledge of the potential role of rehabilitation (Worthington et al, 2009).

This highlights the need to increase awareness among healthcare providers about the rehabilitation needs of people living with HIV, who have both knowledge of rehabilitation services and the ability to make referrals. However, as healthcare providers often lack time to access new knowledge and remain informed of advances in multiple areas, targeting them directly with a knowledge translation (KT) intervention is challenging (Cabana et al, 1999). Alternately, people living with HIV could themselves advocate for rehabilitation services with their healthcare provider. However, they may also lack information about the role and availability of rehabilitation, creating a barrier to discussing accessing these resources with their healthcare provider (Worthington et al, 2009).

By increasing knowledge among people living with HIV, about the diversity of HIV-related disability and the benefits of rehabilitation services, they can be helped to self-manage their condition and advocate for rehabilitation services. A scoping review of self-management programmes for people living with HIV revealed a common focus on skill development related to self-care, interpersonal relations, knowledge, positive attitudes, cognitive strategies and planning for future roles (Bernardin et al, 2013). Yet, knowledge and skills for managing HIV-related disability and accessing rehabilitation services were absent. Although client education improves knowledge and health literacy, people living with HIV also require training and support to effectively self-manage their health, communicate their potential need to access rehabilitation services, and participate in shared decision-making with their healthcare provider. Client activation, or the degree to which people understand they must play an active role in managing

their own health and healthcare, is an important element of self-managing chronic disease (Hibbard et al, 2005). Client activation includes an individual's knowledge, skill and confidence to manage his/her own health and healthcare (Hibbard et al, 2005).

Based on an international environmental scan, client activation interventions specifically designed to promote rehabilitation of people living with HIV do not exist (Canada-UK HIV and Rehabilitation Research Collaborative, 2013). Additionally, in countries with limited access to rehabilitation services such as occupational therapy, physiotherapy and speech language pathology, training in self-management skills can support the development of strategies for clients to deal with their disability over the long term.

The goal was to develop a sustainable evidence and theory-informed client activation intervention to increase the capacity of people living with HIV to: 1) self-manage their health-related challenges using rehabilitation strategies, and 2) communicate their rehabilitation needs to their health- care providers to improve access to rehabilitation. This paper describes the design and novel features of the intervention.

Theory and Evidence-based Design

This intervention is a community-based workshop with the overall goal of helping people living with HIV to better understand the role of rehabilitation in managing their health-related challenges and to facilitate access to rehabilitation services. A fundamental assumption is that these people need knowledge of when and how rehabilitation services would be appropriate, and the skills to help them advocate for referral to appropriate rehabilitation professionals.

Since an aim of this workshop is to facilitate appropriate access to recommended rehabilitation services through activation of people living with HIV, this is considered a patient-mediate KT intervention (Wensing et al, 2005). The intervention is complex as it comprises a number of elements that make it difficult to define the active ingredients (Craig et al, 2008). Leading KT researchers (Grimshaw et al, 2004a; Eccles et al, 2005; Grimshaw et al, 2004b) and the Medical Research Council (Craig et al, 2008) have underscored the importance of using theoretical frameworks, such as social cognitive theory, in the development of complex interventions to provide a basis for selection of variables, hypothesis development and testing and interpretation of study findings.

The intervention incorporated the social cognitive theory of self-regulation of Bandura (1995), which posits that beliefs in one's own capabilities to organise and execute the courses of action required to handle situations in the future influence how people think, feel motivated and act. Interventions that incorporate strategies for increasing these self-efficacy beliefs are expected to lead to better self-management behaviour (Bandura, 1995). Self-efficacy theory proposes four mechanisms by which to increase self-efficacy: performance accomplishments (experiences of success in performing the behaviour of interest), vicarious experience (observing peers performing the behaviour successfully), verbal persuasion (receiving positive feedback about ability from a respected individual), and emotional arousal (minimal levels of fear and anxiety during performance) (Bandura, 1995).

The workshop is designed to be facilitated, interactive and delivered in small groups. It incorporates the self-efficacy learning principles in several ways. Small-group learning in a supportive community setting provides opportunities for performance accomplishments with minimal anxiety (emotional arousal). Interaction with peers who have successfully incorporated rehabilitation self-management strategies and navigated access to rehabilitation services with their healthcare providers offers opportunities for vicarious experience. Feedback on performance from community workers with expertise in rehabilitation is a form of verbal persuasion.

