Our purpose was to develop process recommendations and guiding principles for future clinical practice guidelines in HIV rehabilitation. We conducted a scoping study that included focus group and interview consultations with 28 participants including people living with HIV, researchers, clinicians, educators, and policy stakeholders with expertise in HIV and rehabilitation. We used qualitative content analysis techniques to identify emergent themes related to the development of clinical practice guidelines. Results included seven recommendations for the process of developing clinical practice guidelines in HIV rehabilitation that spanned areas of flexibility, scope, adopting existing evidence from concurrent health conditions, format, interprofessional approach to development and implementation, terminology, and knowledge translation. Three guiding principles emerged to inform the philosophical approach for guideline development. These findings serve as a foundation for the development of clinical practice guidelines in HIV rehabilitation to enhance the care and treatment of people living with HIV.

HIV increasingly is experienced as a lifelong episodic disease, characterized by unpredictable cycles of wellness and illness. More individuals are living with the long-term health-related consequences of HIV, its treatments, and concurrent health conditions (Weiss, Osorio, Ryan, Marcus, & Fishbein, 2010; Willard et al., 2009). These health-related consequences are known as disability, defined as symptoms and
impairments, difficulties carrying out day-to-day activities, challenges to social inclusion, and uncertainty about future health that a person may experience daily and over the course living with HIV (O’Brien, Bayoumi, Strike, Young, & Davis, 2008). HIV is a complex and multisystemic disease affecting the cardiorespiratory, endocrine, neurological and musculoskeletal systems of the body. A 2004 survey documented a high prevalence of disablement among people living with HIV. At least 80% of respondents experienced a minimum of one impairment (e.g., fatigue, pain, memory problems), activity limitation (e.g., difficulty carrying out daily activities), or social participation restriction (e.g., employment, financial independence) in the previous month (Rusch et al., 2004). Results highlighted the role for health communities to respond to the disablement needs of people living with HIV.

Rehabilitation is broadly defined in the context of HIV as any services and activities that address or prevent impairments, activity limitations, and social participation restrictions experienced by an individual (Canadian Working Group on HIV and Rehabilitation, 2010; World Health Organization, 2001; Worthington, Myers, O’Brien, Nixon, & Cockerill, 2005). Rehabilitation can assist people living with HIV in managing disablement such as adverse effects of medications, fatigue, pain, cognitive problems, and issues related to income and vocational support. However, few rehabilitation professionals work with this population. A Canadian survey documented only 39% of rehabilitation professionals (occupational therapists, physical therapists, and speech-language pathologists) had knowingly worked with people living with HIV (Worthington et al., 2008). Many respondents felt they needed specific knowledge and training in HIV to adequately serve this population. Findings emphasized the need to develop guidelines to inform and enhance clinical HIV rehabilitation practice.

Over the past decade an increasing amount of research has explored the rehabilitation interventions for symptoms and impairments experienced by people living with HIV. Systematic reviews and meta-analyses examining the effect of exercise, massage and cognitive behavioral and stress management therapies for people living with HIV exist (Brown & Vanable, 2008; Crepaz et al., 2008; Hillier, Louw, Morris, Uwimana, & Statham, 2010; Himelhoch, Medoff, & Oyeniyi, 2007; O’Brien, Tynan, Nixon, & Glazier, 2008; O’Brien, Nixon, Tynan, & Glazier, 2010; Scott-Sheldon, Kalichman, Carey, & Fielder, 2008). This emerging evidence coupled with the relative lack of rehabilitation professional exposure to people living with HIV suggests the need for developing clinical practice guidelines in this area.

Clinical practice guidelines are defined as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (Field & Lohr, 1990). Guidelines are designed to improve patient outcomes by translating or implementing evidence-based medicine into actionable “best practices” (Roudebush, Allen, Dodd, & Novotny, 2004). Leaders in the field remind us that the underlying value and motivation for using evidence is to help guide clinical decision making for individual patients by considering case complexity, the best available evidence, the provider’s expertise and experience, and the patient’s preferences and beliefs (Triano, 2008). Clinical practice guidelines can help people living with HIV and clinicians with decision-making surrounding care, treatment, and support. Given the emerging role for rehabilitation in the context of HIV, this is an opportune time to adopt a coordinated and rigorous approach to developing guidelines to assist people living with HIV, rehabilitation professionals, and other health providers in preventing or reducing disablement associated with
HIV. However, no known best practices specific to the development of rehabilitation clinical practice guidelines in the context of HIV currently exist.

