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Equity, diversity, and inclusion in rehabilitation sciences

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Equity, diversity, and inclusion in rehabilitation sciences

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Editorial: Equity, diversity, and inclusion in rehabilitation sciences

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KEYWORDS

equity, diversity & inclusion, rehabilitation, physiotherapy, occupational therapy, anti-racism, intersectionality

Editorial on the Research Topic
Equity, diversity, and inclusion in rehabilitation sciences

Equity, Diversity, and Inclusion have become critical issues in the field of rehabilitation sciences (1). Like many other professions, physiotherapists, occupational therapists and other rehabilitation providers are reckoning with the ongoing impacts of colonialism, racism, stigmatization, and discrimination that form part of the fabric of our health care systems (2–10). Now, perhaps more than ever, there is a demand for equitable and timely access to rehabilitation. Incorporating principles of equity, diversity, inclusion, and accessibility into education, clinical practice, and research are essential for addressing the unique needs of rehabilitation clients. There is also a call to integrate anti-oppressive and anti-racist frameworks into rehabilitation care. Strategies that promote accessible and affordable participation, health promotion, technology, and interdisciplinary collaboration in rehabilitation are needed. Intersectionality is a concept that highlights how various aspects of an individual's identity (such as race, gender, sexuality, class and disability) can intersect and interact to create unique experiences of discrimination, advantage or disadvantage, or privilege (11). Within the context of rehabilitation science, we need to understand these concepts and illuminate how to better serve equity-deserving groups.

We are pleased to serve as guest associate editors for the Research Topic: Equity, Diversity, and Inclusion in Rehabilitation Sciences. While it is not possible to address all aspects of Equity, Diversity, and Inclusion in one issue, this Research Topic may be thought of as the beginning of the conversation. What is missing from the Research Topic is an examination of the impact of gender, sexual orientation, race and religion, and socioeconomic status on rehabilitation service delivery and outcomes. We hope that this Research Topic will inspire focus on these areas as they pertain to rehabilitation.

We are fortunate to have nine articles included in this Research Topic, five of which are original research articles (Jiancaro et al., Sekome et al., Ibáñez-Carrasco et al., Chumo et al., Claus et al.), two are perspective articles (Lurch et al., Dorsey Holliman et al.), and two are brief research reports (Fricke et al., Oancea-Matei et al.). From these nine articles, two main themes emerged. The first theme is *the importance of knowledge transfer of Equity, Diversity, and Inclusion principles* within the rehabilitation sciences professions. Lurch and colleagues provided an introduction to African philosophies and how these ways of thinking may challenge Western biomedical approaches to health care (Lurch et al.). The authors argue that the default physiotherapy identity, curricula, and practices are derived from Western epistemologies which have devalued other ways of knowing. Lurch et al. describe African philosophies that can benefit rehabilitation providers and their clients across the world. Fricke et al. provide an assessment of the impact of an anti-racism simulation workshop among rehabilitation providers as a strategy to address racial microaggressions toward Indigenous peoples in the workplace. As part of this study, the authors asked workshop participants to fill in a post-workshop survey. Four themes emerged from the participant surveys: so much to unlearn, remain humble, resist the silence, and discomfort is okay. Sekome et al. describe undergraduate physiotherapy training in South Africa aimed at providing equitable services for disadvantaged rural and urban communities. The study emphasizes the theoretical and classroom-based learning experiences of physiotherapy students and propose that students can become agents of change to expand access to rehabilitation services for equity-deserving communities. Ibáñez-Carrasco et al. describe the development, implementation, and evaluation of a community of practice (HIV in Motion) aimed at advancing rehabilitation interventions for people living with HIV. The community of practice consisting of people living with HIV, researchers, representatives from non-profit organizations, exercise personnel, trainees, and health professionals had a total of 451 participants and 72% reported connecting with another participant because of the 8 online sessions. Outcomes of this study included sharing the lived experiences of people living with HIV, the inclusion of diverse voices, and the mentorship of peer-researchers. These four articles highlighted ways in which knowledge transfer has begun in the area of equity, diversity, and inclusion in rehabilitation sciences and also identify opportunities for ongoing work.

The second theme that emerged from the articles was *identifying the attitudes, needs, and barriers of equity-deserving groups*. Dorsey Holliman et al. used the 2018 National Health Interview Survey to assess the unmet healthcare needs of Black and Hispanic adults with disabilities. Their study revealed that Black and Hispanic individuals living with disabilities experienced greater healthcare access disparities than Black and Hispanic adults without disabilities. Their findings also indicated that almost 30% of Black and Hispanic adults with disabilities forewent healthcare services due to cost compared to individuals with no disabilities. Claus et al. described the needs and social determinants of health of racially and ethnically diverse uninsured patients with rehabilitation diagnoses during the COVID-19 pandemic. The authors reported medical issues, equipment needs, and mental health concerns as the top three needs identified by participants. Another study investigated attitudes of Romanian participants toward people with bionic eyes and limbs, cochlear implants, and people with disabilities as represented by character vignettes (Oancea-Matei et al.), revealing that personalities that were more agreeable, extraverted, open-minded, intellectually complex, and less neurotic were associated with more positive attitudes to disability. Interestingly, the most negative attitudes were directed toward the character vignette with a bionic eye, suggesting that more work should be done to educate individuals about bionic devices. Jiancaro et al. investigated factors influencing implementation of a pilot online community-based exercise intervention for people living with HIV, identifying 55 factors influencing implementation spanning natural, societal, organizational, personal and human factors. Chumo et al. conducted interviews with employers, entrepreneurs, and officials in Kenya to find out how to socially support employed people with disabilities in informal settlements. Participants reported that inadequate or poorly administrated resources, work dissatisfaction, and workplace conflict that contributed to non-inclusion were challenges to social support for people with disabilities. Clearly there is much work to be done in empowering equity-deserving groups in the field of rehabilitation.

This Research Topic highlights the advances in our collective knowledge and advocacy that are already taking place in this field. Many of the articles offer strategies to change rehabilitation professions for the better, while others suggest priorities for further research. We hope that rehabilitation science practitioners, trainees, and researchers feel inspired to have brave conversations moving forward.

Author contributions

AQ: Conceptualization, Writing – original draft, Writing – review & editing. HM: Writing – review & editing. CM: Writing – review & editing.

Conflict of interest

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Needs of an uninsured equity-deserving minority patient cohort with physical disabilities during the first wave of the COVID-19 pandemic

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Background: Patients with disabilities and those from diverse equity-deserving backgrounds have been disproportionately affected by the SARS COV-2 ("COVID-19") pandemic.

Objective: To describe the significant needs and social determinants of health that affected a group of uninsured patients (from equity-deserving groups) with rehabilitation diagnoses during the early months of the COVID-19 pandemic.

Design: Retrospective cohort study utilizing a telephone-based needs assessment from April to October, 2020.

Setting: Free interdisciplinary rehabilitation clinic serving patients with physical disabilities from equity-deserving minority backgrounds.

Participants: 51 uninsured, diverse patients with spinal cord injuries, brain injuries, amputations, strokes, and other diagnoses requiring interdisciplinary rehabilitation care.

Methods: Using a non-structured approach, telephone-based needs assessments were collected monthly. Reported needs were summarized into themes and the frequencies of each theme were recorded.

Results: From the total number of concerns, medical issues were reported with the highest frequency (46%), followed by equipment needs (30%) and mental health concerns (30%). Other frequently mentioned needs centered around themes of rent, employment, and supplies. Rent and employment were more frequently cited in earlier months, and equipment problems were more frequently cited in later months. A minority of patients reported they had no needs, some of whom had acquired insurance.

Conclusions: Our objective was to describe the needs of a racially and ethnically diverse set of uninsured individuals with physical disabilities seen at a specialized interdisciplinary rehabilitation pro bono clinic during the early months of COVID-19. Medical issues, equipment needs, and mental health concerns were the top three needs. To optimally serve them, care providers must be aware of current and future needs for their underserved patients, especially if future lockdowns occur.

