



3-31-2017

## A Service Delivery Model for Addressing Activity and Social Participation Needs of People Living with HIV

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DOI: 10.15453/2168-6408.1258

### Recommended Citation

Restall, Gayle; Sullivan, Theresa; Carnochan, Tara; Etcheverry, Emily; Roger, Kerstin; and Roddy, Pumulo (2017) "A Service Delivery Model for Addressing Activity and Social Participation Needs of People Living with HIV," *The Open Journal of Occupational Therapy*: Vol. 5: Iss. 2, Article 4.

Available at: <https://doi.org/10.15453/2168-6408.1258>

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# A Service Delivery Model for Addressing Activity and Social Participation Needs of People Living with HIV

## **Abstract**

*Background:* Occupational therapy can contribute to the health and well-being of people with human immunodeficiency virus (HIV) who are experiencing health consequences of living long term with this disease. However, there are no comprehensive rehabilitation service delivery models to guide this emerging area of practice. The purpose of this study was to obtain critical feedback about a service delivery model to address the activity and social participation needs of people living with HIV.

*Method:* We developed a service delivery model from a synthesis of the literature. Using a qualitative research design, we conducted individual and focus group interviews with 35 informants from diverse backgrounds and involvement in HIV-related research, service provision, and policymaking to provide critical feedback about the model. The interviews were audio-recorded, transcribed verbatim, and analyzed using inductive qualitative methods.

*Results:* The informants identified the strengths and limitations of the model and supports and barriers to its implementation. They highlighted the importance of principle-based services, increasing resources for service navigation, building capacity of rehabilitation services to address the needs of people with HIV, and increasing research and program evaluation targeted to achieving activity and social participation outcomes.

*Conclusions:* The model provides a framework for occupational therapists to design and evaluate services for this population.

## **Keywords**

Chronic Disease, Episodic Disability, Qualitative Research, Rehabilitation, International Classification of Functioning, Disability and Health

## **Cover Page Footnote**

We thank Hal Loewen, librarian, who provided valuable assistance with literature searches, and Stephanie Giberson-Kirby, who coordinated literature searches and data collection. We are grateful to the study participants for their willingness to engage in dialogue about this topic. We also acknowledge the contributions of the four members of our community advisory group for their insights at the beginning of the project, and the three members who reviewed and provided feedback on preliminary findings. Funding for this research was provided by a grant from the Canadian Institutes of Health Research, reference number 112454.

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The widespread availability of highly active antiretroviral therapy medications has meant that people diagnosed with human immunodeficiency virus (HIV) can live longer but often with impairments, activity limitations, and participation restrictions. These challenges can manifest episodically in physical, psychological, and social forms over time, so that HIV is now considered a chronic disease (Deeks, Lewin, & Havlir, 2013). In addition, normal aging processes, drug toxicity from medications to treat HIV and other concurrent chronic diseases, combined with persistent immune dysfunction and lifestyle risks, are believed to lead to premature aging (Deeks & Phillips, 2009). People living with HIV (PLWHA) can experience periods of good health with unpredictable periods of disability (Barkey, Watanabe, Solomon, & Wilkins, 2009; O'Brien, Davis, Strike, Young, & Bayoumi, 2009).

In addition to facing poor physical and mental health outcomes resulting from HIV, many PLWHA also confront social factors that can contribute to poor outcomes, including housing instability and homelessness, poverty, and unemployment (Martin Spigelman Research Associates, 2002). Hence, there is a need for supports and services that address both personal and environmental components. Health services for PLWHA have increasingly focused on community-based chronic care approaches (Deeks et al., 2013; Misko, Nelson, & Duggan, 2015).

Rehabilitation generally, and occupational therapy specifically, have become emerging areas of practice in addressing the consequences of HIV as a chronic disease. In the context of HIV,

rehabilitation has been defined as “a dynamic process, including all prevention and/or treatment activities and/or services that address body impairments, activity limitations and participation restrictions for an individual” (Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005, p. 268). However, there is a gap between conceptualization of HIV as a chronic and episodic health condition and the development of rehabilitation and occupational therapy specific strategies to prevent and reduce its disabling effects.