Developing clinical practice guidelines is a complicated and iterative process requiring extensive resources (Browman et al., 1995). In particular, guideline development in HIV rehabilitation will require a coordinated and comprehensive approach in order to address the complexity of the disease and its resulting disablement. In comparison to other chronic conditions, a paucity of research evidence from which to build clinical practice guidelines exists (O’Brien, Wilkins, Zack, & Solomon, 2010). Nevertheless, a small group of clinicians, researchers and people living with HIV possess growing expertise in this field. Hence, we conducted a comprehensive multistakeholder consultation as a first step to identify recommendations and principles to inform future guideline development (Schunemann, Fretheim, & Oxman, 2006). The purpose of this study was to develop process recommendations and guiding principles for future clinical practice guidelines in HIV rehabilitation.

METHODS

We conducted a scoping study in the field of HIV and rehabilitation. Scoping studies include a literature review and consultation phase that may be used to map key concepts, opinions, and types of evidence available in a given area (Arksey & O’Malley, 2005). Results from the literature review phase are previously published and demonstrated a lack of rehabilitation guidelines in this area (O’Brien et al., 2010). In this article, we focus on the consultation phase of focus groups and key informant interviews to identify recommendations and guiding principles to inform the future development of clinical practice guidelines in HIV rehabilitation.

We obtained ethics approval from McMaster University, Hamilton, Canada. All elements of this research were guided by the Canadian Working Group on HIV and Rehabilitation (CWGHR), Research, Education and Practice Advisory Committee. CWGHR is a national, multisectoral organization aiming to improve the lives of people living with HIV through integrated rehabilitation research, education, policy and practice (Canadian Working Group on HIV and Rehabilitation, 2010). An overview of the consultation phase of the scoping study methodology is provided in Figure 1.

FOCUS GROUP AND KEY INFORMANT INTERVIEW PHASE

Twenty-eight key informants participated in this study: 16 in focus groups (12 in the first focus group and 4 in the second focus group) and 12 in key informant interviews between June and October 2007. Participants included people living with HIV, researchers, educators, clinicians, and policy stakeholders with expertise in HIV and rehabilitation across Canada and in the United Kingdom who were identified by members of CWGHR’s Research, Education and Practice Advisory Committee and recruited by authors (K.O. and A.W.). Two authors (K.O. and A.W.) facilitated the interviews and focus groups. Interviews were held in various cities across Canada as well as London, United Kingdom either face-to-face or by telephone. Focus groups were held face-to-face in order to maximize the opportunity to consult with a larger number of stakeholders from across Canada, some of who attended the CWGHR Annual General Meeting in Toronto, Ontario. Furthermore, focus groups enabled us to explore the interactions among stakeholders in HIV and rehabilitation, specifi-
cally related to the level of agreement surrounding recommendations for best practice guidelines (Freeman, 2006).

Participants responded to a series of semistructured questions to explore recommendations and guiding principles for the development of clinical practice guidelines in HIV rehabilitation. We specifically asked focus group and interview participants to discuss (1) their experience with, or general knowledge of, the development or use of clinical practice guidelines; (b) considerations that should be taken into account when developing clinical practice guidelines in the context of HIV; (c) how guidelines in HIV rehabilitation might be used (i.e., purpose, scope); (d) who should be involved in HIV rehabilitation guideline development; and (e) who could use the guidelines. We used the same discussion guide for the focus groups and interviews. Focus groups and interviews were audio-recorded and later transcribed verbatim. Field notes were taken throughout to supplement the thematic analysis.

Focus group and interview data were analyzed together given both data collection techniques were used to collectively achieve the same study purpose (Lambert & Loiselle, 2008). We used a line by line coding procedure to identify key themes that related to recommendations for HIV and rehabilitation guidelines. We conducted a constant comparative method of analysis whereby data collection and analysis occurred simultaneously (Strauss & Corbin, 1998). We categorized data from the

FIGURE 1. Overview of Consultation to Develop Process Recommendations and Guiding Principles for Future Clinical Practice Guidelines in HIV Rehabilitation
focus groups and interviews and compared them systematically with new emerg-
ing categories that related to guideline development, looking for any similarities or
differences that arose in the data. When all data were analyzed, we devised a list of
recommendations for HIV rehabilitation guideline development and philosophical
elements that should be taken into consideration.

VALIDITY CHECK CONSULTATION PHASE
We conducted a final validity check phase in a full-day consultation workshop
held in February 2008. Seventeen new and returning participants including peo-
ple living with HIV, clinicians, HIV researchers, representatives from HIV research
organizations, and other AIDS service organizations (ASOs) attended from across
Canada. We reported preliminary findings including a draft list of recommendations,
refined the results based on their feedback, and established the principles for the
development of HIV rehabilitation guidelines.