KEYWORDS

access to health care, rehabilitation, minority health, spinal cord injuries, brain injuries, stroke, amputation, interdisciplinary/multidisciplinary

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Introduction

Individuals living with physical disabilities faced considerable hardship during the initial months of the SARS-CoV-2 (COVID-19) global pandemic (1, 2). During early discussions about the allocation of scarce healthcare resources, individuals with disabilities were often considered a lower priority (2) and were more likely to die within the first two months of the pandemic (1). In addition, lockdowns exacerbated mental health concerns (3, 4) and led to a reduction of family and healthcare support for those with physical disabilities (3, 5). As the pandemic continued, despite improved access and usage of telemedicine for the general population, this technology still presented barriers for persons with disabilities (6). Overall, people with disabilities were shown to have less access to healthcare, education, social services, food, and emergency supplies during the pandemic (4, 6).

Equity-deserving minority groups also experienced disparities during the COVID-19 pandemic (7). Especially vulnerable populations included those who were homeless, incarcerated, undocumented, or immigrants (8–10). Additionally, African American, Latinx, and Native American populations suffered disproportionately compared to the Caucasian population (11). During the first months of the pandemic, Hispanic and Latinx communities had higher rates of hospitalizations and death compared to Caucasians (11). Factors such as access to healthcare, immigration status, and language barriers contributed to the disparities seen in Latinx communities (11). Similarly, correlations demonstrated higher mortality from COVID-19 for African Americans and Asian Americans (12).

Given the existing literature, persons with a physical disability who also belong to equity-deserving ethnic or racial minority groups may have experienced exponentially greater difficulty, especially during the beginning of the COVID-19 pandemic (13). Even before COVID-19, a recent narrative review suggests that Hispanic patients may be at risk for worse outcomes after stroke, spinal cord injury (SCI), or traumatic brain injury (TBI), due to lack of access to rehabilitation and disparities regarding referral to specialized care (14). Similarly, another narrative review found that Black persons who had experienced a stroke, TBI, or SCI were less likely to receive care aligned with clinical guidelines (15).

Identifying specific needs of those patients with physical disabilities within the context of COVID-19 is necessary to inform public health recommendations and healthcare policy considerations that promote accessible participation in rehabilitation (16). It is especially important to describe the specific needs of individuals with physical disabilities who identify with an equity-deserving racial or ethnic minority group. In general, little is known regarding this population (13). There is a paucity of literature that reports specifically on the needs of those with physical disabilities from minority groups during the COVID-19 pandemic. This knowledge could be used to better equip healthcare systems in the event of other regional or worldwide health crises.

Accordingly, this manuscript aims to identify and describe the needs of a racially and ethnically diverse set of uninsured individuals with physical disabilities seen at a specialized interdisciplinary rehabilitation pro bono clinic located in Denver, Colorado, USA, during the first wave and lockdowns of COVID-19.

Methods

This was a retrospective cohort study conducted at a local pro-bono clinic. This needs assessment was approved by the local institutional review board and conducted in accordance with the Declaration of Helsinki. Informed consent was obtained from all individual participants included in the study.

Setting

Our specialized interdisciplinary rehabilitation pro-bono clinic serves equity-deserving uninsured individuals with catastrophic injury or physical disability (primarily from stroke, SCI, TBI, or amputations). The disciplines involved with our clinic include (but are not limited to) physiatrists, physical therapists, occupational therapists, speech language pathologists, social workers, pharmacists, rehab psychologists, adaptive equipment specialists, prosthetists, orthotists, nurses, and interpreters. Between April and June 2020, the clinic was closed due to the COVID-19 pandemic. To continue to serve patients, a virtual clinic was developed and telephone-based needs assessments were conducted for all patients previously served by the clinic. The calls served as an informal, monthly means of communicating with patients to assess their specific needs. When needs were identified, the clinic leadership attempted to assist in any way possible. These calls started in April 2020 and continued through November 2020.

Participants

All patients previously referred to, or evaluated by, our clinic were eligible to be included. The majority of patients belong to equity-deserving ethnic and racial minority groups. Many patients are Spanish-speaking and from Latinx communities in the Denver metro area.

Data collection

A team of volunteer patient navigators attempted to call all of the patients described above. Using a non-structured approach, the volunteers asked about a variety of topics related to health and healthcare, as well as social determinants of health (SDoH). Each patient was called once per month. The patients' answers were collected by multiple volunteers and stored in a secure online spreadsheet.

Analysis

Patient reported needs were summarized into themes by one investigator, and the frequencies of each theme were recorded. Those themes included: medical issues; skin integrity; equipment or supply needs; disruption to patient or family employment; mental health concerns; and ability to afford rent, food, and medications. Themes were then confirmed independently by two separate investigators as an effort to reduce bias.

TABLE 1 Demographics.

Age		
Age Range	21–77	
Sex assigned at birth	**N**	**%**
Male	37	72.54
Female	14	27.45
Primary Language	**N**	**%**
Spanish	35	68.62
English	14	27.45
Other	2	3.92156863
Primary Diagnosis	**N**	**%**
Stroke	23	45.09
SCI	10	19.60
TBI	7	13.72
Amputation	7	13.72
Other	4	7.84

Results

Out of 89 previously served patients that were contacted, 51 answered and completed the needs assessment. 21 patients completed the needs assessment multiple months in a row because they had ongoing needs. Demographic information is summarized in Table 1. The majority of the patients were male and identified Spanish as their primary language. The most common diagnosis was stroke followed by spinal cord injury (Table 1).

Overall, the top three reported needs centered around themes of medical issues, equipment needs, and mental health concerns (Table 2). From the compiled reported concerns throughout the duration of the study, medical issues were reported with the highest frequency (46%), followed by equipment needs (30%) and mental health concerns (30%).

Medical needs

Patients described unmet medical needs that went unaddressed due to a lack of access to healthcare. Some of the medical concerns were uncontrolled pain, pressure injuries or wounds, and concern for infection. In addition, patients reported an inability to obtain medication refills or cited prohibitive cost of their medications. Some patients also described lack of access to transportation to medical appointments.

Equipment

Patients also described difficulties with equipment procurement and repairs. These patients experienced mobility

TABLE 2 Patient reported needs during COVID-19 pandemic.

	April	May	June	July	August	September	October	November	Total Number of Concerns (% Total)
Medical Issue	1	12	8	6	4	7	3	5	46 (15.18%)
Equipment	1	6	6	3	3	2	3	6	30 (9.90%)
Mental Health	1	10	6	5	2	2	1	3	30 (9.90%)
Rent	5	11	7	2	1	1	0	0	27 (8.91%)
Food	4	9	8	0	2	1	0	1	25 (8.25%)
Mobility/Functional Ability/ADLS	1	7	4	2	2	4	2	2	24 (7.92%)
Employment	2	12	9	0	0	0	0	0	23 (7.59%)
Cost of Medications	2	9	7	1	0	3	0	0	22 (7.26%)
Supplies	2	5	4	6	2	2	0	1	22 (7.26%)
Wound	0	4	1	1	2	2	1	3	14 (4.62%)
Medication Refills	1	2	2	1	2	1	0	0	9 (2.97%)
Transportation	0	0	5	0	1	1	0	2	9 (2.97%)
No Needs	0	8	5	4	1	2	1	1	22 (7.26%)

challenges due to an inability to have their equipment fixed, adjusted, or replaced.

Mental health

Patients frequently reported feelings of isolation.

Though less frequently reported, patients in this cohort also developed wounds, needed prescription refills, ran out of supplies, did not have accessible transportation, and expressed concern about their source of income and ability to afford basic necessities. Access to essential healthcare and life needs were disrupted.

Patient needs changed over time. Rent and employment concerns were more frequently expressed during early months, and equipment problems were more frequent in later months of the survey. A minority of contacted patients reported they had no needs, some of whom had acquired insurance.

Discussion

During the early months of the COVID-19 pandemic, medical, equipment, and mental health concerns were the most frequent needs reported by our equity-deserving patients served by our pro bono interdisciplinary rehabilitation clinic. This is similar to other findings about individuals with physical disabilities, including prior reports that identified medical and equipment needs as primary concerns during the COVID-19 pandemic (4, 6). Previous studies also found mental health concerns were a significant issue for individuals with disabilities (3, 4).

