

# “It Is an Eye-Opener That There Is a Relationship between Rehabilitation and HIV”: Perspectives of Physiotherapists and Occupational Therapists in Kenya and Zambia on the Role of Rehabilitation with Adults and Children Living with HIV

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## ABSTRACT

**Purpose:** To present the perspectives of rehabilitation providers—physiotherapists and occupational therapists—in Kenya and Zambia on the role of rehabilitation in the care of adults and children living with HIV. **Methods:** This qualitative, interpretivist study was part of a broader project to adapt a Canadian e-module on HIV-related disability for rehabilitation providers in Sub-Saharan Africa (SSA). Focus groups, demographic questionnaires, and knowledge–attitude–belief surveys were conducted with rehabilitation providers in Kenya and Zambia. Focus group data were analyzed inductively using an iterative content analysis. **Results:** Sixty-three rehabilitation providers (52 physiotherapists, 11 occupational therapists) participated in 10 focus groups in Nyanza Province, Kenya, and Lusaka, Zambia. The participants described the role of rehabilitation in HIV care in terms of missed opportunities related to (1) HIV disclosure; (2) inter-professional and inter-sectoral collaboration; (3) community-based rehabilitation; (4) training for rehabilitation providers; (5) pediatric rehabilitation; and (6) the connections among disability, HIV, and poverty. **Conclusions:** The results point to the need for HIV policy and practice leaders to develop new models of care that recognize the crucial role of rehabilitation in the long-term management of HIV to address the shifting needs of the 25 million people living longer with HIV in SSA.

**Key Words:** attitudes; global health; HIV; rehabilitation; Sub-Saharan Africa; survey.

## RÉSUMÉ

**Objectif :** présenter le point de vue qu'ont au Kenya et en Zambie les fournisseurs de services de réadaptation – physiothérapeutes et ergothérapeutes – sur le rôle que joue la réadaptation dans les soins aux adultes et aux enfants vivant avec le virus de l'immunodéficience humaine (VIH). **Méthodes :** cette étude qualitative et interprétative faisait partie d'un projet plus large visant à adapter, pour les besoins des fournisseurs de services de réadaptation de l'Afrique subsaharienne, un module d'apprentissage électronique canadien sur l'incapacité liée au VIH. Nous avons recueilli des données auprès de fournisseurs au Kenya et en Zambie au moyen de groupes de consultation, de questionnaires démographiques et d'enquêtes portant sur les savoirs, les attitudes et les croyances. Les données provenant des groupes de consultation ont été analysées à l'aide d'une méthode itérative et de manière inductive. **Résultats :** au total, 63 fournisseurs de services de réadaptation (52 physiothérapeutes, 11 ergothérapeutes) ont participé à 10 groupes de consultation dans la province de Nyanza au Kenya et dans la ville de Lusaka en Zambie. Les participants ont décrit le rôle que joue la réadaptation dans les soins aux personnes vivant avec le VIH en termes d'occasions manquées liées à : (1) la divulgation de la séropositivité ; (2) la collaboration interprofessionnelle et intersectorielle ; (3) les projets de réadaptation à l'échelle communautaire ; (4) la formation des fournisseurs de services de réadaptation ; (5) la réadaptation pédiatrique ; et (6) les liens entre incapacité, VIH et pauvreté. **Conclusion :** les résultats soulignent la nécessité pour les dirigeants en matière de politiques et de pratiques relatives au VIH de reconnaître le rôle essentiel que joue la réadaptation dans la prise en charge à long terme qui s'impose pour les 25 millions de personnes qui vivent maintenant plus longtemps avec le VIH en Afrique subsaharienne.

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For the first time in history, many people living with HIV in Sub-Saharan Africa (SSA) have had widespread public access to antiretroviral therapy (ART) for a decade. As a result, millions of people are now living longer with HIV.<sup>1</sup> This increased longevity, however, means that many people are now experiencing HIV-related disabilities as a result of having HIV as a chronic illness.<sup>2</sup> This shift has profound implications for HIV health service delivery in SSA, where 25 million people live with HIV, including 3 million children.<sup>1</sup> The current model focuses heavily on starting and adhering to ART, a regimen that has resulted in a 39% decline in AIDS-related deaths in SSA from 2005 to 2013;<sup>3</sup> it pays far less attention to the rehabilitation needs of the millions living longer with HIV.