The literature on occupational therapy interventions for PLWHA is sparse. Examples include articles addressing issues related to return to work (Barkey et al., 2009), productive participation (Kielhofner, Braveman, Fogg, & Levin, 2008), social participation (Siemon, Blenkhorn, Wilkins, O'Brien, & Solomon, 2013), cognitive functioning (Vance et al., 2012), and case studies of individual interventions (Misko et al., 2015). Although there is clear potential for occupational therapy to contribute to the improved health and well-being of PLWHA who are experiencing episodic disability as the consequence of HIV as a chronic disease, there are no comprehensive service delivery models to guide this emerging area of practice.

Given the complexity of the health and social factors faced by many PLWHA and the sparse literature and clinical practice experience of occupational therapists in this field, we addressed the question of occupational therapy service delivery in the broader context of rehabilitation service delivery. In addition, we used the language of activity and participation from the *International Classification of Functioning, Disability and*

*Handicap* (ICF) (World Health Organization, 2001) that is consistent with occupational therapy's attention to the importance of occupation and environments to health (Kielhofner, 2008; Law et al., 1996). Development of a comprehensive model for rehabilitation service delivery can inform the development and evaluation of occupational therapy and other rehabilitation services to meet the activity and social participation needs of PLWHA.

### Context of the Study

The study took place in Canada, which has a national health insurance program for residents to ensure access to hospital and physician services (Health Canada, 2012). The provincial and territorial governments are responsible for the organization and delivery of health services for their residents across the continuum of care from prevention to long-term care based on funding received from the federal government under certain terms and conditions. Exceptions are the federal government's responsibilities for direct delivery of services to First Nations people on reserves, the Inuit, members of the Canadian Forces, inmates in federal penitentiaries, and some refugee claimants (Health Canada, 2012). These differences in responsibilities result in service variability across jurisdictions.

Prior to this study, we developed a proposed service delivery model and created a 20 min web-based presentation summarizing the results of a synthesis of the literature focused on the question: What interventions address activity and/or participation outcomes for PLWHA and how are these interventions delivered? (Restall et al., 2014).

The model is depicted in Figure 1. We focused

primarily on interventions that targeted outcomes in activity and social participation as key areas of focus of occupational therapy interventions and because these outcomes have often been neglected in the conceptualization and research on HIV as a chronic disease. Activity and social participation outcomes comprise the endpoints of the model. The components of the model include: prominent features of living with HIV; service delivery principles; promising interventions; and person-environment interactions across micro, meso, and macro levels of the environment (Bronfenbrenner, 1977). In our model, micro level environments include the relationships that people have with others in their personal social networks and with health and social care clinicians, such as occupational therapists. Meso level environments include systems in organizations, such as program philosophies, policies, and service models. Macro level environments include socio-political contexts, such as the organization of funding of health systems and the social construction of people living with HIV.

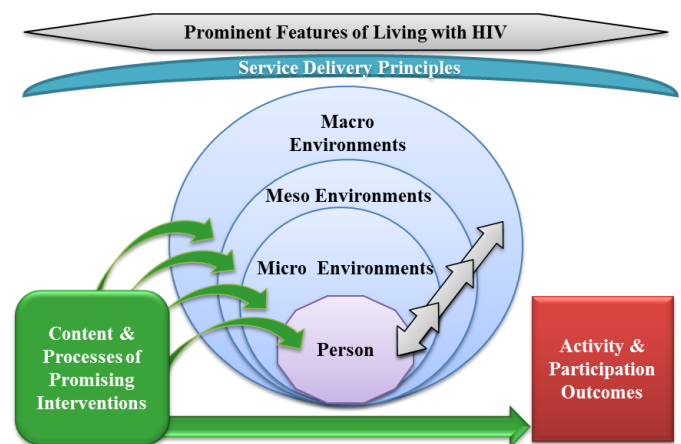


Figure 1. HIV, activity, and social participation service delivery model.

## Purpose

The purposes of this study were to:

1. Obtain critical feedback about a proposed model of rehabilitation service delivery that was developed to address the activity and social participation needs of PLWHA.
2. Develop recommendations regarding the provision of rehabilitation services to PLWHA.

## Method

Our research team consisted of three occupational therapists, a sociologist (with training as a psychotherapist), a service provider at a community-based agency, and a community member living with HIV. We used a descriptive qualitative design (Sullivan-Bolyai, Bova, & Harper, 2005) and a participatory community-based research approach to obtain critical feedback about the proposed service delivery model. We sought to capture the collective voice of multiple participants through focus groups, which are well-suited to facilitating the exchange of information and joint idea generation (Krueger & Casey, 2015) needed to critique a service delivery model. Individual interviews were conducted when a participant was unable to join a focus group or preferred an individual interview. The study was approved by a university health research ethics board. All of the informants provided written informed consent.