The cohort of equity-deserving patients in this study also regularly expressed concerns related to SDoH. For example, patients discussed food insecurity, housing insecurity, and lack of transportation. It is well known that disparities in SDoH can lead to worse health outcomes. Disparate care exists for those with a disability defined by a spinal cord injury, stroke, amputation, or brain injury (3, 5). Medical care and resource allocation is vastly different for those with insurance and those without (8, 9). Those uninsured, equity-deserving patients who have sustained a catastrophic injury have limited access to healthcare, including rehabilitation services, durable medical equipment, and medications. It is the authors' conjecture, through lived experience at the pro bono interdisciplinary rehabilitation clinic, that this disparity was magnified by the COVID-19 pandemic.

Limitations

There are limitations to our needs assessment. Only a fraction of patients could be reached to complete the needs assessment (ranging from 36%–64% of patients contacted each month). This occurred for a variety of reasons, including disconnected phone numbers, inaccurate contact information, or patients who opted not to answer their phone. It is possible that the patients who did not complete the assessment had different needs. In addition, this analysis was not a formal research study where empirical evidence was obtained or causation can be inferred. This needs assessment was conducted at one site, which limits the generalizability of our results.

Despite these limitations, this manuscript focuses on a group of patients that is rarely discussed and can guide future studies. It remains important to understand common needs from the beginning months of the pandemic, and further data collection could assess for potential changes in needs and SDoH over time through the COVID-19 pandemic. In addition, future research should involve prospective data collection to further illuminate the impact of emergencies on access to care. These data could provide a foundation for advocacy and planning, because policy changes are needed to increase access to equipment, supplies, and medical care for this equity-deserving population during times of crisis.

Conclusion

Our objective was to identify and describe the needs of a racially and ethnically diverse set of uninsured individuals with physical disabilities seen at a specialized interdisciplinary rehabilitation pro bono clinic. Our manuscript provides information on high-priority needs for this cohort of underserved, equity-deserving patients during the early stages of the COVID-19 pandemic. Medical concerns, broken or unusable equipment, and mental health challenges were most frequently discussed. In addition, lack of transportation, inability to afford supplies or medication, as well as housing, food or job insecurity weighed heavily on our patients. Our healthcare system needs to understand and address these SDoH to provide appropriate support to these patients, especially if future public health crises or lockdowns occur.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by the local Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

Author contributions

DC, CD, JCB, and WN conceived the study. DC and CD collected the data. DC and ACS wrote the first draft of the manuscript. All authors were involved with data interpretation, subsequent manuscript drafts and revisions, and approval of the final manuscript. All authors contributed to the article and approved the submitted version.

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Addressing racism in the workplace through simulation: So much to unlearn

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Introduction: Racism exists in the healthcare system and is a root cause of health inequities among Indigenous Peoples. When microaggressions of racism are carried out by healthcare providers, therapeutic trust may be broken and quality of care may be impacted. Anti-racism response training is considered best practice in recognizing and addressing racism. The objective of this study was to evaluate the impact of a virtual (synchronous) anti-racism response training workshop among a group of rehabilitation therapists from across Canada.

Methods: A 90-minute virtual anti-racism simulation workshop for rehabilitation therapists was developed and delivered virtually four times across Canada between 2020 and 2021. Following an introduction and pre-briefing, role-playing among participants was used to address microaggressive Indigenous-specific racism, followed by an in-depth debriefing with trained facilitators. A post-workshop survey was conducted to evaluate this anti-racism simulation workshop and assess the impact on participating occupational therapists (OTs) and physiotherapists (PTs). Following each simulation workshop, participants were invited to complete an anonymous post-activity survey ($n = 20$; 50% OTs, 45% PTs). Open text responses were analyzed thematically from the perspective of critical race theory.

Results: The majority of the participants self-identified as women (95%); white (90%); mid-career (52%); and had never personally experienced racism (70%). All participants agreed that the workshop gave them ideas on how to start dismantling racism in their workplace. Thematic analysis resulted in four themes: so much to unlearn, remain humble, resist the silence, and discomfort is okay.

Discussion: Despite feelings of discomfort, OTs and PTs appreciated anti-racism skills-based training and recognized the importance of taking action on racism in the workplace. Findings from this study support online (synchronous) anti-racism training as a viable and effective means of creating space for rehabilitation professionals to lean into brave conversations that are necessary for developing strategies to address racial microaggressions impacting Indigenous persons in the workplace. We believe that these small steps of preparing and practicing anti-racism strategies among rehabilitation therapists are essential to achieving a collective goal of dismantling racism in the health system.

KEYWORDS

racism, anti-racism, reconciliation, virtual, simulation, evaluation, rehabilitation

Introduction

Black, Indigenous, and people of colour continue to experience poorer healthcare and health outcomes (1–5). Indigenous-specific racism is a Canadian health crisis according to the National Collaborating Centre for Indigenous Health (6). Discrimination rooted in racism is a painful reality for many Indigenous peoples seeking health care in Canada (6). This can be explained by the long-term sequelae of racism, colonization and associated implicit biases of healthcare providers resulting in lower quality care (7, 8).

Racism can be understood on three different levels: *institutionalized*, *personally mediated*, and *internalized* (11). *Institutionalized racism* refers to differential access to goods, services, and opportunities based on race; *personally mediated racism* refers to both intentional and unintentional prejudice (assumptions) and discrimination (actions) based on race and; *internalized racism* as acceptance by racialized individuals of negative inferences about their own self-worth and abilities (11).

One way in which racism negatively impacts patient care is through microaggressions. Racial microaggressions are commonly occurring indignities, slights, or insults that send a message of derogatory or negative status to members of marginalized groups, intentional or not (9). These biases can be either overt or implicit, that is, the "unconscious collection of stereotypes and attitudes that we develop toward certain groups of people, which can affect our patient relationships and care decisions" (5). Where microaggressions are carried out by health care providers, therapeutic trust may be broken and quality of care may be impacted (10).

Canada's Truth and Reconciliation Commission (12) calls for "skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism", as well as trauma-informed care and addressing the gaps in health outcomes. Anti-racism response training is considered best practice in recognizing and addressing racism (13).

Rehabilitation is far from exempt from such experiences of racism (14–18). In order to develop strong anti-racist practice, providers need to be able to recognize racism and be prepared to respond in authentic and reflective ways (19, 20). To this end, an innovative educational workshop was developed for post-licensure learners using a simulation teaching and learning strategy. Simulation can provide the learner an opportunity to acquire and improve skills and behavior, which may lead to improved health services delivery (21). The purpose of this study was to evaluate the impact of an anti-racism simulation workshop with occupational therapists (OTs) and physiotherapists (PTs), as a strategy towards informing a practice of self-decolonization.

Methods

This project was exempt from requiring ethics approval as this project fell under the category of program evaluation (Article 2.5 in the Canadian Tri-Council Policy Statement); no funding was received for this evaluation nor were survey respondents financially compensated for their participation.

Simulation workshop description

A simulation workshop using live role-playing was created and delivered virtually to provide an opportunity to explore effective strategies in addressing racial microaggressions towards Indigenous persons in the workplace. Best practice standards in simulation (22) were followed, including a pre-brief, simulation and a comprehensive debrief by trained facilitators, as well as concepts of equity, diversity and inclusion (23). Actual workshop content was based on an original simulation design co-developed by two of the authors (DBD and MF) for entry-to-practice physiotherapy curriculum, and further refined collaboratively by all authors. Two of the authors self-identify as First Nations (DBD & PF), two identify as non-Indigenous academic researchers (MF & SO), two identify primarily as clinicians (AB & PF), and all but one are licensed PTs; all strive to practice critical allyship for action towards anti-racism.

Four 90-minute workshops were delivered virtually to more than 75 participants between December 2020 and November 2021. Workshop objectives included:

1. discuss the ongoing legacy of racism in Canada;
2. reflect on the role of addressing racial microaggressions in the healthcare setting, and;
3. enhance professional communication skills in addressing difficult, courageous conversations.

Following an introduction on racism and its impact on inequitable health outcomes among Indigenous peoples, practical strategies to address racism were reviewed with the participants. Strategies included breaking the silence with micro-resistant responses such as "What do you mean by that?"; responding to colour-blind statements (24) such as "why would you ever want to treat everyone the same and not embrace their individuality?"; and the "Opening The Front Door" technique (25), that is, *Observe*: Describe clearly and succinctly what you see happening; *Think:* State what you think about it; *Feel***:** Express your feelings about the situation, and; *Desire*: Assert what you would like to happen. The role of silence in implying tacit approval was discussed, along with avoiding additional emotional injury such as apologizing to the target after the racial microaggression or asking the target to fix the problem (25).