By *rehabilitation*, we refer to the “dynamic process including prevention and/or treatment activities and/or services that address body impairments, activity limitations or participation restrictions for an individual.”<sup>4(p.268)</sup> For instance, because primary HIV infection and HIV-related conditions can affect any body system, people may experience impairments related to musculoskeletal, neurological, or cardiorespiratory issues.<sup>5</sup> The rehabilitation approach can be used by many providers and is particularly relevant for physiotherapists, occupational therapists, and speech–language therapists in the health care continuum.

This phenomenon mirrors the experience in Canada after ART became widely available in the late 1990s.<sup>6</sup> A crucial early response was bringing the unique contributions of a rehabilitation approach to bear on HIV services, policy, and advocacy,<sup>7</sup> a move that led to the birth of the Canadian Working Group on HIV and Rehabilitation (CWGHR) in 1998. In Canada, two rehabilitation frameworks are commonly used to inform innovative thinking about life with HIV and the rehabilitation responses that can help people live happier, healthier, more productive lives: the World Health Organization’s *International Classification of Functioning, Disability and Health (ICF)*<sup>8</sup> and the Episodic Disability Framework.<sup>9,10</sup>

Africa is now on the cusp of a similar paradigm shift as widespread access to ART transitions HIV to a chronic disease for many. Despite calls for rehabilitation in the context of HIV in SSA,<sup>11–13</sup> empirical data regarding the readiness among providers in the region to take on such a role are lacking. The purpose of this article is to present the perspectives of rehabilitation providers in Kenya and Zambia on the role of rehabilitation in the care of adults and children living with HIV.

## METHODS

### Study design and context

This qualitative, interpretivist study was conducted as part of a broader project to adapt and pilot test a Canadian resource on HIV-related disability for rehabilitation providers in SSA. This new, online, open-access

educational tool<sup>5</sup> was adapted from the E-Module for Evidence-Informed HIV Rehabilitation developed by CWGHR;<sup>14</sup> its purpose is to increase clinical knowledge among health workers in SSA of rehabilitation strategies that can address the challenges of people living with HIV. The ultimate goal is to improve health and reduce disability for adults and children living with HIV in SSA.

The adaptation of the e-module was undertaken in two phases. In phase 1, the Canadian version was reviewed by African people with expertise in disability, rehabilitation, and HIV to identify content that needed to be revised or added to ensure that it was relevant for rehabilitation providers in SSA. On the basis of the feedback from this review, writers in Canada, South Africa, Zambia, and Kenya developed new content. The adapted resource was redesigned by a graphic artist in a format that can be used online, as a mobile application, or as a downloadable version that can be printed. The study presented in this article was derived from phase 2, in which a draft of the adapted resource was assessed in a pilot study. Details of this pilot study are presented here.

### Participants

Individuals were eligible for this study if they were licensed rehabilitation providers (physiotherapists and occupational therapists) located in one of two regions in SSA in which the adapted e-module was piloted: the rural setting of Nyanza Province in western Kenya and the urban setting of Lusaka, Zambia. These two settings were selected because the adult prevalence of HIV there is higher than 15%<sup>1</sup> and because core members of the research team are physiotherapists with widespread institutional ties at these sites. The participants were recruited through a convenience sample in October and November 2014 using word of mouth and local opinion leaders; they received a transport honorarium and lunch or refreshments. Neither setting has many speech–language pathologists; therefore, only physiotherapists and occupational therapists were recruited. We sought at least 25 participants at each site. Informed consent was obtained from all participants.