Community Development

Part of the authors' motivation is to engage in development of the local HIV community-based organisations (CBOs). CBOs help people living with HIV to cope with a wide range of problems and link them to resources in the community (Rapid Response Service, 2015). With the aim of increasing capacity and knowledge of the CBOs and their clients, the authors chose a "train-the trainer" education model as the primary means of workshop delivery (Tobias et al, 2012). The goal is to provide locals with trusted locations and facilitators to deliver the intervention. The workshop is designed to be co-facilitated by a CBO employee and a volunteer peer leader who is a person living with HIV. Train-the-trainer education models are thought to lead to long-term sustainability and promote self-reliance in the community (Tobias et al, 2012). Prior to conducting the workshop, co-facilitators participate in a one-and-a-half-day training session which introduces the process and content of the educational intervention, allows the team to learn how to work

together and promotes skill in basic group facilitation. During the training, co-facilitators complete the workshop to familiarise themselves with the content and structure. The learning is experiential and includes role play and skill-building activities.

Content and Pedagogical Features of the Intervention

The workshop consists of four sessions, each designed to be delivered in a one- to two-hour time frame. Session 1 is an introduction to rehabilitation and self-management; Session 2 focuses on common challenges of living with HIV and self-management from a rehabilitation perspective; Session 3 focuses on getting access to and working with rehabilitation professionals; and, Session 4, titled "Putting it all Together", is a consolidation of previous weeks and reinforces communication skills and strategies for advocating for self-management. Specific objectives of each session are outlined in Table 1.

Table 1: Workshop Session Objectives

Session 1 Introduction to Rehabilitation and Self-Management	1) To understand what rehabilitation is; 2) To describe the rehabilitation professionals that can provide care; 3) To identify why people living with HIV might benefit from self-management.
Session 2 Common Challenges with HIV and How to Handle Them	1) To identify the challenges that people living with HIV face and which rehabilitation professionals can help; 2) To explain how rehabilitation can improve the physical health, mental/cognitive health and how to address day-to-day challenges and challenges in staying involved in your community. 3) To discuss prevention and how self-empowerment can help you advocate for your own care.
Session 3 Getting Access to and Working with Rehabilitation Professionals	1) To describe mechanisms and barriers for accessing rehabilitation services; 2) To explore local rehabilitation services available to HIV+ people; 3) To describe ways that can help HIV+ people to access the care that they need.

Session 4 Putting it All Together	1) To examine skills in negotiating for access to rehabilitation; 2) To illustrate clear communication in advocating for self-management and self-care; 3) To summarise how rehabilitation can help people living with HIV.

Evidence-informed content and pedagogy are incorporated to promote knowledge transfer among people living with HIV. These are summarised below and in Table 2.

Table 2: Pedagogical Features of the Intervention

Key Features	Key Features of the Intervention	Rationale for Inclusion
Flexible format	• Delivered either peer-led face to face or independently • Viewed online, printable as individual modules	• Meet learner preferences • Improve dissemination • Available resource following workshop delivery
Client centred	• Extensive input from people living with HIV • Reflective questions • Questions for key learning	• Incorporates client values and perspectives • Promotes MIPA principles
Problem-based learning	• Use of cases and group discussion to promote learning and integration of knowledge and skills	• Increase relevance • Promote problem-solving • Promote deeper learning (Dolmans, 2016)
Small group and peer interaction	• Small group exercises and discussion prompted through facilitators and activities	• Vicarious learning • Social support
Skills building	• Role- playing and experiential exercises to build strategies for communicating with health providers and for self-management	• Improve self-efficacy • Vicarious learning • Experiential learning
Goal setting	• Activities to promote individual goal setting and attainment	• Improve self-efficacy
Train the trainer	• Provision of training for workshop leaders and peer educators	• Build capacity • Participant engagement • Promote sustainability in the community

Peer educators	• Peer educators trained and supported to deliver and role model experiences	• Increase relevance and engagement • Build capacity for peer educator • Increase community capacity
Evidence informed	• Workshop content and process of delivery based on available evidence	• Promote best practices

Client-centred practice which incorporates client values and perspectives has long been a foundation of rehabilitation (Constand et al, 2014) and is an important principle for all health providers. This is promoted throughout the development and delivery of the intervention in several ways. To ensure that the workshop and accompanying materials are relevant and meaningful, an advisory group comprised of three people living with HIV provided input throughout the steps of development. To help individual participants focus on their personal goals, prompting questions are used throughout the workshop. The intervention also incorporates individual problem-solving and skill-building through facilitator and role-playing activities. Goal-setting and skill-building are key components of building self-efficacy, and ensuring strategies are meaningful to the individual (Bernardin et al, 2013). For example, at the end of each workshop participants are asked: 1) What information will you take away from the workshop? ; 2) What are the key learnings? ; and, 3) What is your action plan?