Part of the pre-brief of the simulation activity described included a warning that workshop participants should expect to feel uncomfortable, as they reflect on their own positionality and challenge their biases. Participants were then divided into small groups using virtual breakout rooms to apply the communication strategies in a fictional scenario. Trained facilitators played the fictional role of a senior colleague, "Mary", who made racially-motivated disparaging remarks about an Indigenous client. Pre-scripted comments by the fictional colleague included, "you know they're all alike; they just don't know how to look after themselves" and "you're not calling me a racist, are you?" Volunteers were asked to address the comments with their fictional colleague in their small groups using role playing. Role playing lasted for 5–10 min, followed by 10–15 min of small group debrief led by trained facilitators. Debrief questions included prompts such as: How did that make you feel and why do you think that is? Is this a realistic scenario? How could Mary's racist biases impact care and health outcomes?

Workshop evaluation

All participants were requested to complete an anonymous electronic survey at the end of each workshop. Closed-ended questions were utilized to evaluate the workshop delivery format and open-ended questions to explore the impact on the participants. For example, "Did this workshop stimulate you to think differently about racism in the healthcare system? If yes, how?" (**Supplementary Appendix S1**).

Descriptive statistics using MS Excel were calculated for quantitative data while open text responses were thematically analysed from a lens of critical race theory. Critical race theory "can be used to understand the structural forces that drive racial inequities in society, and to work toward their dismantling" (26). Following the suggested guidelines for improving intercoder reliability (27), data was inductively analysed independently by two authors (MF & SO) with extensive experience in qualitative research. After sharing individual coding schemes, the two coders discussed the shared meanings of the codes and consensus was reached between the two coders on a framework of analysis. At this point, both coders returned to the data for repeat analysis from which no new codes were identified (27). The four final themes were shared with the other co-authors, who supported the results and no further refinements were made to any of the themes.

Results

Close to one third of the participants completed the post-workshop survey ($n = 22$; response rate of 29%). Half (50%) identified themselves as OTs, 45% identified as PTs and 5% as "other". The majority of the participants self-identified as women (95%); white (90%); mid-career (52%); and had never personally experienced racism (70%). All participants agreed that the workshop gave them ideas on how to start dismantling racism in their workplace: 100% of respondents either agreed (60%) or strongly agreed (40%) with the statements: "This workshop has clarified what role I can personally and professionally play in addressing microaggressions in the healthcare system" and "This workshop gave me ideas and tools on how I can start to dismantle racism in my workplace."

Thematic analysis resulted in four themes: so much to unlearn, remain humble, resist the silence, and discomfort is okay.

So much to unlearn

Participants spoke and wrote openly about the challenges of facing a history of colonization and racism in Canada that only recently they had been made aware of. As one respondent wrote, "I feel there is so much to unlearn!" [Participant (*P*) #7]. A different workshop participant stated, "Historical facts are key, but also reality right now from Indigenous perspectives. I have read a few books, attended several different education sessions through work and church, but there is much to learn!" [P#16]

Racism itself was not understood by all participants in its multi-layered complexity prior to the workshop as expressed by this individual. "I used to think of white privilege more so in terms of money and power vs. discrimination based on appearance and/or skin color". [*P*#5]. While racism in the workplace may not always be overt and obvious, individuals expressed a readiness to acknowledge and face implicit racism head on. One individual wrote, "I think bringing it to the forefront is a good reminder of how much racism impacts us all…even if it's not always that obvious". [P#1] Another wrote, "I think it (the workshop) reminded me that it (the health care system) is racist; reminders are important though because it's easy to become complacent, especially when I am not experiencing the racism". [P#17]

During the workshop, participants spoke about the difficulty of having conversations about racism in the workplace, either with colleagues or with clients. As the same workshop survey respondent above stated, "white fragility is pretty rampant and has deep roots". [*P*#7] Workshop participants recognized "how power differentials can affect interactions". [#9]

Workshop participants were also asked to comment on any lingering emotional responses to the workshop on a personal level. One respondent wrote that the workshop content "continues to provoke thought as to how I fit within the systemic racism of healthcare and general society". [*P*#12] Another wrote, "I want more! [P#14]"

Remain humble

Respondents articulated the need to acknowledge the power they hold as healthcare professionals, while striving to learn more about their clients and ways to fight oppression. As this participant stated, "It (the workshop) served as a reminder of the immense impact we all have, as we work closely with others, clients and co-workers alike. For me most importantly, to remain humble and to always listen." [*P*#1]

Participants recognized they were not experts in the lived experiences of others around them, and there was an opportunity for personal and professional growth. "I think the most important tools are education about true history and others' perspectives". [*P*#16]

Workshop participants were introduced to various communication tools and specific phrases they could use to disrupt racial microaggressions in the workplace. For many participants, actual phrasing of what they might say in a moment of potential confrontation with a co-worker was helpful but they admitted that initially, it might not be easy. As this person wrote, "I feel that using the tools and/or disruptive questions will take practice".[*P*#3]

The realization that the work of dismantling racism is an on-going journey was articulated by this individual as follows. "I used to think that I did a good job at sticking up for others, and now I think I can do even more." [*P*#9]

Resist the silence

Workshop participants recognized the poignancy of responding to racism with their voices and not to stand by in silence. "Try to have the hard conversation" [*P*#2] as this participant wrote. They knew it was easier to say nothing, but that remaining silent would not move efforts forward towards dismantling racism, and would, in fact, perpetuate racism. "It is important for all of us to actively participate in improvement" [*P*#11] and "don't shy away from labelling it" [P#10].

Participants acknowledged the role they could and need to adopt if there is to be real change moving forward. They recognized the positive impact they could have by "ensuring that we do not contribute to it, perpetuate it, or to allowing it to continue" [*P*#9]. They accepted the fact that they need to "check the language you use from the perspective of others…is it hurtful to others and perpetuating white fragility?" [P#19]

When facing the authenticity of the scenario, participants found strength in their groups and felt compelled to speak up.

> "My small group was really great and I could feel my anxiety rising when the facilitator playing Mary was so accurate in portraying this character. It was frustrating to hear these things, typical comments that we do hear day in and day out…I think they become so commonplace you almost tune them out…so I think hearing them said in this situation really made me wake up and go "wow, this really does happen this way'. I think it really reinforced the message with me to call this wrong behavior out." [*P*#17]

It was also clear that participants were reflecting on how anti-racism training would benefit them not only in the workplace, but also beyond as evidenced by the following remarks.

> "I think this (workshop) really helped me to clarify why it is so important to no longer be silent as it indicates passive agreement. I have even encountered it within my own family of extended relatives and don't say anything because I don't know what to say or how to confront it. Having the discussions we did in the breakout session really helped me to understand that when we stay silent, we are hurting the person on the receiving end…just as much as if we had instigated it ourselves…Before this workshop, I used to think that I wasn't participating in racism if I was silent or didn't give it any attention (that is, ignore bad behavior, don't draw more attention to it) and now I think when I remain silent I am hurting the person being targeted as much as if I had said it myself." [P#19]

> Before this workshop I used to think that I should let microaggressions go; and now I think I should try my best to address them, even with a microresponse.[*P*#17]

As this participant stated,

> "Before this workshop, I used to think there's not much I could do systemically to change this type of rhetoric; and now I think I might be correct, unless I get REALLY loud and courageous." [*P*#12]

Discomfort is okay

A continuum of skill and confidence in having these conversations was observed by the facilitators, regardless of the years of professional experience of each participant. Not all individuals volunteered to participate in the role play activity, preferring to observe. Finding the appropriate words required courage and taking risk. As this participant stated, "I felt unsettled afterwards and did a lot of reflecting." [*P*#15] Participants described their own emotional responses to the scenario and for some, their desire to be ready to respond. "Racist comments tend to trigger me and I get angry and irritable. I would like to be more mindful of my responses so as to be effective with my intentions." [*P*#7]

Participants described accepting the feeling of discomfort, despite not always having the definitive response ready at hand.