### Data collection

The participants completed a demographic questionnaire about their educational background and current clinical practice as well as a one-page survey on their knowledge and awareness of and their confidence in treating HIV and including rehabilitation in that treatment. They then had an opportunity to review one or more of the five sections of the e-module on the basis of their interest, expertise, or both.<sup>5</sup> Once they had reviewed the material, focus groups were convened in English to reflect on the participants’ overall impressions of the e-module, information deemed the most and least relevant to their clinical practice, how the e-module had influenced their thinking about rehabilitation, and the potential barriers to using the e-module in practice. The

focus groups were co-facilitated in English by the Canadian research coordinator and a local research assistant. English is the language of instruction in the physiotherapy programmes in these settings and was widely spoken by the participants. Finally, a one-page survey was administered to obtain additional feedback on the e-module (e.g., ease of use, language, clarity of information presented, and relevance). Ethical approval was received from the University of Toronto, the Kenya Medical Research Institute, and the University of Zambia.

### Data analysis

Data from the demographic and feedback surveys were entered manually using the Survey Monkey online survey platform (<https://www.surveymonkey.com>). Detailed field notes, including verbatim quotes, were developed during each focus group discussion; we used Microsoft Excel (Microsoft, Redwood, WA) to help organize these qualitative data. During our initial review of the data, we noted that the participants had spoken at length about the challenges they faced as rehabilitation providers caring for people living with HIV. On the basis of this knowledge, we inductively derived a coding framework that we used to organize the qualitative data. An iterative content analysis was then conducted to identify common themes related to this topic.

## RESULTS

### Participant characteristics

A total of 63 rehabilitation providers (52 physiotherapists and 11 occupational therapists) participated in 10 focus groups, 5 each in Nyanza Province, Kenya, and Lusaka, Zambia, between October 21 and November 20, 2014. Each group lasted approximately 3.5 hours, and the number of participants in each group ranged from 7 to 9, except for 3 groups with 3 participants each. The participants were evenly split between men and women (49% and 51%, respectively) and ranged in age from 22 to 60 years (average age was 39 y in Kenya and 34 y in Zambia). All participants had completed post-secondary education (3 master's, 18 bachelor's, 36 diplomas, data missing for 6) between 1978 and 2014 (average of 2001 in Kenya and 2009 in Zambia). At the time of the study, most participants were actively practising in admitting hospitals. Approximately one-third of the participants treated 11 or more clients per day, and slightly more than half (53%) estimated that of the patients they treated, 25% or more were HIV-positive.

The majority of the participants (88%) in Kenya indicated that they had received at least some education related to HIV; only 55% of participants in Zambia indicated that they had received HIV education. In both countries, this training was often delivered in workshops hosted by non-governmental organizations (NGOs), the ministry of health, or the hospital where they worked. For those who had received HIV training, total hours

varied widely, from 15 to 2,000 hours in Kenya and from 2 to 480 hours in Zambia.

### Missed opportunities

The rehabilitation providers in Kenya and Zambia described the role of rehabilitation in caring for people living with HIV largely in terms of missed opportunities. Despite the high local prevalence of HIV, many participants described their participation in this study as an eye opener regarding the role of rehabilitation in HIV care. They explained that rehabilitation in general was commonly viewed as “a last resort and not preventive,” resulting in referrals only once people were already very sick and disabled (e.g., after having a stroke) and those “on bed” (i.e., needing end-of-life care). In Kenya, one participant stated that “rehab is only thought of after other treatment has failed—it is a dumping ground.” As a result, the participants advocated for the value of engaging earlier in rehabilitation. As one participant stated, “There is a need to provide care to prevent disability and not wait for disability to manifest and then take action.”

These reflections were offered in the context of non-communicable diseases such as stroke; however, participants explained that rehabilitation is rarely considered to manage HIV-related disability. As one participant stated, HIV care has “not taken rehab as a strategy yet.” The result was a sense of missed opportunities for using rehabilitation to mitigate disability and promote wellness among adults and children living with HIV.

These missed opportunities fell into six themes: (1) HIV disclosure; (2) inter-professional and inter-sectoral collaboration; (3) community-based rehabilitation; (4) training for rehabilitation providers; (5) pediatric rehabilitation; and (6) awareness of the links among disability, HIV, and poverty (see Figure 1). The results in each of these areas are presented next.

