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AIDSImpact special issue – broadening the lens: recommendations from rehabilitation in chronic disease to advance healthy ageing with HIV

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ABSTRACT

People living with HIV are ageing with a combination of physical, mental and social health challenges, known as disability. Although rehabilitation can address disability, the field is still emerging. Our aim was to identify similar disability experiences across complex chronic conditions and establish recommendations for future rehabilitation research and practice to advance healthy ageing with HIV. We conducted a consultation with 77 stakeholders from the United Kingdom, Canada, and Ireland with expertise in the fields of rehabilitation and HIV, cancer, cardiovascular disease, renal disease, or chronic obstructive pulmonary disease who attended a one-day symposium. We used facilitated discussions to identify how rehabilitation issues in complex chronic disease translate to people ageing with HIV, and prioritised recommendations for future practice and research. Disability issues experienced across HIV and other complex chronic diseases included: (i) frailty, (ii) uncertainty and worrying about the future ageing with complex chronic disease, (iii) mental health, (iv) pain, and (v) stigma. We highlight six recommendations for clinical practice and research to advance healthy ageing with HIV. Opportunities for cross-collaboration exist with other more established areas of chronic disease management and rehabilitation. Recommendations can be used to inform future HIV clinical practice and research in this emerging field.

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Introduction

People living with HIV (PLWH) are ageing with a range of health related challenges, known as disability due to HIV and concurrent multimorbidity (Brown & Guaraldi, 2017; Johs et al., 2017; Willard et al., 2009). More individuals are living with comorbidities such as cardiovascular disease, mental health conditions, respiratory diseases, diabetes, and cancers (Brown & Guaraldi, 2017; Brown, Smith et al., 2016; De Francesco et al., 2018; Kendall et al., 2014; Wong et al., 2018) which are compounded by potential issues of polypharmacy (Guaraldi et al., 2018) adding further complexity to disability for those ageing with HIV (Rodriguez-Penney et al., 2013). Disability is multi-dimensional including physical, cognitive, mental, emotional symptoms, difficulties carrying out functional daily activities, challenges participating in society, and worrying about future health; all of which can be experienced as episodic in nature due to fluctuations in health (O'Brien et al., 2008).

Rehabilitation is increasingly required as part of routine care as PLWH age, and involves any prevention or treatment interventions or services that address disability experienced by an individual (Worthington et al., 2005). Despite evidence on the role and effectiveness of rehabilitation interventions in HIV (deBoer, Andrews et al., 2019; O'Brien et al., 2016), PLWH seldom access the physical therapy and occupational therapy services (Worthington et al., 2008) that are more established in other chronic diseases such as pulmonary (McCarthy et al., 2015), cardiac (Anderson et al., 2016) and stroke rehabilitation (Veerbeek et al., 2014). These chronic conditions offer an opportunity to learn from and apply to rehabilitation for ageing PLWH. Our aim was to identify similar disability issues among HIV and other complex chronic conditions and establish

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recommendations for rehabilitation research and practice to advance the field of HIV, ageing and rehabilitation.

Materials and methods

We conducted a multi-stakeholder consultation with rehabilitation research and clinical experts from areas of HIV and chronic disease and rehabilitation who attended a one-day symposium entitled: *Broadening the Lens: What can we learn from other complex conditions for successful ageing with HIV?* The aim of the symposium was to facilitate knowledge transfer and exchange (KTE), and build partnerships in ageing and rehabilitation research in HIV and other chronic and potentially episodic conditions. The symposium was held at the Cicely Saunders Institute, King's College London in collaboration with the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC), an international network of over 90 researchers, clinicians, people living with HIV, representatives from community organisations and policy stakeholders who collectively work to advance and translate HIV and rehabilitation research (O'Brien et al., 2018).

The symposium included sessions focused on (i) the role and evidence for rehabilitation, using HIV as an exemplar, including a community member's personal lived experience ageing with HIV, followed by (ii) the role and evidence for rehabilitation in other complex chronic conditions (chronic obstructive pulmonary disease (COPD), cardiovascular disease, renal disease, cancer, stroke), and (iii) advancing patient-reported outcome measures (PROMs) in rehabilitation research. Stakeholders discussed; (1) how research in other areas of chronic disease and rehabilitation translates to the work done in HIV, what we can learn from the field of rehabilitation across conditions moving forward and; (2) key areas and emerging priorities that transcend across other chronic diseases. Attendees were encouraged to use Twitter throughout to share highlights from the symposium (#RehabHIV). Speaker presentations are openly accessible at the following link: https://www.youtube.com/user/CSIKCL We collated notes documented during the discussion and comments on the evaluation forms, and used content analytical techniques to identify similar disability issues and recommendations for rehabilitation (Hsieh & Shannon, 2005).