RESULTS
Results from the thematic analysis of focus group and interview data yielded recom-
mendations and guiding principles for the development of clinical practice guidelines
in HIV rehabilitation.

PROCESS RECOMMENDATIONS FOR DEVELOPING HIV
REHABILITATION GUIDELINES
Seven process recommendations for developing clinical practice guidelines in
HIV rehabilitation emerged that spanned areas of flexibility, scope, adopting exist-
ing evidence from concurrent health conditions, format, interprofessional approach
to development and implementation, terminology, and knowledge translation (Fig-
ure 2). We describe each recommendation with supporting quotations.

1. HIV Rehabilitation practice guidelines should be flexible to account for an indi-
vidual’s needs and goals. Participants expressed enthusiasm and caution toward the
development and implementation of clinical practice guidelines in the HIV context.
Although participants felt guidelines were important, they believed they should re-
main flexible to account for an individual’s needs and goals.

Clinical practice guidelines in my mind are important but . . . they can be dangerous in
the sense that they become very prescriptive and one of the key things . . . for clinical
practice guidelines . . . not every person is going to fit in or under the model of what is
preferred just based on the variability and multicomplex nature of HIV in and of itself.
(Focus Group 2; Participant 1, policy stakeholder)

2. HIV Rehabilitation practice guidelines should possess a balance between a broad
and specific scope. Some participants felt that the scope of guidelines should remain
broad to promote the overall understanding of rehabilitation in the context of HIV
among patients, care providers and policy makers.

A lot of people still don’t know what that [rehabilitation] means or what it means to
look at rehabilitation in that context [of HIV] so maybe that’s where best practices can
focus on . . . is that global picture. (Focus Group 1; Participant 8, clinician)
Others cautioned that guidelines should be specific enough in order to provide practical and useful advice for clinicians working in HIV care. Rehabilitation professionals specifically identified areas in which guidelines would facilitate the treatment of patients living with HIV presenting with specific clinical problems.

I have a lot of questions about HIV and the brain... as an occupational therapist we focus on what they [people living with HIV] can do... and what happens... when... the referral comes to me... a cognitive assessment... I’d like to know especially when it’s a 67-year-old male who has some cognition issues... We’re not sure if it’s Alzheimer’s, we’re not sure if it’s stroke, we’re not sure if it’s because it’s HIV... I would love to get some more information about just cognition and HIV. That’s something very specific... and to me... valuable. (Focus Group 1; Participant 7, clinician)
3. HIV Rehabilitation practice guidelines should include evidence from existing guidelines for concurrent health conditions that share similar forms of disablement with HIV. Some rehabilitation professional participants were comfortable prescribing exercise with people living with HIV given the level of research evidence supporting this intervention but less comfortable with rare complications or emerging comorbidities associated with HIV. Concurrent health conditions faced by people living with HIV such as inflammatory arthritis, diabetes, obesity, cardiovascular disease, and issues related to aging pose added complexity to rehabilitation practice and should be considered in the scope and development of clinical practice guidelines. In the absence of HIV-specific research evidence related to these conditions, participants suggested using practice guidelines established in other diseases to assist clinicians working with people living with HIV who share similar types of disablement.

4. HIV Rehabilitation practice guidelines should take on a variety of formats depending on the end user. Participants indicated that guidelines could take on a variety of forms, such as a check-list, flow sheet, tip sheet, or pathway; a list of questions; or criteria that could help guide assessment when working with a person living with HIV. The format of the guideline would ultimately depend on the end user of the guideline, including a person living with HIV, clinician or policy maker.

5. HIV rehabilitation practice guidelines should include an interprofessional approach to development and implementation. Given the paucity of literature in this emerging field, participants felt that guidelines should adopt an interprofessional approach to development and implementation. The development process should include a broad range of stakeholders, including a diversity of people living with HIV, service providers, policy stakeholders, and researchers, using a participatory process in the development, dissemination, implementation, and evaluation of their use to make sure that information is as spot on as possible and . . . that there's buy-in you know that you have some opinion leaders . . . who within the speciality areas actually believes they're important . . . people living with HIV . . . HIV specialists . . . doctors and nurses . . . whoever is at the front line of their HIV care . . . I love the idea of it being driven by people with expertise in disablement, disability and rehabilitation] which is CWGHR. (Interview Participant 7, researcher)

6. HIV rehabilitation practice guidelines should be referred to as “evidence-informed recommendations.” Additional recommendations around guideline development included the terminology and current semantics of the terms best practice and practice guidelines. Concerns were expressed by clinician participants that practice guidelines are increasingly used to sanction practice and contain costs. Some participants suggested we consider alternative terminology to incorporate a range of belief and health systems such as position paper, good practices, wise practices, preferred practice guidelines, care maps, care pathways and minimum specifications. The validity check discussion resulted in evidence-informed recommendations as the preferred terminology from which to move forward with development.