### *Don't ask, don't tell*

This theme addressed the missed opportunity to provide rehabilitation for HIV-specific needs because clients' HIV status was often not discussed as part of the therapeutic interaction. The participants described how they were often unaware of a patient's HIV-positive status because (1) the patient did not know her or his status; (2) the patient did not disclose her or his status, if known; or (3) the rehabilitation provider did not ask about the patient's status, despite the fact that the prevalence of HIV in these settings is greater than 15%.

The participants explained that patients were not routinely asked about their HIV status during their assessment, although it might surface as a “by-the-way” comment later in the therapeutic relationship. HIV status might also become known if the client was an inpatient and her or his HIV status was recorded in the chart. However, many of the rehabilitation providers in this study described thinking that they did not have the skills



**Figure 1** Perspectives of rehabilitation professionals in Kenya and Zambia on the role of rehabilitation for people living with HIV.

to negotiate disclosure or guide patients for testing if they suspected HIV on the basis of clinical signs. The participants stressed their need for psychosocial counselling skills to help navigate these discussions.

The participants explained that not knowing a patient's HIV status limited the scope of the care they provided and might affect the outcomes of rehabilitation. Conversely, they identified numerous opportunities for rehabilitation providers to support people known to be living with HIV, including

- Identifying how HIV or HIV drugs may be the etiology of particular impairments, which would influence rehabilitation management and referrals
- Offering HIV drug adherence support and counselling to prevent patients' missing doses (e.g., social barriers to adherence, understanding and managing side effects)
- Offering psychosocial counselling (e.g., related to stigma, disability, disclosure)
- Providing support for nutrition (e.g., on issues of food security, impact on wellness and adherence)
- Encouraging patients to understand and become active rather than passive participants in their care (e.g., explaining a prognosis, managing expectations about improvements)
- Advocating (e.g., for the rights of people living with HIV and people with disabilities, for the role of rehabilitation in HIV)

- Acquiring additional rehabilitation skills (e.g., speech-language therapy) to provide this care in the absence of these professionals
- Supporting mental health challenges in the context of limited access to psychiatric care.

The participants also noted the possible increased risk of occupational exposure if an individual's HIV status was not known. That is, although universal precautions are the appropriate standard of care when working with people living with HIV,<sup>15</sup> barrier precautions (such as gloves) might be used less frequently than indicated when resources are scarce; this situation can occur in some settings in Kenya and Zambia.

#### ***Let's work together: interdisciplinary and inter-sectoral collaboration***

The participants noted that links rarely exist between rehabilitation and ART clinics, tuberculosis (a common HIV comorbidity) clinics, or NGOs providing HIV services; improved links could facilitate earlier introduction to rehabilitation care. They described how rehabilitation providers were largely marginalized from HIV workshops, HIV policy dialogues, HIV program development, and HIV care (except for end-of-life care) and that, as a result, they often worked in isolation. They indicated that the culture of inter-professional collaboration varied greatly by practice setting and influenced the degree to which rehabilitation providers were included in clinical meetings or rounds. The participants described a lack of inter-professional practice related to patient charts, noting, "In some places, other health providers do not even read the notes of others." They also described a perceived and experienced hierarchy among providers, explaining that "authority that comes from physicians does not warrant [give] attention to physiotherapists."

The participants explained that the widespread lack of understanding and awareness of the role of rehabilitation negatively affected their inclusion in continuing education, policy discussions, and health service delivery. The example of a mobile care team was offered, whereby rehabilitation providers were included "on paper but not in practice" in delivering a primary health care project.

The participants also stressed that rehabilitation delivery in SSA requires the engagement of other health professional colleagues and community-based, non-professional providers (e.g., community health workers). As one participant stated, "Involvement of interdisciplinary service providers in rehabilitation enriches one's knowledge. It is energizing and is effective in terms of achieving results."