Elements of problem-based learning (PBL) are incorporated through active discussion of cases. PBL, through engagement of learners with cases designed to promote activation of prior knowledge and problem-solving, is thought to promote deeper learning and application of information (Dolmans et al, 2016). The PBL process encompasses small group learning and interaction which promotes learning from one another, provides social support and incorporates vicarious experience.

Online resources were developed to support the workshop. An extensive community consultation process was carried out to adapt a clinical resource originally developed for rehabilitation professionals to meet the needs of people living with HIV (Solomon et al, 2018). The engagement of people living with HIV in the process incorporated clients' values, needs and preferences, resulting in a relevant and meaningful "e-guide" that can be referred to as needed.

Additionally, a manual was developed to accompany the workshop. The manual incorporates specific goals for each workshop, brief content with links to in-depth resources and questions to promote problem-solving, reflection and application to the case studies. The participant manual is freely available online [http://www.realizecanada.org/wp-content/uploads/e-module-December-1.pdf].

Finally, the goal was to design a process and materials that are flexible and accessible. While a face- to- face intervention was preferred, it was recognised that this would not be feasible for all. Thus, the workshop manual has been made available online and is downloadable. For those wanting more comprehensive information, the online version includes links to relevant resources and to a detailed electronic reference.

DISCUSSION

The authors have described a complex, multi-step educational intervention to promote self-management and increase access to rehabilitation services for people living with HIV. The use of evidence and theory to inform the intervention is a strength. The incorporation of novel elements was to facilitate problem-solving, actively engage participants, and build knowledge and skills to enable them to communicate their rehabilitation needs. Health providers in other countries and contexts could use these pedagogical features in Table 2 to develop a workshop to meet their local needs. For example, the details of the case studies could easily be altered to reflect the local environment. The workshop model may be of interest to those in communities where access to rehabilitation for people living with HIV can be limited due to a lack of knowledge of the potential role of rehabilitation and/or a lack of resources. Interested providers are encouraged to adapt the manual to their own context.

Learning to advocate for referral to rehabilitation is a unique feature of this intervention, given that most knowledge transfer interventions aim to change clinician behaviour. While client-mediated interventions such as client decision aids have been shown to change health professional behaviours, there is a need to provide a link between the client and the health provider (Stacey & Hill, 2013). Interventions such as coaching and prompt sheets have demonstrated improvement in clients' ability to ask questions and in their overall satisfaction with care (Kinnersley et al, 2007). Thus, in addition to role-playing activities to build skills, the manual for participants can serve as a resource after the workshop.

This may be of particular importance for long-term survivors of HIV given that HIV associated neurocognitive disorders can result in memory impairment (Woods et al, 2009).

Engagement of the HIV community in education and research initiatives is longstanding and is an important component of the intervention, both in developing and reviewing the materials and in delivery of the workshop. CBOs have an important role in linking clients to local resources to help them cope with HIV. In addition to increasing the relevance of the workshop, community engagement promotes client-centred practice (Constand et al, 2014). Additionally, through engaging CBO staff in delivery of the intervention, the aim is to increase their knowledge of rehabilitation to have broader applicability in their day-to-day interactions with clients.

Self-management programmes often include people living with a variety of chronic diseases, as it is assumed that skills are universally applicable across diseases. However, people living with HIV are often from vulnerable populations with unique needs related to multilayered stigma and the episodic nature of the illness. Thus, it is important for people living with HIV to be able to identify health challenges that may be amenable to rehabilitation, to learn how to incorporate self-management strategies in their lives and to be confident in negotiating their needs with their primary health provider.

Limitations

There are limitations to this educational intervention. It is recognised that this workshop may not be suitable for all people living with HIV as some may not be ready to engage in self-management strategies. Requirements to actively participate in one's own health care may disadvantage those who are less likely to engage in health promoting behaviours related to broader determinants of health, such as those with fewer financial resources, less education and low health literacy (Gruman et al, 2010). Also, it is likely that even with knowledge and skills, people living with HIV may not be able to access rehabilitation services due to financial or geographical barriers or unavailability of services. Future research will evaluate the outcomes of the intervention and determine who will most benefit from this type of education.

More broadly, people living with disabilities experience widespread barriers to accessing services including multidisciplinary rehabilitation (World Health

Organisation, 2011). The process of developing a workshop intervention promoting health literacy and advocacy skills is relevant to many people living with disabilities and across chronic diseases.

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