## Participants

We recruited informants through the electronic mailing list of the Canadian Working Group on HIV and Rehabilitation by identifying individuals through publications and public websites and by asking informants who else was

knowledgeable in the field. Thirty-five of the informants provided feedback on the model. The majority (89%) were women. Nine of the informants (26%) were between the ages of 21 and 35 years, 17 (49%) were between the ages of 36 and 50 years, and 9 (26%) were between the ages of 51 and 65 years. The informants' involvement in the context of HIV included health policy and planning (n = 3), management in public health services and AIDS service organizations (ASOs) (n = 5), direct service provision (n = 23), and research (both academic and community PLWHA researchers) (n = 7), with some having multiple roles. Ten of the informants identified themselves as being focused exclusively on HIV care, while 15 worked in chronic episodic disease care, which included HIV. Sixteen of the informants (45%) had between 0 to 5 years of experience with HIV care, six (17%) had between 6 to 10 years of experience, three (9%) had between 11 to 15 years of experience, and 10 (29%) had worked for over 15 years in HIV care.

## Procedures

Two group interviews (focus groups), one in a large city (n = 11) and one in a medium-sized city (n = 8), were conducted in person and facilitated by the first author and the research coordinator. Two additional focus groups (n = 6; n = 7) were conducted via teleconference with informants from across Canada and facilitated by the first author, the second author, and the research coordinator. The first author conducted three individual interviews, two via tele-conference and one in-person. Each participant was provided with a definition of rehabilitation paraphrased from Worthington et al. (2005) and asked to view the 20-min presentation

about the service delivery model prior to participation in a group or individual interview.

The semi-structured group and individual interview question guide included:

1. What stood out for the informants about the model.
2. How the model fit with the informants' clinical, research, or policy work.
3. How the model compared to the informants' ideal vision of service delivery.
4. How the model would need to be modified to address the need of specific populations.
5. Supports and barriers to implementation of the model in the informants' own settings.

## **Analysis**

Focus groups were audio-taped and transcribed verbatim. The transcripts were verified by a member of the research team. The first author conducted initial analysis of the transcripts following procedures described by Miles, Huberman, and Saldana (2014). The transcripts were read and an initial coding scheme was developed by identifying the major topics discussed during the individual and group interviews. Next, categories were identified and added through line-by-line coding of each transcript. Memo writing served to document assumptions and links in the data. The third author reviewed the coding scheme through line-by-line review of the transcripts, noting additional codes. Discrepancies between the first and third author in the naming of codes and categorizing of text (for example, should stigma be

a separate code or should it be included in a broader code called social inclusion and exclusion), were resolved by discussion between the two authors. Two additional authors read all of the transcripts and provided their insights at a team meeting to discuss the results.

## **Trustworthiness**

Triangulation adds rigor by combining multiple investigators, theories, methods, and data sources (Denzin, 1978). In this study, triangulation included having multiple members of the research team analyze data as described above, including at least two members of the research team in data collection during focus groups; using both interviews and focus groups as data collection methods; recruiting multiple people from diverse backgrounds as data sources; and including the perspectives of the research team members with diverse backgrounds (including one member living with HIV). An audit trail was maintained through a research coordinator, the principal investigator's notes, and meeting minutes.

## **Results**

Our aim was to contribute to the development of the model through a process that valued the perspectives of experts in the field. Through the analysis process we identified the informants' descriptions of the strengths and limitations of the model as well as challenges and supports to implementation.

## **Strengths of the Model**

Overall, the informants were positive about the model. Many noted that it resonated with their own work and experiences. They highlighted three components of the model as particularly positive:

inclusion of service delivery principles, identification of multiple layers in the environment, and emphasis on intervention processes and content.