> "I learned so much from this diverse panel on how to begin these conversations and feel ok with being uncomfortable. Knowing that we all have to begin these conversations and trust that we don't always know the right answer and that's ok." [*P*#20]

Leaning into this discomfort was exemplified by one respondent as follows.

> "It (the workshop) gave me a bit more courage to call out things that are not right. I am often hesitant for a number of reasons to do this, but this experience has helped me feel more confident in how I approach these situations…While having conversations with people in this regard is difficult and uncomfortable, these conversations take courage and are worthwhile; I want the system to change so I need to be courageous…" [*P*#17]

Discussion

Recent literature reviews suggest that multiple strategies exist for education in antiracism (28–31), but there has been little rigorous evaluation of the actual teaching methods and impact on the learners (29, 31). This evaluation provides the input of post-licensure learners on anti-racism training using simulation to address racial microaggressions in the workplace and beyond.

Participants in this anti-racism simulation workshop voiced appreciation for skills-based training, as uncomfortable as they may have felt in the moment of addressing racism or during the activity of role-playing. Individuals reported being reluctant to call someone a "racist" or use the term "racism". They were very conscious of potentially disrupting collegial relationships even though they acknowledged that quality care could be impacted when saying nothing. This finding is consistent with the anti-racism response training literature (13). A teaching and learning environment that embraces "brave classrooms and courageous conversations" (32) must be established that challenges our assumptions, beliefs and biases, where risks are taken for the benefit of learning. While no facilitators can ever guarantee a universally safe space for all teachers and learners, efforts must be made at creating safer spaces for all to engage in courageous conversations.

Psychological safety has been defined as "a shared belief that the team is safe for interpersonal risk taking" (33). It has also been described as a space where learners feel safe to be uncomfortable (34). All facilitators of this simulation workshop had explored their own positionality of privilege and experience of racism extensively prior to the workshops, but only some had experience as educators. It has been reported elsewhere that education for addressing cultural humility and racism requires trained and knowledgeable faculty (30, 35), but this does not negate the emotional impact the experience may have on the facilitators themselves. Following each simulation workshop, the facilitators held their own debrief session to unpack and navigate their own responses to the discussions on racism that took place. This important step has been referred to as *debrief the debriefing* (36). The support and insight that the facilitators were able to offer one another was critical to the ongoing adaptation and success of the workshop series.

In the context of psychologically safe learning environments in simulation, three defining attributes have been identified (37): (1) The ability to make mistakes without consequences; (2) the qualities of the facilitator, and; (3) foundational activities such as orientation, preparation, objectives and expectations. A psychologically safe learning environment in simulation is described as "a feeling or climate whereby the learner can feel valued and comfortable yet still speak up and take risks without fear of retribution, embarrassment, judgment or consequences either to themselves or others, thereby promoting learning and innovation" (*p*. 49). Contrary to this definition, authentic and meaningful ways of addressing racism in simulation should not be expected to keep learners (and facilitators) feeling "safe" as participants lean into and embrace feelings of discomfort as they reflect on their own positionality. As has been argued elsewhere, true learning only occurs when we are at the edge of discomfort (32). Workshop participants acknowledged this discomfort and recognized this emotional response was necessary to be part of the solution in explicitly and consciously addressing and redressing racism. Individuals need to be comfortable with their discomfort; to talk about privilege and ways to use privilege to redress racism and discrimination; practice engaging in anti-racism discourses and activities; to hold systems accountable in dismantling racism, and; respectfully engage Indigenous communities in responding to racism (38). Notwithstanding the need to engage with Indigenous partners, Indigenous persons should not be the ones who are burdened with this work. Dismantling Indigenous-specific racism is the responsibility of those who sustain and benefit from the structures and systems that uphold this type of racism.

"Allyship" in the context of anti-oppression has been defined as "a lifelong process of building relationships based on trust, consistency, and accountability with marginalized individuals and/or groups of people" (39). Similarly, the goal of "critical allyship" refers to working in solidarity with people who are disadvantaged by structures and systems of society that uphold inequities (40). This critical allyship is necessary to guide actions of people in power and privilege to resist unjust structures that perpetuate health inequities (40). Alternatively, "structural competency" (41) is the learned ability to recognize health issues as implications of upstream administrative decisions, attitudes, biases, systems and structures. Recognition of structural forces can lead to an awareness of a host of environmental, systemic, attitudinal and contextual factors impacting health and wellness. Advancing this concept further has been a call for anti-racism as a professional competence, where healthcare professionals must act in solidarity with affected communities to advocate for structural improvements (42).

Along the continuum of competence training, anti-racism competence can also be explored through the lens of Indigenous ways of knowing, such as restorative justice practices (43). Restorative justice utilizes a collaborative decision-making approach that includes individuals who have been harmed and perpetrators who have caused intentional or unintentional harm. The process includes holding offenders accountable by having them accept and acknowledge responsibility for racist behavior, by repairing the harm they caused and to reduce the risk of re-offense by building positive relationships. This unique approach to implementing restorative practices can ensure fair treatment of all, protect the climate of the work or learning environment, and boost morale and trust while minimizing institutional liability. Healthcare providers trained in restorative justice practices would be well positioned to assist others to behave in ways based on humility, while responding sincerely and effectively to racist attitudes and behaviors by others.

Limitations

The survey response rate was approximately one third of the 75 individuals who participated in this anti-racism simulation workshop. While a 29% response rate provides valuable information, it is not known why the response rate was not higher. It can be speculated based on the small group discussion and debriefing that participants reacted emotionally to the workshop and may have needed to sit in their silence while navigating a mixture of feelings at the conclusion of the workshop. The option to complete the workshop evaluation at a later date was not provided, something our team will consider in future workshop sessions.

This study was not intended at the outset to be a rigorous qualitative study. We did not explore the impact of the virtual teaching and learning environment compared to an in-person environment, nor the lived experiences of the facilitators.

It must also be acknowledged that the survey questions were written and responses analysed by two qualitative researchers who themselves bring their own colonial settler biases and perspectives. Efforts were made to counter any colonialist settler biases through repeated discussion by the collective group of authors on their personal experiences and emotive responses following each workshop.

Conclusions

This program evaluation provides evidence that virtual (synchronous) anti-racism response training provides a viable and effective means of leaning into brave conversations for OTs and PTs. Although the case that was utilized was based in racial microaggressions towards an Indigenous person by a colleague in a healthcare setting, there are elements of the simulation activity that are transferrable to different contexts and settings. It is clear that anti-racism workshops are one small step forward to taking action against racism in the workplace that provide hope for mitigating the harms of racism in the health system in the future.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

All authors contributed to the delivery and evaluation design of the described anti-racism workshop. MF and SO completed the data analysis; MF, DB, and SO contributed to the actual writing of the manuscript. All authors contributed to the article and approved the submitted version.

Conflict of interest

AB was employed by Community Therapy Services Inc. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2023.1126085/full#supplementary-material.

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Challenging power and unearned privilege in physiotherapy: lessons from Africa

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Power and unearned privilege in the profession of physiotherapy (PT) reside in the white, Western, English-speaking world. Globally, rehabilitation curricula and practices are derived primarily from European epistemologies. African philosophies, thinkers, writers and ways of healing are not practiced widely in healthcare throughout the globe. In this invited perspectives paper, we discuss the philosophies of Ubuntu and Seriti, and describe how these ways of thinking, knowing, and being challenge Western biomedical approaches to healthcare. We believe implementing these philosophies in the West will assist patients in attaining the health outcomes they seek. Further we call for Western professionals and researchers to stand in solidarity with their African counterparts in order to move towards a diversity of practitioners and practices that help to ensure better outcomes for all.

KEYWORDS

Africa, physiotherapy, power, social justice, decoloniality

Introduction

The roots of physical therapies may have begun centuries ago in Northern Africa (1) though in the United Kingdom, physiotherapy as a profession emerged in the late 1800s under somewhat dubious origins (2). While the profession has moved away from association with puritanical scandals, there are still some troubling aspects of physiotherapy that remain scandalous despite our more than one hundred years of movement. We argue in this paper that a) the centre of power and unearned privilege in physiotherapy still rests very squarely in the United Kingdom and its English-speaking "first-world" former colonies, and b) that we need more diversity of thought and people in order to move the profession forward.