The participants recognized the importance of raising awareness among other health care providers (e.g., on hospital educational rounds) of the contribution that rehabilitation can make to managing HIV. This increased

awareness would help facilitate earlier referral for care to improve outcomes and promote interdisciplinary practice. The participants identified a need to advocate, champion, and highlight the role of rehabilitation as part of an interdisciplinary team providing care for individuals living with HIV. As one participant stated, "As physiotherapists, our work is not so open. We don't publish or publicize what we do, so there is low awareness in the community and among other health care providers about at what point a physiotherapist is supposed to be involved."

### **Community-based rehabilitation can help**

The participants stressed the importance of incorporating a community-based rehabilitation approach into hospital-based services, such as developing rehabilitation capacity among community health workers. Such workers are often the first point of contact for people living with HIV in the community, in ART clinics, and in outpatient clinics. They may know who has struggled with ART adherence, withdrawn from treatment, or experienced side effects. As a result, these community-based providers can advise these individuals on when and where to seek care. They can also educate other health care providers (e.g., in ART clinics and outpatient clinics) about the role of rehabilitation. One challenge of home-based programmes is that they are often funded by external donors and therefore run only when funding is available. The participants advised that there is a need for stable domestic funding for these programmes.

The participants also noted that providing better community-based rehabilitation could address some of the challenges associated with accessing rehabilitation, including transportation (not available, not affordable), lack of follow-up and continuity of care, and other health care competitors (e.g., spiritual leaders and traditional healers). For example, the participants explained that patients often see traditional healers first because they usually live close by, and this can delay care, undermine confidence in rehabilitation, and affect outcomes. Conversely, collaboration between rehabilitation providers and traditional healers could offer more comprehensive care.

### **We need training**

The participants described receiving limited or no HIV education during their rehabilitation degree or diploma program or through continuing education. As one participant stated, "HIV is not even included in our curriculum" and, therefore, "the knowledge is not there." HIV was described as being, at most, included in passing in other subjects (e.g., pharmacology and virology) and not in relation to the holistic rehabilitation approach conceptualized by the *ICF*. As one participant stated,

This document [e-module] has brought a paradigm shift in thinking, for we have not learnt that rehabilitation covers all conditions in our daily life . . . We have believed for a long time that as physiotherapists, we should only be concerned with physical rehabilitation. This [e-module] will build a lot of confidence since the scope is now big.

Another participant explained that he did not realize that rehabilitation professionals had a role to play in lipodystrophy (a common HIV comorbidity), and yet they "see this every day." Another rehabilitation provider said that she "did not know that peripheral neuropathy was linked with HIV and more diabetes and [that she] now will think about this."

The education provided by the e-module during this pilot study was described as "broadening one's mind," providing a "new energy in the way we approach our patients" and offering "a new dimension for providing health care to HIV patients." One participant described this as "a major call" for rehabilitation providers in managing HIV.

Because the participants perceived the role of rehabilitation in the context of HIV as new, they suggested that additional training was required (both in pre-licensure curricula and as continuing education) with regard to

- HIV-related pharmacology, to better understand the range of HIV treatment and side effects
- HIV disease progression, signs, and symptoms and effect on bodily systems and functioning, to understand how "HIV might have been the underlying cause of presenting conditions"
- Psychosocial counselling skills, to support people living with HIV to address HIV-related stigma and help negotiate disclosure
- Understanding and using outcome measurement tools (i.e., what tests to use; with whom; and how to access, administer, and interpret them)
- Standard precautions to prevent occupational exposure and the use of post-exposure prophylaxis
- Aging and HIV
- Interdisciplinary practice.

The participants in both Kenya and Zambia strongly recommended that other health care providers and facility administrators receive training on the contribution that rehabilitation providers can make in managing HIV. They advised that such training would help facilitate referrals (both frequency and earlier timing) and contribute to rehabilitation providers being included in professional development opportunities, ultimately contributing to a more collaborative and interdisciplinary model of care for people living with HIV.

The participants also identified the need for educational opportunities for non-professional care providers

so that they could learn about the role of rehabilitation in HIV care. Non-professional providers include community-based rehabilitation and health workers, spiritual leaders, and traditional healers, who are often the first point of contact for people living with HIV in the community and the gatekeepers to other services.