### **Inclusion of service delivery principles.**

The informants overwhelmingly supported the inclusion of service delivery principles in the model that emphasized adherence to approaches that are client-centered, strengths-based, culturally proficient, and holistic. The informants noted that client-centered and strengths-based services were important due to the heterogeneity of PLWHA and the importance of facilitating personal empowerment to address clients' needs and goals by building on clients' resources. The communities to which people belonged could act as resources for instrumental and peer support. Cultural proficiency was highlighted by several of the informants as a means to increase acceptability of services across broad definitions of culture, such as the cultural and spiritual beliefs of Aboriginal peoples and the culture of online communication of young people. The informants, particularly direct service providers, also emphasized the importance of holistic care to address the multitude of issues confronting many PLWHA, including co-occurring health conditions (e.g., substance-use disorders, Hepatitis C, and mental illness) and social conditions, such as poverty. Due to the multiplicity of issues facing PLWHA and challenges for many in accessing supports and services, particularly as they age, several of the informants talked about the importance of the coordination of supports and services for PLWHA. The informants noted that they appreciated the holistic approach to service delivery depicted in the model.

**Layers in the environment.** Several of the informants talked about the importance of including micro, meso, and macro layers of the environment in the model. They believed that understanding layers of the environment could facilitate greater awareness among service providers about a social model of disability and the ways that environments can affect the experience of disability. One of the informants in a focus group commented:

And definitely, the way you've encompassed those environmental factors ... that there's the different levels of environmental factors right up to the kind of that socio-political. So, my thought is that that framework does a good job of, of capturing that whole continuum.

The informants felt that understanding the layers of environments could assist service providers to understand how organizational policies and structures could facilitate or impede access to services. One service provider noted:

Taking into consideration sort of the meso environment I think is important because, you know, hours of operation, child care, um, you know, accessibility by bus like or other forms of transportation is important to consider because folks can't access programs if they can't afford to get there so. Or have somewhere they can put their child safely. So I think that's important.

Awareness of environmental impact on disability could not only assist service providers in envisioning their roles in addressing the issues, but also assist PLWHA to better understand the ways in which many of the challenges they confront are

created by environments rather than themselves.

One of the informants described this as follows:

“We’re really getting at more medical model versus social model in terms of whether people view a problem as being inside themselves or being part of their context and community.”

One of the most salient issues raised in relation to environments was the issue of HIV-related stigma, which the informants discussed across all three (micro, meso, and macro) levels of the environment. The informants frequently noted stigma as creating barriers to social engagement, activity, participation, and access to HIV-related services. Although the informants perceived societal attitudes toward PLWHA at the macro level as prejudicial, the tradition of social activism in the HIV/AIDS community at the macro level was perceived as a facilitator in addressing stigma at this level. One of the informants summarized this dichotomy as follows:

While we’re looking at the social political context, um, there is that layer of stigma and discrimination. But there’s also a layer of political activism and self-directed engagement, you know, the empowerment philosophy. So, I think it’s, there’s two, two dimensions to that outer (macro) layer. There’s two layers to that. One is where there’s the marginalization (or) stigma and the other where there’s activism or resistance.

**Emphasis on intervention processes and content.** The informants appreciated the identification of “promising interventions” in the proposed service delivery model. However, most of

the discussion about interventions in the interviews and focus groups focused on the “processes” of delivering interventions rather than the content. This discussion noted the importance of improving access to interventions for some populations through technology, such as telephones, video links, and social media. The informants also talked about the importance of interpersonal relationships in the context of delivering services. For example, one service provider commented that “whatever it is that individual is wanting to work towards, it is the process of how you relate to them, how you move forward and follow their direction.”

The informants acknowledged the consistency of the proposed model of service delivery with other chronic disease models. The congruence between models reinforced the idea that living with HIV has many similarities to living with other chronic diseases leading to potential synergies in terms of efficient and effective provision of services.

### **Limitations of the Model**

The informants also identified several limitations of the model. These included the language of rehabilitation, lack of research on activity and participation outcomes, and co-occurring disorders and social conditions.

**The language of rehabilitation.** One concern the informants raised, particularly those who were leaders in advocacy groups, was the language of “rehabilitation”. The informants expressed resistance to preconceived notions about rehabilitation. One service provider noted, “It’s the whole rehab framework based on years of being seen as people around a sexual orientation, or a drug



use, or a marginalized status in society (who) are problems to be fixed.” This informant went on to say that the language of rehabilitation is not “an easy language to apply to the context of HIV and AIDS for a variety of reasons and that’s something, I think, that is a barrier that will need to be worked with.” Other informants linked lack of knowledge about rehabilitation with limited access to services.