Results

Seventy-seven stakeholders including researchers, community leaders, clinicians, research and health professional trainees, and people living with HIV from the United Kingdom (UK) ($n = 74$), Canada ($n = 2$), and Ireland ($n = 1$) convened at the symposium to exchange evidence related to rehabilitation, HIV and complex chronic disease. The majority of attendees indicated that they worked at a hospital (52%) or university (30%), followed by a community-based organisation (8%). Attendees identified as a clinician (60%), student or trainee (8%), researcher (6%), educator (6%), community member living with HIV or other chronic disease (4%), or "other stakeholder" (12%) including research coordinators, biostatisticians and program implementers.

Framework of disability and rehabilitation for healthy ageing across HIV and complex chronic conditions

The consultation resulted in the *Framework of Disability and Rehabilitation for Healthy Ageing across HIV and Complex Chronic Conditions* comprised of three components that reflect: (A) similar disability issues experienced among people ageing with HIV and other chronic conditions; (B) recommendations to advance future HIV ageing research and practice; and (C) strategies for moving forward (Figure 1).

Overall the symposium highlighted the important reciprocal relationship between (i) researchers, clinicians and community members; and (ii) rehabilitation in HIV with other chronic conditions. This Framework can be used as a knowledge transfer and exchange (KTE) tool that can be used by researchers, clinicians, people living with chronic conditions, and policy stakeholders to inform clinical practice and research.

Disability priorities in HIV and other complex chronic conditions

Five issues emerged as disability priorities across HIV and other complex chronic conditions (Table 1). These health challenges may be experienced separately, or in combination as represented by overlapping domains in the Framework (Figure 1).

Recommendations for HIV and ageing rehabilitation practice and research

Recommendations for HIV rehabilitation ageing practice and research spanned four areas: (1) rehabilitation approaches to care; (2) evidence for rehabilitation; (3) rehabilitation interventions; and (4) patient-reported outcome measures (Figure 1). They are in no order of importance.