Physiotherapy (3) and other health science curricula (4) are built on European epistemologies. In Africa, where English is often a second or third language and resources are often non-existent (euphemistically referred to as "constrained"), there exists past and present communities of distinguished physiotherapy practitioners, thinkers and researchers with ideas and practises that are not new but rather are yet to be explored by the Western world. That is, ideas, practices and philosophies that differ from those of the West have not permeated the profession of physiotherapy in any meaningful way. If, as someone from the global majority, you can speak the language of physiotherapy (both literally and metaphorically) you may receive a conditional pass into the exalted upper echelons of the trade, but to do so it helps to toe the line and not suggest too many changes to the status quo. Identity matters here. If you come from a distant unknown land you have more chance of being accepted in the Global North if you happen to be white, straight, able bodied, middle class, able to speak English, have been educated at an "acceptable" institution and have published in the requisite high-impact international (read: Western) journals. Therein lies the default PT identity (5).

Any discussion of power and privilege in physiotherapy has to acknowledge that representation in the profession (in most if not all countries) rarely reflects the population at large—white people make up a minority of the world's population. People who are Black, identify as living with disability, as a member of the LGBTQ2S+ community and/or having come from rural, low socio-economic backgrounds and other historically marginalised groups are underrepresented in the physiotherapy student and qualified professional ranks. The interconnected nature of these social categorizations create intersecting systems of disadvantage that make it less likely for people from equity-denied communities to enter and thrive in our profession (5, 6). Intricately linked to this is the often-implied message that "Western is better", in terms of what is taught, learned and practiced, where and what research is conducted, and who are deemed to be experts generally (7).

This invited perspectives paper highlights the need for a transformative anti-oppressive and anti-racist approach to rehabilitation care. This paradigm shift cannot be achieved without recognition of the work being done in Africa and by those of African descent. There are philosophies that are well-known in Africa and central to the way people live. These philosophies are not widely practiced in physiotherapy or the health professions but they may indeed hold the answers to some of the world's most pressing issues. In this paper, we discuss African philosophies such as *Ubuntu* and *Seriti* and describe how these ways of thinking challenge Western biomedical approaches to health care. Further we call for Western professionals and researchers to stand in solidarity with their African PT counterparts in order to move towards a diversity of practitioners and practices that help to ensure better outcomes for all. We question the prevailing flow of information from the global minority to the global majority and will introduce readers to work published by African scholars in order to mobilize new ways to think, teach and practice.

Positioning ourselves

The authors of this article are a team that bring a diversity of perspectives, experiences and identities. We are leaders, university faculty, post-doctoral students, clinicians, and community members. We each have our own history, language, memory and identities. Four hundred years and counting after the start of the colonial experiment, we are described thus: We are Black, white, and brown; male and female, Canadian and South African; of middle class origins and from humble beginnings; able bodied, heterosexual, Christian, agnostic and atheist. We are not all knowing, but we do have expertise credentialed by our scholarship and lived experience. Neither are we unbiased. What we all have in common is this: Our people come from Africa, we have all worked in Africa and we are all physiotherapists. We see not only the much-vaunted "potential" of the African continent but the significant lessons that the world can learn from Africa if only it resolves to listens. Not at some mystical time in the future. But right now.

There are, and have been for some time, a growing group of renowned physiotherapists from Africa who have been boldly addressing some of the most challenging questions in our profession and the broader fields of health sciences and health, including those arising and compounded by the COVID-19 pandemic. While it is important to declare our own positionality, we are intent on addressing this topic with as balanced a view as possible. Adopting a social justice lens (8), we insist that one cannot be selective on issues of power and privilege. While we extol the myriad benefits of embracing African approaches to health care, we are certainly not blind to some of the stark contradictions that exist on the continent. For example, no discussion of equity in our profession can ignore the highly problematic laws and attitudes that threaten people from the LGBTQ2S+ community in Africa, a situation that is itself compounded by the colonial project (9).

Coloniality and systems of oppression

Analysis of systemic oppression must include a contextual and historical analysis of its root causes. Indeed, anti-oppression action can never be non-contextual or ahistorical (10). Neither can discussions about the root causes of oppression omit a critical analysis of power as illustrated by Quijano in his conceptual framing of the Colonial Matrix of Power and Western modernity (11). These serve to describe how hierarchical structures- racial, political, social, economic- ensured power resided with white Europeans and shaped the Western modern world (11, 12). This is the orientation we take here.

Quijano (11) notes one of the primary axes of global power was the social classification of the world's population around race, which considered white Europeans as biologically superior and racialized non-Europeans as inferior. This became the criterion for separating people into ranks and roles- superior/inferior, dominated/dominator, white/Black. Over time, and in the course of the global expansion of colonial domination, a systematic racial distribution of labour was implemented. Europeans associated unpaid labour with inferior races/non Europeans and paid labour with superior races/Europeans. It is vital to note that race is a social construct, meaning it is made up. There is absolutely no biological basis for race (13).

Notably, domination over the new model of global power concentrated the control of knowledge and knowledge production in the West. Indeed, Europe was (and we posit remains) the centre of global epistemic power (4), and white European men remain "the canons of knowledge production in Westernised universities" (7). This model of power, based on coloniality, rendered non-European knowledge as inferior and primitive (12). The colonized had their forms of knowledge production, meaning making, symbolism, means of expression, and objective and subjective realities replaced by those of the colonizers resulting in the erasure of entire knowledge systems. Thus, "colonization did not only occur through physical seizing and displacement of peoples from land, but also through the colonization of minds" (7). This legacy of colonialism permeates contemporary society (including physiotherapy) and has negated the legitimacy of other forms of knowing, understanding and seeing.

African philosophies of healthcare

Ex Africa semper aliquid novum. This is a Latin phrase translated as "out of Africa there is always something new", attributed to Pliny the Elder in AD79. This is over 2000 years ago, and African ways of healing and philosophies of healthcare long predate this, but we feel it is important that readers are exposed to what to them may be "new" ways of thinking. Ramose (14) proposes that Western European understandings of Africa are based more on their historical interaction with African people, rather than a true appreciation of African people's own self-understanding. Whether African people would have defined the much-contested term of "philosophy" in the same way as European scholars is a moot point. What is clear is that, across Africa, there is no doubt that there is a commonality in the way human interaction is practiced and understood, and this certainly extends to the domains of healthcare and healing. Perhaps the most well-known of these African philosophies is the concept of *Ubuntu*. Ubuntu is an isiXhosa/isiZulu word that can be defined as the idea that a person is a person through other people. It is known throughout Africa by other names—*Bomoto* (Democratic Republic of Congo), *Unhu* (Zimbabwe), *uMunthu* (Malawi), *Vumuntu* (Mozambique) and *Utu* (Kenya and Tanzania)—but the philosophy remains the same (15). Ubuntu describes personhood as something that is communally determined and does not emerge from an autonomous self (16). With regard to healthcare, this understanding of the self has a number of important ramifications. It should never be possible to treat a patient or teach students about healthcare without a very real focus on gaining a holistic understanding of all of the patients' relationships with family members and the broader communities in which they live, work and play. By centreing the values of Ubuntu both structurally and institutionally and reinforcing the state of being human, Sambala et al. (15) argue that both health education and public health can be improved. The Northern Sotho/Setswana word *Seriti* describes the understanding that the essence of a human being is spiritual and can thus not be explained in material terms. It pertains more to ethical and metaphysical qualities that all people have. Not having an appreciation and understanding of a person's Seriti, would render it impossible for them or their wider communities to achieve full dignity or health. Seriti and health are inextricably linked, one cannot fulfil one without the other (17).