A third concern related to the language of rehabilitation was the definition of “rehabilitation”. The model focused on rehabilitation interventions to promote activity and participation outcomes. However, one researcher informant noted that many AIDS service organizations actively focus on promoting activity and social participation, but these interventions are not called “rehabilitation” and are not provided by traditional rehabilitation professionals (i.e., occupational therapists, physical therapists, and speech-language pathologists). This informant noted that it was important to acknowledge the valuable contribution that these organizations have in supporting PLWHA to achieve their activity and social participation goals.

**Lack of research on activity and social participation outcomes.** One of the limitations of the model noted by the informants was that, with a few exceptions, there was a lack of research literature on effective interventions to facilitate activity and social participation outcomes for PLWHA. This issue tended to be highlighted by the occasional disconnect between the interventions commonly provided by rehabilitation professionals and the ways the outcomes of these interventions were measured in research studies. For example, some of the informants noted that exercise as an

intervention for groups of PLWHA has shown promising positive outcomes, but the outcomes measured in these studies tended to focus on improvements in body structures and functions, such as muscle mass and exercise tolerance, rather than activity and social participation.

Another limitation identified by one of the informants was the lack of attention to research on outcomes related to interventions that addressed macro level environments, such as advocacy work to influence public policy. This informant noted that it may have been beyond the scope of this research but also noted the importance of that issue: “But if you go back upstream a little bit to the policy contexts. I wonder what, if there’s literature that speaks to interventions around influencing or shaping policy.”

**Co-occurring disorders and social conditions.** The informants suggested the need to identify more clearly in the model the issue that many PLWHA have co-occurring disorders (e.g., hepatitis C, addictions, mental illness) and social conditions (e.g., poverty) that can contribute to their vulnerability and marginalization. These concurrent conditions raised issues for the informants about the importance of service co-ordination and integration that can address multiple health and social needs. In addition, the informants noted that PLWHA living in poverty would require supports to address basic needs, such as housing and food security. One service provider noted how these basic needs could pre-empt rehabilitation: “It is a little bit hard to wrap my mind around rehabilitation when the needs are so basic.” Although the model identified the importance of taking a determinants-of-health

approach in relation to issues such as food security and housing, the informants suggested that the complexity of multiple health and social conditions experienced by some PLWHA should be further highlighted.

### **Challenges to Implementing the Model**

The informants in the interviews and focus groups talked about the challenges to implementing the model. These challenges included the availability of resources to access rehabilitation, stigma, traditional roles of rehabilitation professionals, diversity of the population of PLWHA, and creating opportunities to integrate rehabilitation services.

**Availability of resources to access rehabilitation.** The informants spoke about the scarce resources available for rehabilitation services outside of institutional settings. This issue appeared to be particularly troublesome in rural and remote areas. Some service provider informants working in a medium-sized urban city noted that HIV specialized services were only available in the provincial capital. One of the informants described the challenges for PLWHA outside the provincial capital as follows:

So you get on the bus at six in the morning and you get there for nine and then you don't get the bus back until five and then you have to eat and you have no money to eat. And, maybe you've missed an appointment or two and your social assistance person is not going to fund you anymore because they've paid for your meals for once or twice. And then they say, you didn't go (to the appointment), so

you're on your own. Well that still doesn't help them get there or connect (with HIV services).

Another informant noted the challenges of working in an AIDS service organization in small and remote areas:

This is a northern community. The place that we cover as an AIDS service organization is about 49,000 square kilometres so it's, it's less practical for individuals who are further afield to, to do these kinds of activities (engage in services) unless we can figure out a way to get the material to them to participate.

The informants also noted the challenges of jurisdictional issues in providing services to First Nations communities in Canada:

The weird boundary between on-reserve and off-reserve is, is very challenging when it comes to actually providing support for people, um, because we, we often have to translate that support into what people can carry with them as opposed to something that we can provide on an ongoing basis for those who come in from, from (First Nations) communities.

The informants also noted challenges for people who are immigrants and refugees and may not have the resources to seek or access services. One of the informants described some of these challenges this way:

... (if) English is not your first language or you're living in poverty and you're dealing with other issues. I mean like with anything, you're going to have greater struggles in,

um, accessing all the supports that are available to you because you might just not be able to ask the right questions because you don't have the skills, you don't have the language, don't have the opportunities.

A final challenge was noted by another informant who talked about distributing limited funding among service providers and agencies who provide care and support for PLWHA. She stated: "I guess where it could get contentious is where there's money involved to do rehabilitation work in HIV."