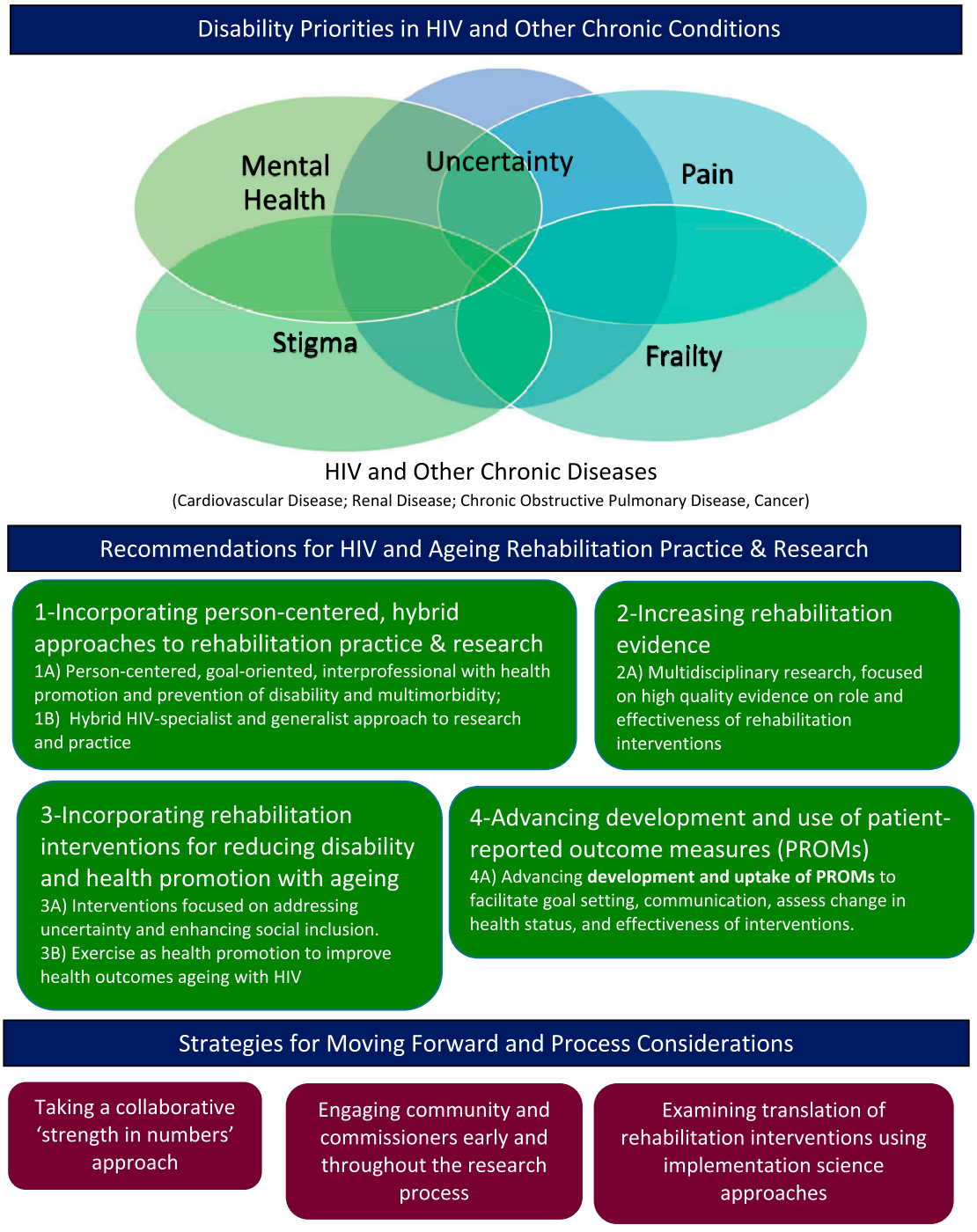

Figure 1. Framework of Disability and Rehabilitation for Healthy Ageing across HIV and Complex Chronic Conditions.

Recommendation area 1 – Incorporating person-centered hybrid approaches to rehabilitation practice and research

1A) Rehabilitation should be person-centered and goal-oriented, involving interprofessional approaches to care including health promotion and prevention of disability and multimorbidity. Rehabilitation is a critical component of care for people ageing with chronic conditions and key to promoting health and preventing disability. Models of care should include a person-centered, interprofessional, needs-based and goal-oriented approach aimed at mitigating disability and enhancing social inclusion and well-being. Coordination of HIV care should encompass a team-based approach including rehabilitation, medical, community and other health and supportive services (e.g., Mental health, substance use, sexual health, specialist care, general practice) in order to streamline care and reduce patient burden.

Table 1. Disability Priorities in HIV and Other Chronic Conditions.

Disability Priority	Description
Mental health challenges	Mental health challenges such as anxiety and depression was an important aspect of disability experienced among adults ageing with HIV and complex chronic conditions. Stakeholders highlighted how anxiety was closely linked and exacerbated by uncertainty and worrying about future health.
Uncertainty and worrying about the future	Uncertainty, closely linked to mental and emotional health, was an important dimension of disability experienced among those ageing with complex chronic conditions that requires comprehensive assessment and management. Stakeholders discussed how uncertainty can be similarly experienced due to the potentially unpredictable and episodic nature of cancer, renal disease and respiratory disease due to occasional unpredictable fluctuations in health. Possessing knowledge about the condition can help to alleviate uncertainty or worrying about the future and was identified as a potential rehabilitation intervention.
Chronic pain	Chronic pain in the form of headaches, musculoskeletal or neuropathic pain was a physical form of disability identified by stakeholders commonly experienced by adults ageing with HIV and other chronic conditions. Challenges with pain management can also have implications for mental health and social inclusion. Stakeholders identified the need for rehabilitation management interventions to address pain.
Frailty	Frailty is an important and emerging form of disability and rehabilitation consideration for people ageing with HIV and other chronic conditions. Fatigue was described as a key component of frailty that negatively affected engagement in daily functional activities and social participation. Stakeholders highlighted an increasing opportunity to draw on the fields of gerontology to identify strategies for comprehensively assessing frailty among people ageing with HIV and the role for rehabilitation in addressing and preventing frailty to promote healthy ageing.
Stigma	Stigma emerged as a priority issue for people ageing with HIV closely linked with fears of disclosure and discrimination that could pose barriers for accessing care and rehabilitation services. Stigma was similarly raised as an important issue for individuals living with other chronic conditions. For instance, people ageing with respiratory disease can experience stigma associated with breathlessness, requiring home oxygen; and smoking. Specific to HIV, challenges accessing sexual health services in the UK raised by stakeholders highlighted the need to invest in sexual health services in order to address stigma, sexual health and HIV prevention.