7. HIV rehabilitation practice guidelines should include a clear strategy for knowledge translation. Participants felt that knowledge translation will be vital to ensure guidelines are disseminated in an appropriate form and broadly adopted and inte-
I don’t think there’s any point in developing them [guidelines] unless there’s a really active dissemination plan . . . not just dissemination but a whole sort of knowledge translation strategy because . . . putting them in a journal or even sending them in the mail to . . . is not going to have an impact . . . have a patient version have a provider version . . . making providers who are looking after patients with HIV and people living with HIV themselves aware that there is a rehab dimension and certain treatments are or can be effective for their conditions. (Interview Participant 10, clinician and researcher)

**GUIDING PRINCIPLES FOR DEVELOPING HIV REHABILITATION GUIDELINES**

Twelve themes emerged that informed the development of guiding principles. In the validity check phase, these themes were grouped into three guiding principles for the development of clinical practice guidelines (see Figure 2).

**Guiding Principle 1.** Clinical practice guidelines should incorporate an understanding of the diversity of people living with HIV; and the social justice issues they may face because of social and economic circumstances, multiple vulnerabilities, and stigma or discrimination; these guidelines should recognize the importance of self-determination, self-help, and support networks (see Figure 2). Participants recognized the diversity of people living with HIV, the social and economic vulnerabilities they face, and how these should be acknowledged in a client-centered and individualized approach to future guidelines. Social determinants of health, such as housing and income support, could also help place overall access to rehabilitation into context. Participants felt that in an environment fraught with barriers to accessing rehabilitation services, self advocacy, management, and informal support networks should be considered a strategy in guideline development.

Ultimately it has to come down to people being comfortable with self advocacy because the OTs and PTs aren’t going to be there all the time . . . It’s similar to self-management. (Interview Participant 8, researcher)

**Guiding Principle 2.** Clinical practice guidelines should incorporate a client-centered and holistic approach; the most current knowledge of HIV and its treatments and the principles of evidence informed rehabilitation (see Figure 2). Participants felt that given the rapidly changing field, clinicians and people living with HIV need to be constantly updated on new treatments and approaches to care. Clinical practice guidelines that demonstrate the impact of rehabilitation may serve as leverage to promote funding and enhanced access to rehabilitation for people living with HIV.

The better research we have the more power we have behind what we’re saying and the more we can go back to the funding agencies we can go back to the people who aren’t accessing services and say this is what we’re doing. Look we have proof. That is incredibly important. (Focus Group 1; Participant 8, clinician)

**Guiding Principle 3.** Clinical practice guidelines should address access to care and include strategies to maximize access to rehabilitation services; acknowledge the role of rehabilitation as a component of optimal care; acknowledge the role of government policy and advocacy in the provision of services; and incorporate communication strategies to ensure that all stakeholders understand rehabilitation and its role.
in HIV prevention and care (see Figure 2). Participants felt that guidelines may be used to enhance access to rehabilitation services. Strategies to communicate recommendations from clinical practice guidelines will be essential to ensure that evidence is translated to rehabilitation providers, other care providers, policy stakeholders, researchers, and people living with HIV.

Communication strategy is so important so that you have the key messages and the channels already in place when needed . . . There's wonderful research out there but until it's packaged in such a way that's attractive to those people who need to hear it at the right time it's going to sit on a shelf. (Interview Participants 4; educator and researcher)

**DISCUSSION**

Developing clinical practice guidelines is an extensive and iterative process that involves several phases of input and consultation (Browman et al., 1995; Graham, Harrison, Brouwers, Davies, & Dunn, 2002; Shekelle, Woolf, Eccles, & Grimshaw, 1999). This study is the first to establish process recommendations and guiding principles for the development clinical practice guidelines in HIV and rehabilitation. A large number of characteristics have been used to describe the nature and intent of clinical practice guidelines (Oxman, Schunemann, & Fretheim, 2006). In this study, the guiding principles refer to the philosophical approach to developing the guidelines; the recommendations specifically refer to the process of going about their development and implementation (Moulding, Silagy, & Weller, 1999; National Initiative for Telehealth Guidelines, 2003). Using scoping study methodology allowed us to seek expert opinions and perspectives from stakeholders in the field in the absence of research evidence. This multistakeholder consultation was integral to the process given the emerging field of HIV and rehabilitation research and guideline development.