**Stigma.** The informants identified stigma as a major challenge to implementing the model and talked about potential stigma originating from families, cultural communities, geographic communities, service providers, laws, and social policies. They noted how stigma could affect peoples' decisions to seek treatment, the types of treatment they would seek, and with whom they would engage in treatment. Layers of stigma create increasingly complex challenges for PLWHA when issues of sexuality, sexual orientation, race, ethnicity, substance use, and poverty are present. The informants noted that these layers of stigma could affect whether an individual was willing to access services specifically designed for PLWHA and whether he or she would join a group that was focused on addressing HIV related health issues.

**Traditional roles of rehabilitation professionals.** The informants noted that rehabilitation professionals, such as occupational therapists, physical therapists, and speech-language pathologists, are not typically integrated into HIV specific care. As noted earlier, PLWHA have often

faced challenges accessing rehabilitation services. The informants stated that these services often get initiated only when another health condition, such as a lower limb amputation or a respiratory disease, was an indication for rehabilitation. One therapist noted:

The rehab professionals don't have very much understanding of any of the issues related to HIV/AIDS and have often not dealt with people before, or didn't realize they dealt with people before. So I think there's a huge need for education for rehab professionals around all of these different issues.

**Diversity of the population.** Many of the informants noted the huge diversity of the population of PLWHA. Differences such as age, gender, stage of disease, time the disease was contracted, and economic resources could make it difficult to provide services that meet the diversity of needs and goals of PLWHA.

**Creating opportunities to integrate rehabilitation services.** There was no consensus from our informants on whether rehabilitation services should be integrated with HIV specific services, or whether services for PLWHA should be integrated with services for people with other chronic diseases, or both. Some of the informants talked about the importance of integrating rehabilitation services into "one-stop shops" rather than being "stand alone" entities. One service provider gave an example of an organization where clients can receive a range of services, including lab tests, and see a variety of professionals including "a pharmacist, a nutritionist, mental health therapist,

physiotherapist, home care nurse, as well as a coordinator who's running a peer support program.” On the other hand, another informant noted the importance of recognizing the ethnic and cultural diversity of PLWHA and the potential that some services may need to address the needs of specific populations.

### **Supports to Implementation of the Model**

Although the informants acknowledged the challenges in implementing the model, they also noted the potential supports. These supports included education, collaboration and integration, emerging use of technology, and the principle of Greater Involvement of People Living with HIV (GIPA) (UNAIDS, 2007).

**Education.** The informants identified the need for the education of rehabilitation professionals about HIV and PLWHA, and for the public, government officials, and PLWHA about rehabilitation and the existence of educational opportunities. Specifically, the Canadian Working Group on HIV and Rehabilitation was identified as an important source of information related to the role of rehabilitation and HIV. One policy maker also noted the opportunities for government departments to act as think tanks for introducing new ways of understanding and addressing issues. This informant suggested that a centralized government department can have the capacity to educate local health authorities about “new tactics, new strategies, experiences from other countries, evidences of lessons learned, successful lessons learned from other programs in other provinces or in other countries.” The informants also highlighted the need to use accessible and understandable

language.

**Collaboration and integration.** The informants described existing networks of collaboration not only around HIV but also around other chronic diseases as opportunities to support the implementation of the service delivery model. Collaboration was particularly evident in smaller communities where service providers may “know the resources out there” and “have a good understanding of each other’s roles.” The informants believed this type of collaboration and integration of services needed to be considered in the planning and development of new services.

**Emerging use of technology.** Several of the informants noted the potential use of technology for implementing interventions, particularly in rural areas in which HIV services were not being provided. The informants shared ideas about using texting, e-mailing, social media, phones, and other digital technologies and noted the potential for these types of technologies to provide accessible and confidential services. One example was the use of tele-health in a community that allows a physician in a large urban center to connect with PLWHA in the distant community.

**Greater involvement of PLWHA.** The documented principle of GIPA and the history of activism in the HIV community were also seen as a potential support for implementation of the model. One of the informants stated:

One of the frameworks that we work with is the greater involvement of people with AIDS, the GIPA principles ... that’s been really useful to us as a guiding document for how do we really practice person-centered

care where the individual is truly at the center and able to decide what they want, why they want it, when they want it, and it's facilitated or supported, and getting clarity about that and then having those gaps filled.

As this quote suggests, the principle of GIPA can provide a framework for both client-centered care as well as facilitating action that will fill gaps in services for PLWHA.