Stakeholders referred to the need for "navigating the landscape" to enhance seamless access and delivery.

Despite rehabilitation needs involving community and home-based care, services were not universally accessible and differed across geographical jurisdictions. Innovative forms of service delivery such as online or remote access, peer and social supports (e.g., Telehealth, online support networks) are important for reducing burden of attending in-person appointments and minimising geographical barriers to accessing care. Evaluating the cost-effectiveness of remote or online interventions is needed as these do not always translate into cost-benefits to health outcomes. Stakeholders discussed the value of a "one-stop-shop" or "hub" for comprehensive care. An exemplar included the Silver Clinic in Brighton, UK which offers a comprehensive range of health and support services for adults ageing with HIV with complex needs (Santos et al., 2018). The Kobler Rehabilitation Class at Chelsea and Westminster Hospital NHS Foundation Trust in London, UK is an exemplar of a physiotherapy-led group-based goal-oriented rehabilitation intervention evaluated for its ability to improve function, quality of life and goal attainment for adults living with HIV (Brown, Claffey et al., 2016). This rehabilitation intervention, was modeled from education and exercise evidence for cardiac and pulmonary rehabilitation interventions. The Kobler Rehabilitation Class is open access, meaning people can attend, return or restart depending on episodes of health, wellness, illness or disability (Brown, Claffey et al., 2016). This HIV-specific intervention has led to collaborations between physiotherapists in Canada and the UK fostered by the CIHRRC collaborative, helping to inform the development and integration of a new physiotherapy service for adults living with HIV in Canada (deBoer et al., 2019; deBoer, Cudd et al., 2019) and could prove beneficial for other chronic condition services with experiences of episodic disability.

1B) Clinicians and researchers should adopt a hybrid approach drawing on strengths of an HIV "specialist" and chronic condition or "generalist" approach to practice and research. The timing is opportune to bridge the fields of HIV with gerontology and to promote opportunities for ongoing education and mentorship with current and future health professionals in this emerging field. In the era of increasing multimorbidity and need to coordinate HIV care, there are complementary benefits to combining specialised HIV clinical knowledge with generalised expertise across medicine, rehabilitation and gerontology. Stakeholders discussed how current models of service delivery and research were often tied to funding structures and opportunities. For instance, some adults ageing with HIV may benefit from a comprehensive geriatric assessment where clinicians possess expertise in geriatric syndromes, frailty and polypharmacy.

Recommendation area 2 – Increasing rehabilitation evidence

2A) Research should be multidisciplinary, focused on developing high quality evidence on the role and effectiveness of rehabilitation for adults ageing with HIV. Stakeholders emphasised the need for high quality research evidence and embedding cost-effectiveness analyses

into rehabilitation research for determining the optimal timing, duration and value of rehabilitation. The cost-benefits of hospital-based rehabilitation among people with traumatic brain injury (Turner-Stokes et al., 2019) was presented as a model and the group considered how cost–benefit analyses could be applied in other chronic conditions such as HIV, and in other settings, such as outpatient and community-based care. This approach will be critical for justifying the benefit of and sustainability of services as well as informing optimal and timely approaches to referral, choice of interventions, and duration of treatment.

Recommendation area 3 – Incorporating rehabilitation interventions for reducing disability and enhancing health promotion with ageing

3A) Rehabilitation interventions should address uncertainty and enhance social inclusion. While a number of disability priorities were raised during the symposium, uncertainty and social inclusion emerged as particularly complex dimensions of disability that require careful consideration in practice and further evidence on the effectiveness of interventions.

3B) Exercise is an effective rehabilitation intervention with high level evidence to support its potential to reduce disability and improve health outcomes, and should be promoted among adults ageing with HIV. Stakeholders stressed exercise as a core rehabilitation intervention with strong evidence across chronic diseases (respiratory disease, cancer, HIV, renal disease), despite persistent challenges of long-term adoption. Clinicians should tailor person-centered approaches to promote sustained physical activity. Consideration of readiness to engage and self-management strategies are critical to empower and increase self-efficacy within limited health care resources.