Imafidion (16) describes how African philosophies of healthcare focus not only on healing the body and the mind, but in order for true health to be attained, one has to also focus on healing and building relationships and addressing any imbalances that may exist in an individual's life. This resonates with the *Nguzo Saba* (Swahili for seven principles), which were conceptualised in 1966 by Dr Maulana Karenga, the professor of Black Studies at California State University, as a way of defining commonalities between North American peoples of the African diaspora (18). White and Estreet (19) describe how these principles can be applied to healthcare. For example Ujima (the principle of collective work and responsibility) dictates that family and political structures must not be ignored in any analysis of individual health or macro health systems. Gebremikael et al. (20) emphasise that the Nguzo Saba, Ubuntu and other African philosophies clearly understand health as being more than just the absence of disease, and far broader even than how the West conceptualises the social determinants of health. This brief summary of some of the African approaches to life and healthcare is not exhaustive. We strongly encourage practitioners and educators in our profession to read more, and engage directly with African people, listen more and learn. We are further aware that there are clear similarities between these philosophies and other Indigenous approaches to healthcare. We, the authors, are not in any way qualified to discuss North American Indigenous philosophies in depth. It appears clear, however, that there are similarities in African and Indigenous knowledge systems that can transform Western systems of healthcare practice and education. They both bring together opportunities for relationality, accountability, and creating safe spaces for healing and learning. Indeed, the Indigenous principles of Etuaptmumk (the Mi'kmaw word for Two-Eyed Seeing) have the potential to resolve the conflicts between Indigenous approaches to healthcare and the so-called scientific evidence-base that informs Western practice and teaching (21).

Taking care to the people

Africa holds great profundity as a nation of people and offers valuable lessons on approaching change in healthcare. It is a continent that boasts a great diversity of people, who are often let down by lackluster healthcare systems where only the privileged thrive. Researchers have delved deep into these colonial-derived systems in trying to address the gaps that continue to prejudice the majority of people who access public healthcare services. A primary healthcare approach, predicated on the philosophy of Ubuntu, can improve access to care for people living in equity-denied communities, by providing health services in or near to the homes of people living with impairments and/or disabilities (22). A successful example of this is TAIBU (the Kiswahili word for "Be in good health") Community Health Centre, a community driven organization offering culturally affirming primary care, health promotion and disease prevention to Black-identifying communities in Toronto, Canada. While this approach does show promise in Africa, gaps related to geopolitical challenges still hinder its successful implementation.

Another example of how current African approaches to health education and practice may prove beneficial to other regions across the globe is the growing implementation of decentralized approaches to clinical education. This approach sees student learning shifted from urban centres to rural communities where predominantly Black African people reside, and has proven useful to promote learning that is contextually-relevant for future health care practice (23). A study with physiotherapy students in KwaZulu-Natal, South Africa, demonstrated how this approach also increases the opportunities for students to be real advocates for equity-denied community members (24). Pillay and Kathard (25) described students' exposure to longitudinal community engagement as a means to promote context-specific learning and decolonization of health education. This can also overcome some of the deficits in the content of health sciences curricula that often fail to integrate traditional medicine approaches in the management of African patients and where assessment tools have been developed within a colonial framework and for Eurocentric populations (26).

The future of our profession reimagined

The future is an open temporal territory (10). The path we are suggesting is not an easy one, but challenging the accepted status quo in any profession in any era, has never been. Decolonial curricula open up, rather than close, possibilities for the expansion of the knowledge project, but prevailing systemic injustices are difficult to overcome (27). People of the privileged global minority, where the power of the profession undoubtedly resides, can choose to attend a few diversity workshops, and then return to doing the same work they have always done. Or they can do the real hard work, that necessarily involves ceding some of one's own power to the collective as in Ubunto and Seriti, not only because it seems to be the right and just thing to do but because this is the best for the future of our profession, communities and humanity. This will also require not only a political and economic resolve but a social resolve to consciously shift power and allow care to evolve using anti-colonial praxis. Lane et al. (28) argue that we need "brave spaces" rather than safe spaces in order to decolonize physiotherapy curricula and humanize healthcare. Standing in solidarity with equity-denied communities requires that people who hold power recognise their social location (i.e. the intersection of their identities) and use their unearned privilege to actively challenge the oppressive systems and practices that are still pervasive in the health professions (29). This includes making way for people from different backgrounds and with different experiences to their own, including African practitioners, thinkers and researchers. We do not want to romanticize Africa, and know full well that the continent has many challenges. But we have no doubt that ideas and practices related to African philosophies of healthcare can benefit practitioners and patients across the world, as it has in Africa for centuries. This approach will help researchers to ask the right questions, result in more diverse, socially-aware graduate cohorts and ensure better outcomes for all the people that we treat and advise.

Data availability statement

The original contributions presented in the study are included in the article, further inquiries can be directed to the corresponding author.

Author contributions

All four authors conceptualized the main ideas contained within this paper and were involved in the writing and editing of the final, submitted manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Social inclusion of persons with disability in employment: what would it take to socially support employed persons with disability in the labor market?

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Introduction: One of the major challenges that persons with disabilities (PWDs) are facing globally is unemployment. The challenge is attributed to systems that are not built with inclusivity in mind by employers. As such, the work of inclusion is not inviting PWDs to do more but to make a difference through social support. Most research on inclusion in the employment of PWDs in low-income settings has been concentrated upon the labor "supply" side, and to the best of our knowledge, no specific studies moved toward inclusion in employment issues from the employers' perspective in informal settlements. Notably, our research question is: "what would it take to socially support employed PWD in informal settlements building from the perspectives of employers."

Methods: This paper used data from in-depth interviews with 38 service providers in the education, health, water, sanitation, and solid waste management sectors and two sub-county officials in two informal settlements in Nairobi, Kenya. The service providers were employers or entrepreneurs who had hired PWDs in their workspaces and the sub-county officials that had vast experiences with employed PWDs. Data from transcripts were analyzed by the research team using content analysis.

Results: The social support offered to employed PWDs included listening to them with a concern; identifying their strengths and obstacles; planning for them based on their qualities, knowledge, and experience and linking them with existing opportunities; creating specific opportunities and facilitating their access to opportunities; gradual withdrawal of support by support group; and, lastly, compromise by employers with PWD inclusion strategies. Study participants described how misdirected and inadequate resources, dissatisfaction and unhappiness, and conflicts at the workplace associated with non-inclusion were constraints to social support. Employment matters affecting PWDs are complex and require multi-pronged context-specific social support approaches. Essential to the functioning of an inclusive workplace for PWDs were communication, coordination, sharing of the workload, and supporting individual PWD.

Abbreviations
APHRC, African Population and Health Research Center; COREQ, Consolidated Criteria for Reporting Qualitative Research; CRPD, Convention on the Rights of Persons with Disabilities; ESRC, Ethics & Scientific Review Committee; IDIs, in-depth interviews; LSTM, Liverpool School of Tropical Medicine; NACOSTI, National Commission for Science, Technology and Innovation; NUHDSS, Nairobi Urban Health and Demographic Surveillance System; OECD, Organisation Economic Cooperation and Development; PWD, persons with disabilities.

Conclusion: Inclusion of PWDs in the labor market is about generating a supportive workplace where people are valued and appreciated without judgement for what they can contribute. Notably, in the absence of jobs for everyone and high unemployment rates among every segment of the population, there is a need for an awareness creation, mobilization, and sensitization of employers and investors around the competencies of PWDs and their need to socially support on an impartial basis. On the other hand, employment centers could establish stations in low-income areas to advise and support PWDs on career opportunities that are disability-friendly and partner with employers to avail information about the capabilities of PWDs. Conversely, the government should provide some tax-related benefits to employers to upsurge employer incentives for hiring PWDs and empower employers on benefits and positive culture of employing PWDs. At all times, employers should be hands-on and involve diverse stakeholders to implement current policies and frameworks in different work contexts across the country and beyond.

KEYWORDS

social inclusion, persons with disability (PWDs), informal settlements, employment, sustainable development

1. Introduction

The Sustainable Development Goals 2030 agenda and its 17 goals offer a framework to guide local and international communities toward the accomplishment of a disability-inclusive progress (1). It pledges to leave nobody behind, including persons with disabilities (PWDs), and has acknowledged disability as a cross-cutting concern to be considered in the execution of all the 17 goals (2). Similarly, it recognizes that vulnerable groups including PWDs must be empowered in all spheres of life including in the labor market (1, 2). PWDs include individuals who have long-standing impairments (i.e., physical, mental, intellectual, or sensory), which interacts with diverse barriers, hence hindering complete and active participation on an equivalent basis with others (3, 4). Employers are obliged to ensure complete, active, and equal enjoyment of basic human rights and autonomy in the labor market for economic balance (5). Sustainable Development Goal 8.5 specifically targets to achieve “full and productive employment and decent work for all,” including PWDs by 2030 (1).