### ***Don't forget children***

Participants described the ability to provide pediatric HIV-related rehabilitation as another missed opportunity. They stressed the important role of parents and caregivers in supporting rehabilitation for children living with HIV, especially given the scope of the epidemic among children in SSA. One participant pointed to the need for family-centred care, stating, "You can't just treat a child. [You] need to give parents information." Appropriate care begins when both rehabilitation providers and caregivers understand HIV and its impact on childhood development.

The participants emphasized the importance of being able to identify when developmental milestones are missed to prevent situations in which a caregiver brings a child in for assessment and presents too late for intervention. Also, when a child does require care, the participants stressed the importance of empowering the caregiver through education and skills so that the caregiver can work with the child at home.

The participants discussed the particular challenges of telling children that they are living with HIV, including when (e.g., a child's age), who should tell them, and how (e.g., process of disclosure). They noted that children have asked, "Why am I here?" or "Why do my siblings not take drugs?" Several participants described devastating situations in which young people had stopped their treatment or, at worst, committed suicide after being told that they had HIV. The participants also described the need for more training so that they could provide care to children that was directly related to psychosocial counselling (e.g., to handle disclosure and stigma) because counselling was more often focused on testing, viral load, and CD4 count.

### ***Disability, poverty, and HIV are connected***

The participants recognized the importance and interconnectedness of disability, poverty, and HIV as well as their implications for well-being and health. That is, disability, poverty, and HIV can negatively influence each other in a vicious spiral that increasingly worsens an individual's opportunities for well-being. Conversely, breaking any part of this cycle, including providing rehabilitation to mitigate disability, can slow down or reverse the spiral—hence, the missed opportunity for rehabilitation to intervene in this nexus. The participants acknowledged the pervasive poverty in both Kenya and Zambia, particularly in rural areas, and how this poverty limits access to education, health care, food security, and shelter.

The occupational therapists and physiotherapists participating in this study provide rehabilitation services primarily in acute-care hospital settings. They identified the challenges that patients in the more rural settings face in accessing rehabilitation because of the distance from a hospital (e.g., the level of ability required to travel independently, lack of transportation and its prohibitive cost). These challenges have an impact on continuity of care and rehabilitation plans, which require multiple visits over a period.

The participants recognized that as a result of the socio-economic profile of many people living with HIV or disability in Kenya and Zambia, rehabilitation services need to be located closer to them (e.g., through outreach services or home-based care in their communities). These services could be provided by rehabilitation professionals (although the participants noted that these human resources were scarce) or, more likely, by trained community-based health workers.

The participants in both countries identified lack of food security as a major issue, one that influenced both drug adherence and overall well-being. Food programmes delivered by NGOs are often only temporary because they depend on donor funding. One participant described giving some of her own money to a patient so that the patient could buy food, but she noted that this is not a sustainable solution.

Overall, the participants characterized rehabilitation for people living with HIV as a series of missed opportunities in clinical, educational, and policy responses. As one participant explained, "We have seen there is a large scope of [HIV] management that we have been missing."

## **DISCUSSION**

This is the first study to present the perspectives of rehabilitation providers in SSA on rehabilitation for people living with HIV. The current approaches to HIV in this region are largely biomedical, focusing on testing, treatment, drug adherence, and side effects. Framing HIV in a rehabilitation model refocuses attention on the broader health- and life-related consequences of living with HIV, but the participants described rehabilitation as a missing component of the HIV response in many parts of SSA.<sup>11–13</sup> This omission is evidenced and exacerbated by the lack of rehabilitation experts involved in developing HIV policy, from regional and national planning down to implementation at the grassroots level.