Recommendation area 4 – Advancing development and use of patient-reported outcome measures (PROMs)

4A) Universal development, uptake and implementation of patient-reported outcome measures (PROMs) among clinicians and researchers is critical to facilitate goal setting, enhance communication, assess change in health status, and evaluate effectiveness of interventions to inform future practice, programming and policy in HIV, ageing and rehabilitation. Accurate and reliable PROMs are critical to comprehensively and accurately measure the nature and extent of the disability experience among adults ageing with HIV and to determine the effectiveness of rehabilitation interventions. Successful implementation can be achieved through clinical-research partnerships posturing PROMs as beneficial to both clinicians and researchers, offering a "win-win" situation with immediate feedback to inform clinical decision-making. Data can be utilised to inform policy and programming, contributing to universal measurement of outcomes to document changes in health, and cost effectiveness of rehabilitation interventions over time.

Strategies for moving forward

Stakeholders highlighted strategies to address the recommendations moving forward: (1) Taking a "strength in numbers" approach by collaborating with other chronic conditions can increase access to research funding to develop PROMs and examine the effectiveness of rehabilitation interventions across chronic conditions; (2) Engaging community members and commissioners (or policy stakeholders) early to ensure relevant and timely and appropriate uptake of any changes in evidence-based interventions or services; and (3) Responding to the shifting rehabilitation needs from inpatient to outpatient care by examining how rehabilitation interventions work outside of formalised health care settings using implementation and improvement science approaches (Balasubramanian et al., 2015) to inform future practice and research (Figure 1).

Discussion

The *Framework of Disability and Rehabilitation for Healthy Ageing across HIV and Complex Chronic Conditions* emerged from the collective international multi-stakeholder perspective of researchers, PLWH, and clinicians. This symposium was the first known to bring rehabilitation specialists, researchers, clinicians and community members in the fields of HIV, COPD, cancer, cardiovascular disease, and renal disease, which represent common concurrent health conditions among adults ageing with HIV (Negredo et al., 2017).

The HIV field can learn from other complex chronic conditions with more established rehabilitation evidence and models of service delivery. The Framework highlights common disability issues across conditions and recommendations provide a platform for collaborative research and practice efforts across rehabilitation in complex chronic disease to promote healthy ageing for PLWH. Given the focus of our symposium, our recommendations are specific to HIV. Expanding the recommendations beyond HIV requires a culture shift from traditionally siloed disease-specific approaches in

rehabilitation to ageing with multiple chronic conditions (Tinetti et al., 2019). Nevertheless, the similar disability issues spanning HIV and other chronic conditions provide a common foundation for future collaborations and partnerships for moving the agenda forward.

Uncertainty, mental health and chronic pain were profiled as common disability priorities shared across chronic conditions, all of which are conceptualised in the PLWH-derived Episodic Disability Framework (O'Brien et al., 2008). Uncertainty and worrying about future health is a key form of disability experienced (Solomon et al., 2014) and predictor of mental health challenges among adults ageing with HIV (O'Brien et al., 2019). Anxiety and depression are more common among people ageing with HIV compared to those without (Jallow et al., 2017) and older adults are more likely to experience mental health challenges compared with adults without HIV (Rueda et al., 2014), which supports our recommendation that rehabilitation address uncertainty and mental health challenges. When identifying strategies to address uncertainty, clinicians and researchers working in the HIV field can draw from evidence in other chronic conditions, such as COPD whereby authors found reduced uncertainty was associated with social factors, such as participation in support groups among people with COPD (Hoth et al., 2015). Pain is prevalent in over half of people living with HIV, affecting daily function, mental health and quality of life (Parker et al., 2014). While clinical guidelines for managing chronic pain in HIV exist, many involve pharmacological interventions, hence there is an emerging role for rehabilitation as a non-pharmacological and self-management approach to addressing pain in person-centered care (Bruce et al., 2017).

Not surprisingly, frailty emerged as a commonly shared disability given our symposium focus on ageing. Frailty is a complex geriatric syndrome of increasing importance among older adults with HIV (Willig et al., 2016). Frailty phenotype criteria includes weight loss, fatigue, physical activity, weakness and diminished walking speed, and can also be associated with pain (Fried et al., 2001). Frailty, disability and comorbidity are closely linked concepts – frailty can include forms of disability, and be exacerbated by the presence of comorbidity (Fried et al., 2004). Functional impairment and disability are vital to frailty assessment and hence rehabilitation is well poised to prevent and reduce frailty among people ageing with HIV (Bloch, 2018; Erlandson et al., 2014). Screening for frailty in clinical practice can help to identify individuals with HIV who might benefit from early rehabilitation interventions such as balance training, and aerobic and progressive resistive exercise.