### **Discussion**

Occupational therapy and rehabilitation in the context of HIV is an emerging field of practice. We developed a model for the implementation of services that can support adults living with HIV to achieve their goals for activity and social participation. The informants in our study from diverse backgrounds and perspectives contributed important feedback about the model and its application in the context of current services for PLWHA. This feedback provided helpful suggestions for revising the model to include more emphasis on issues of sex and sexuality and the associated criminalization experienced by PLWHA in many countries (UNAIDS, 2008). In addition, stories from experts in the field highlighted the importance of addressing the concurrent health and social conditions experienced by many PLWHA (Cuca & Rose, 2015). Considering the multiple needs of PLWHA, occupational therapy needs to be closely integrated with existing health and social services. Working in collaboration with primary care community and social support services may provide occupational therapists with the best opportunities to support people to live longer, in relatively good health, and to fully participate in

their communities. Although the model was developed to address activity and participation as broad outcomes, our informants did not often specifically mention occupational therapy, suggesting the need for increased awareness of the role that occupational therapists can play in addressing the activity and social participation needs of PLWHA as a chronic disease.

In relation to developing the model, our informants were very supportive of the use of the model to guide provision of services that address the activity and participation needs of PLWHA. The results of our study suggest that principles, specifically holistic, client-centered, and strengths-based approaches, combined with cultural proficiency are critical for successful services that address the complex and diverse needs and goals of PLWHA.

Recognition of levels of environmental influences on the ways that people experience the functional and social consequences of living with HIV was also acknowledged by our informants as an important component of our model. This understanding can create greater awareness about the potential for service providers to consider and intervene at multiple levels of the environment that include the person, their social networks, the organizations with which they interact, and the social political environment. For example, access to rehabilitation services was identified by our informants and others (Barnes, Dolan, Gardner, Stevens, & Zack, 2012) as an issue for people living with chronic conditions in the community. Attention to the layers of environments suggests that access could be improved at the person and

micro levels by educating people and their support networks about the ways that rehabilitation and occupational therapy services can support people with activity and participation needs so they can advocate for access to these services. Access could also be addressed at the meso level by considering organizational structures that make it easy or difficult for people to engage in services (e.g., hours of operation, child care, opportunities to use technology-based services). Finally, access could also be addressed at the macro level by taking action to reduce stigma related to HIV in communities, thereby potentially increasing the willingness of individuals to receive HIV specific services. The experiences of HIV-positive sex workers illustrate the inter-sectoral nature of stigma and discrimination and how HIV can cut across layers of environments and relate to multiple personal factors including sex, race, and sexual orientation (Logie, James, Tharao, & Loutfy, 2011). Understanding stigma and discrimination in relation to layers of the environment can assist in organizing strategies for addressing these issues (Logie et al., 2011; Stangl, Lloyd, Brady, Holland, & Baral, 2013). Finally, the structures of health system funding need to address the broader implications of where and how occupational and other rehabilitation therapists work and the ways they can be integrated into community-based chronic care services.

Understanding the disabling features of environments can help service providers to consider and develop new ways of intervening but can also assist PLWHA to better understand that many of the challenges they experience associated with activity

and participation goals may be more related to environmental factors rather than personal factors. This awareness can create new opportunities for addressing personal health issues as well as acting to ameliorate environmental barriers and create more inclusive communities. Attention to layers of the environment can highlight facilitators to achievement of activity and participation goals, such as the strong history of political activism of PLWHA (Altman & Buse, 2012) and the development and articulation of the ongoing need of the greater and meaningful involvement of PLWHA in service planning, evaluation, and research (UNAIDS, 2007).

Access to rehabilitation services for PLWHA was identified by our informants as an important issue. Access can be affected by the structure of health care systems and the capacity of rehabilitation professionals to address the needs of this population. Worthington et al. (2008) found that few Canadian rehabilitation professionals had provided interventions for PLWHA and few had received training about HIV. Of those who had worked with PLWHA, most addressed issues of impairments and activity limitations rather than community participation.

Our study identified promising practices to achieving positive activity and participation outcomes for PLWHA. However, considerably more attention needs to be paid to these outcomes. Thus, evaluations of occupational therapy and other rehabilitation interventions should ultimately question whether the intervention has improved participation in valued activities and society. In addition, our informants emphasized the importance

of the processes of service delivery in addition to the outcomes. Ongoing intervention research and program evaluation can assist in determining the most effective interventions to achieve activity and participation outcomes as well as the processes that promote access to services and acceptability by PLWHA.