One explanation for this oversight is that rehabilitation personnel themselves have inadequate knowledge, as emphasized by the participants in this study. The implications for education are glaring: Rehabilitation providers (e.g., physiotherapists, occupational therapists, and speech therapists) in SSA need to learn about HIV. There is a body of education scholarship on teaching rehabilitation providers about HIV (much of it developed in Canada), and it can be used to inform educational initiatives.<sup>16–18</sup> Interdisciplinary practice is viewed as a

key factor for success, both in past research and among the participants in this study.<sup>16,17</sup> Furthermore, the new e-module for rehabilitation providers in SSA is an important tool for responding to these educational needs. This study was the first exposure that many participants had to the role of rehabilitation with people living with HIV, despite the high prevalence of HIV (>15%) where the study was conducted. This exposure to the potential role of rehabilitation in HIV also led participants to broaden their perspectives on rehabilitation for other conditions, such as diabetes. Advocacy for rehabilitation is urgently needed.

Education about rehabilitation in the context of HIV is also required for other HIV care providers, such as physicians and nurses, who make referrals to rehabilitation. We note, however, that many parts of SSA are experiencing a strain on human resources in health care, and it is extremely important that community-based workers support and deliver rehabilitation in the region. Thus, community-based rehabilitation workers need HIV education,<sup>19</sup> and community-based HIV caregivers require rehabilitation education. Traditional healers as well as leaders of HIV support programmes, advocates, and policymakers also need education on rehabilitation so that they can contribute to a comprehensive, long-term approach to HIV management.

Whereas the participants described rehabilitation for adults living with HIV as limited, pediatric rehabilitation for HIV-positive children was nearly nonexistent. This neglect of children's needs mirrors the other areas of HIV care, treatment, and support, in which pediatric priorities have fallen far behind those of adults.<sup>20</sup> Progressive opportunities exist for pediatric HIV rehabilitation, but services are largely unavailable;<sup>21</sup> thus, rehabilitation needs to be added to the broader advocacy agenda for children living with HIV.

Finally, knowledge translation research is needed to investigate how to change the practice patterns of rehabilitation providers in SSA and thereby better meet the needs of adults and children living with HIV. Research should also investigate the development of HIV advocacy skills among rehabilitation students to set the stage for system change as they move into practice. This research could include the role of the newly developed educational e-module designed for health care providers in SSA.<sup>5</sup>

This study has two limitations that should be kept in mind. First, the purpose of the overarching project was to obtain feedback on a prototype of an educational e-module, not to intentionally explore the perceived role of rehabilitation providers in providing HIV care. The results presented in this article were identified inductively in the focus group data. Therefore, they are limited to reflections that emerged during the pilot study and may have had more depth if this research question had been pursued from the start. Second, the data were not ana-

lyzed according to discipline; as a result, we do not know, for example, whether certain perspectives were more common among occupational therapists as opposed to physiotherapists.

## CONCLUSION

This study identifies comprehensive HIV education for rehabilitation providers in their undergraduate training and through continuing education as a crucial next step for the HIV response in SSA. Given that many national strategic plans on HIV throughout Africa recognize the importance of addressing HIV-related disability, the stage is set for this shift.<sup>22</sup> We call on HIV policy and practice leaders to recognize the crucial role of rehabilitation in the long-term management of HIV and the opportunities for new models of care to address the shifting needs of the 25 million people in SSA who are living longer with HIV.

## KEY MESSAGES

### What is already known on this topic

Many of the 25 million people living with HIV in Sub-Saharan Africa (SSA) now have access to life-extending HIV drug treatment, but they often experience a broad range of HIV-related disabilities that limit their well-being, function, and social inclusion. As a result, rehabilitation (e.g., physical therapy and occupational therapy) has an important role to play in the care of adults and children living with HIV. However, awareness of the role of rehabilitation in the context of HIV in SSA is limited, including among rehabilitation providers themselves.

### What this study adds

This is the first study to present the perspectives of rehabilitation providers (e.g., physiotherapists and occupational therapists) in SSA on rehabilitation in the context of HIV. The participants live in settings in which the prevalence of HIV is higher than 15%, yet awareness of the role of rehabilitation in HIV is limited. The participants described the role of rehabilitation largely as missed opportunities for improving the lives of adults and children, and they called for a paradigm shift to bring rehabilitation into the HIV care continuum.

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