This work is unique as it encompasses cross-disease perspectives and poses rehabilitation recommendations for both research and practice in the context of HIV and ageing. This work builds on an earlier conceptual frameworks of HIV rehabilitation practice, which emphasised the need for a goal-oriented and client-focused approach to disability (Worthington et al., 2005) and the role of physiotherapy in outpatient HIV care while considering factors such as ageing, the episodic nature of the illness, multimorbidity, stigma, and social isolation, many of which are similarly pertinent across chronic disease (deBoer et al., 2019; deBoer, Cudd et al., 2019). Our Framework builds on research priorities in HIV, disability and rehabilitation which similarly highlighted the need to focus on disability, effectiveness of rehabilitations, and methodological advances such as outcome measurement (O'Brien et al., 2014a). Results specify the types of disability and interventions of particular importance in HIV and ageing. Evidence-informed rehabilitation recommendations for older adults with HIV were derived from high quality systematic reviews on rehabilitation in common comorbidities (O'Brien et al., 2014b). This work builds on existing evidence to highlight the importance of conducting rehabilitation intervention research outside the hospital-based setting to community-based organisations and health centers using implementation science approaches that consider cost-effectiveness outcomes, which are critical in times of fiscal restraint for informing policy and programming.

Our recommendation for PROM use is critical for determining the nature, extent and change in self-reported health and disability status for PLWH (Harding et al., 2012). Benefits of using PROMs in routine HIV care exist at the level of the individual living with HIV (e.g., Enabling person-centeredness, facilitating empowerment and comfort with articulating health concerns), clinician (e.g., Better understanding health challenges living with HIV, identifying areas to target referrals, evaluating change in health over time) and commissioner (e.g., Evaluating programs and services, informing resource allocation) (Bristowe et al., 2019). While an HIV-specific measure of disability exists (O'Brien et al., 2015), future work should involve adapting PROMs to measure health across complex chronic conditions.

Finally, our recommendations for moving forward suggest stakeholders adopt a collaborative "strength in numbers" approach to advance research and clinical practice across HIV and other chronic and episodic conditions. *Realize* is a national HIV organisation in Canada fostering strategic collaborations with other chronic disease groups featured in this symposium through an Episodic Disability Network that promotes access to

rehabilitation for people living with HIV and other episodic conditions (*Realize*, 2017). The Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC) provides a mechanism for researchers, clinicians, people living with chronic conditions, community organisations, and policy stakeholders to come together, virtually or in-person, and to translate HIV and rehabilitation research, to identify new and emerging priorities in HIV and ageing, and to develop new and strengthen existing partnerships in the field (O'Brien et al., 2018). To date, the CIHRRC has hosted four *International Forums on HIV and Rehabilitation Research* in Canada (2013; 2016; 2018) and the UK (2014) [http://cihrrc.hivandrehab.ca/forums.php]. CIHRRC's involvement in this symposium marks an initial step for the collaborative moving beyond HIV, and partnering with other stakeholder groups representing chronic and episodic conditions in the field. Future work may lead to CIHRRC establishing a set of core PROMs commonly used in physiotherapy to facilitate future international comparisons of episodic disability, and working with stakeholders on future grant applications to examine the impact of physiotherapy interventions using implementation science approaches across complex chronic and episodic conditions.

Strengths of our consultation included our focus on the complexities of ageing with HIV and other chronic conditions, the diversity of stakeholder engagement with breadth of knowledge across disciplines, and opportunities for networking, collaboration and KTE among clinicians, researchers and community members across different disease realms. Nevertheless, the number and types of diseases represented were limited due to our finite one-day symposium with stakeholders primarily from the HIV field. Further in-depth consultation should more broadly engage health professionals and community members living with other chronic conditions commonly experienced by adults ageing with HIV, as well as a diversity of rehabilitation professionals including occupational therapists working in areas of cognitive and mental health. Lastly, the majority of symposium stakeholders were from the UK with a few from Ireland and Canada, countries that share similarities in disability and rehabilitation service delivery. As adults continue to age globally with HIV, future work should consider the applicability of these recommendations with those advancing HIV rehabilitation practice in low to middle income contexts (Chetty & Hanass-Hancock, 2016).

In conclusion, the need for rehabilitation is vital as more people age with HIV and the common disability issues experienced across chronic conditions. Rehabilitation is an emerging area of inquiry and practice that effectively bridges academic disciplines, clinical practice areas and community efforts. The *Framework of Disability and Rehabilitation for Healthy Ageing across HIV and Complex Chronic Conditions* highlights disability priorities and recommendations that can be used as a foundation for future clinical practice and research.

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