The recent publication of evidence-informed recommendations for rehabilitation with older adults with HIV (O'Brien et al., 2014) and guidelines for HIV and employment (Wagener et al., 2015) are relevant to occupational therapists practicing in this field. However, the quality of evidence is poor for most recommendations (O'Brien et al., 2014) and further rigorous research and evaluation needs to be done in the area.

### **Recommendations**

The development of the service delivery model and expertise from our informants highlighted several recommendations for implementing the service delivery model. Actions to address many of these recommendations can be made at one or more contextual levels (micro, meso, macro) depending on each therapist's role and level of influence.

1. Ensure that occupational therapy and other rehabilitation services for PLWHA are principle-based. Articulating the principles identified in the proposed model will create opportunities for occupational therapists and other service providers to evaluate the ways that they can implement these principles in day-to-day work.
2. Increase resources for service navigation that specialize in assisting people in finding

occupational therapy and other rehabilitation supports and services that may be outside of specialized HIV services. AIDS service organizations and peer support networks have an important role in helping people to understand the services available and how to access them.

3. Build capacity of mainstream rehabilitation services, whether hospital based or integrated into primary care settings, to be inclusive of PLWHA. Ongoing and easily accessible education about HIV, its treatments and functional implications to occupational therapy and other rehabilitation students, clinicians, service providers, and the general public is required. The Canadian Working Group on HIV and Rehabilitation (2015) has provided early leadership in this area through E-modules and other resources.
4. Build capacity of occupational therapy and other rehabilitation students and clinicians to address broad determinants of health and barriers to activity and participation across layers of the environment. For example, interventions can include promotion of food security through teaching skills for budgeting and growing food in community gardens, as well as policy advocacy to improve food security for people living on social assistance.
5. Increase research and program evaluation on the effectiveness of interventions in achieving activity and participation outcomes. Research and evaluation need to encompass both the content of interventions

as well as the processes by which the interventions are implemented. O'Brien and colleagues (2014) suggest several self-report measurement scales for evaluation of disability and rehabilitation in HIV, and we add the importance of including measures that focus on the individual's client-centered goals and outcomes, such as the well-validated Canadian Occupational Performance Measure (Law et al., 2014). In addition, we recommend greater emphasis on understanding the outcomes of interventions that are targeted at changing meso and macro level environments. Occupational therapy models of practice have emphasized the importance of environmental change (Kielhofner, 2008; Law et al., 1996) and occupational therapists can become leaders of intervention and evaluation in this area. Partnerships among clinicians, academics, community organizations, and PLWHA are important means to develop capacity and expertise in evaluating relevant outcomes.

### **Limitations**

Although our sample size was only 35 informants, the participants were located in large urban, medium-sized urban, and rural areas and had diverse roles related to HIV providing a wide range of perspectives. When considering our method, the approach of conducting both group and individual interviews has strengths and limitations. Group interviews, in the form of focus groups, were our primary source of data. Focus groups can limit the ability to understand individual perspectives

because the data results from a blended voice of all participants rather than the unique voice of an individual. Thus, although we encouraged diverse perspectives, it may be that more prominent voices became dominant (Krueger & Casey, 2015). The size of our groups ranged from 6 to 11 persons, which allowed opportunity for participation of all group members with greater opportunity in the smaller groups. Our participants were all from Canada, so their perspectives on health services delivery have been shaped by the context of the Canadian health care system. We focused our service delivery model to address the needs of adults living with HIV, so the model may not be applicable to children and youth.

### **Conclusions**

This study obtained expert feedback about a model for rehabilitation service delivery to support the achievement of the activity and social participation goals of PLWHA. The model was determined to have use in identifying principles important for service delivery, emphasizing the layers of the environment that can affect the achievement of activity and participation goals for PLWHA and, although initially developed in a Canadian context, can also have broad use in other health care systems because of the focus on activity and participation. The feedback obtained about the model also highlighted the value of creating effective processes, as well as content, when designing, delivering, and evaluating interventions. The model can be used to: (a) facilitate discussion among occupational therapists, other rehabilitation professionals, PLWHA, and other stakeholders about critical principles of service delivery; (b)



facilitate understanding about needs, goals, and potential interventions; and (c) provide a framework to compare current occupational therapy and other rehabilitation practice with the service delivery model to plan more effective future services.

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