Clinician participants working in HIV care highlighted the need for specific guidelines to address types of disablement particularly for issues related to aging. As individuals age with HIV they may experience the premature onset of concurrent health conditions such as bone and joint disorders, cardiovascular disease, metabolic syndrome, cancer, and neurocognitive decline (Goodroad, 2003; Justice, 2010). It is often difficult to separate HIV-related symptoms from those related to concurrent health conditions associated with aging (Becker, Lopez, Dew, & Aizenstein, 2004). In the absence of research evidence on rehabilitation interventions specific to HIV and aging, opportunities exist to consider whether guidelines established in other health conditions that share similar impairments, activity limitations and participation restrictions are applicable or modifiable for people living with HIV.

Some participants expressed concern that guidelines might be too restrictive given the complex presentation of HIV often requires flexible approaches to treatment. A concern associated with clinical practice guidelines is that governments and other funding agencies can look to guidelines to regulate practice (Graham, James, & Cowan, 2000; Heimer, 2008; Holmes, Murray, Perren, & McCabe, 2008; Jacobson, 2008) and may be linked to physician and institutional remuneration (Doran & et al., 2006; Hartig & Allison, 2007). Alternatively, rehabilitation clinician participants less familiar working with people living with HIV suggested guidelines would increase their comfort level in treating patients and may increase patient trust. Given so few rehabilitation professionals knowingly serve people living with HIV (Worthington et al., 2008), guidelines may help to increase the overall knowledge and
confidence among providers to better serve this population. Because of the complexity of HIV, participants favored interprofessional guidelines in HIV rehabilitation, that acknowledge all members of the health team, an approach similarly supported in the literature (Kaldy, 2007; Kresse, Kuklinski, & Cacchione, 2007; Singleton, Levin, & Keefer, 2007).

Terminology used in the field of clinical practice guidelines varies. Increasingly terms such as best practices or clinical practice guidelines are used in medical models to demonstrate the “best” care, based on high-quality research evidence (Oxman et al., 2006). Given the paucity of high-quality HIV and rehabilitation research, participants suggested evidence-informed recommendations as an alternative term to proceed with development (Aass, McConnell, Perrier, Woodbury, & Sibbald, 2009; Bowen, Erickson, Martens, & Crockett, 2009; Bowen & Zwi, 2005).

Participants recommended a balance of focusing on a specific and practical area of practice (e.g., exercise) and remaining broad in scope to help advance policy in areas of labor force participation and access to health services. Many agreed that guidelines should promote understanding that rehabilitation is an important component of care among health care providers, people living with HIV, AIDS service organizations, employers, insurers, and policy makers in order to promote access to rehabilitation. Regardless of the scope, guidelines should focus on the needs of the end user and include clear statements, decision aids, patient education materials and practical tools to manage clinical practice issues (Grol & Buchan, 2006). Next steps include developing and evaluating practical tools to allow people living with HIV and their health providers to navigate access to rehabilitation services particularly in underserviced areas.

Our methodological approach has potential limitations. We used a convenience sample identified by the CWGHR Research, Education and Practice Advisory Committee; thus, all participants were knowledgeable about the HIV and rehabilitation field. Consulting with experts in clinical practice guideline development in other disease areas might have generated additional guiding principles or recommendations for future development not captured here. Nevertheless, the validity check consultation enabled us to share preliminary findings with the HIV community, and refine the guiding principles for clinical practice guidelines. We are currently applying these recommendations and guiding principles to develop evidence-informed recommendations for rehabilitation in HIV and aging and in our update of a resource manual for rehabilitation professionals on HIV and rehabilitation (Canadian Working Group on HIV and Rehabilitation, 2010).

CONCLUSIONS

In this study we present seven recommendations and three guiding principles to inform the development of clinical practice guidelines in HIV rehabilitation. Next steps will include using these principles and building on existing guidelines in other disease areas to produce evidence informed and consensus based, useful, practical, and accessible guidelines that inform HIV rehabilitation practice. By merging these recommendations and principles with current knowledge in the traditionally separate fields of disability and rehabilitation, we can focus on new knowledge, practices or guidelines that are of high quality, specific and relevant for rehabilitation in the context of HIV.
REFERENCES