Key actors have made efforts both at local and international spheres to upsurge the participation of PWDs in the labor market regarding employment (6). Employment is not only a vital idea in economics but also a crucial element in realizing a good standard of living, as it offers an opportunity for self-reliance (7), dignity (8), and a means of individualism (7). Greater participation of PWDs in labor market can increase their social inclusion (7), thus a key step to their enablement, liberation, and wellbeing (7). It is in this regard that Article 27 of the Convention on the Rights of Persons with Disabilities (CRPD) emphasizes unrestricted right of entry to labor market for PWDs. The article requires that the state-owned parties embark on actions to outlaw all forms of discrimination and to make a conducive and just environment for PWDs at work, while ensuring a professional growth similar to a person without a disability (3). The employment of PWDs has always been a challenge in Kenya; however, the current paradigm shift after the country co-hosted the Global Disability Summit in 2018 has gained traction over other low- and middle-income counties. The commitments on the summit were focused on PWDs, their rights, and their environments, with a sense of direction, purpose, and understanding (9), so as to eradicate poverty. Poverty among PWDs cannot be eradicated easily if they continue depending on their caregivers for financial empowerment. As such, the government and other relevant actors should endeavor to create a supporting environment (i.e., that enforces current laws, avails incentives to employers of PWDs, and actors who offers skills for PWDs) to motivate employers’ obligation to employ PWDs (6). Some informal settlements in Kenya are accommodative of PWDs, due to socialist nature of residents and the existence of support structures (10, 11). Informal settlements (i.e., unplanned sites that are not compliant with authorized regulations) are characterized by residents seeking available opportunities (12). Notably, there are few formal opportunities (13), and residents end up relying on the private and informal sectors for labor (14, 15). Under such circumstances, many residents have unmet needs (16), therefore leaving communities including PWDs to find ways of fulfilling their own needs by seeking employment opportunities. Due to vulnerabilities of PWDs (17), some employers accommodate them in the workplace; yet, no study has uncovered social support of PWDs in informal settlements from the employers’ perspectives.

As Kenya grapples with socioeconomic development due to repercussion of the COVID-19 pandemic, employers must consider the inclusion of PWDs in the new forms of work and industries that have emerged (6, 18). Despite the significance of employment and the right of everyone to access decent jobs without discrimination (18, 19), employed PWDs face significant social support-related challenges (20). Approximately 25% of adults live with a disability (i.e., cognitive, physical, or emotional disability, among others), and many of them have talents (21). Therefore, the task during inclusion is not inviting PWDs to do extra, but to create an accommodative change in the environs that we invite them into (4, 19). The challenge does not lie with a PWD, but with systems that are not built with inclusivity in mind by employers or owners (22). Most research on labor, inclusion, and discrimination has been concentrated upon the labor "supply" side of the employment equivalence (i.e., obstacles, limitations, and contests in view of PWDs seeking employment or being employed) (23, 24), and to our knowledge, no specific studies in low- and middle-income countries (LMICs) loomed these employment and inclusion issues from the employers' perspective (20), more so in the informal settlements. Could insights from the employer's side be a resolution to this ostensible challenge? And, has anyone asked employers and entrepreneurs as they are "missing voices"? Concurrently, actors for various justice groups highlighted that some PWDs are ready, willing, and able to work but quit their job once recruited due to lack of support at the workplace (20).

Beyond the lack of consultation on suitable information (i.e., on low-cost technology preferences, inclusive design and its cost, capacity building, and behavior change) (25), less has been uncovered concerning the "software" features of service delivery (i.e., changes needed for organizations to be inclusive for all workers and changes in how programs are planned and executed) (18, 25). To this end, we acknowledge that there are many aspects to the employers' side. First, there is the desire and willingness to address the issue of inclusion. Second, there is how to go about support systems, and, third, there are policies (and funding) for workplace accommodations and flexibility in the design of work tasks and work scheduling. In this study, we focus on the second aspect: social support pathways from the employer's perspectives. We involved service providers who had employed PWDs to uncover available social support that sustained the engagement of PWDs in their specific workplaces and documented their best practices and challenges in creating inclusive work environments. As such, our research question is: "what would it take to socially support employed PWD in informal settlements building from the perspectives of employers?"

1.1. Theoretical background and conceptual framework

We embed this study on the social support theory by Cullen (26, 27). Cullen distinguished between macro-level and interpersonal-level effects of support, emphasizing how supportive societies and supportive relationships can enhance safe and effective working (27). Social support is commonly conceptualized as the social resources on which an individual can rely on when dealing with lived challenges, realities, and stressors. Three important theoretical perspectives on social support research are (a) the stress and coping perspective, (b) social constructionist perspective, and (c) relationship perspective. The stress and coping perspective proposes that support contributes to a person's life by protecting them from the adverse effects of stress. The social constructionist perspective proposes that support directly influences a person's life by promoting self-esteem. On the other hand, the relationship perspective proposes that social support cannot be separated from relationship processes that often co-occur with support, such as creating links, networking and opportunities and low social conflict (28). Social support mechanisms ought to be qualified by the fact that many different interpersonal processes and constructs have been included under the rubric of social support (29) (**Figure 1**). Unlike other societal related theories, social support theory focuses on how something positive can prevent or reduce risks (26, 30).

The theory is applicable to our study because PWDs need social support for their effective functioning. Notably, they often receive negative treatment such as being labelled based on their disability status (31) and are vulnerable to a greater risk of becoming victims of crime (17) and social and psychological problems (31). PWDs have also been perceived as dependent, incompetent, unproductive, ill, burdensome, unattractive, hypersensitive, helpless, passive, and childish, and as such, they have many unmet needs (16). For this reason, some employers have considered their talents and employed them at their workplace. From our position, we believe that there is a need for social support to employed PWDs at the workplace, even when they have talents, more so in the informal settlements where government social rehabilitation services are inexistent or inadequate (17, 32). Despite the talents and the fortune of being employed, PWDs often condemn and hurt themselves since they cannot accept their imperfection and often feel ashamed, anxious, incapable, unfortunate, miserable, inattentive, and meaningless (31). These conditions indicate that their self-esteem tends to be low. Self-esteem determines personality and affects the human health state and effective functioning at work (16).

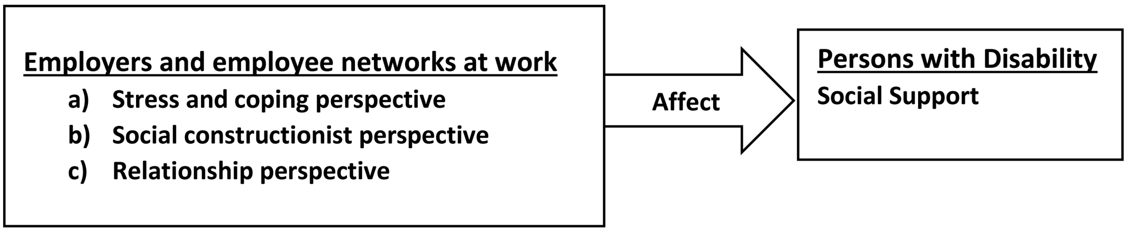

FIGURE 1
Conceptual framework.

2. Methodology

We present our study findings according to a set of standardized Consolidated Criteria for Reporting Qualitative Research (COREQ) (33).

2.1. Study objectives and design

We document lessons on what it takes to socially support an employed PWD in informal settlements, from the perspectives of employers and entrepreneurs. This was a qualitative study using in-depth interviews (IDIs) (33). We designed the study guided by social support theory. As such, questions in the study tools probed on social support strategies by employers to employed persons with disability. The social support theory formed a basis for our objectives, research questions, data collection, analysis, and interpretation of findings.

Beyond reported challenges faced by PWDs relating to negative treatments and associated psychological problems of self-esteem and other stressors in the community and at work, our study, guided by the social support theory, especially the postulation that social resources can be relied upon by individuals when dealing with lived challenges, realities, and stressors, builds on the need to understand the pathways through which PWDs will obtain the social resources they need for their effective functioning in their workplace. We sought to document what it will take to socially support an employed PWD from the perspectives of employers and entrepreneurs. This objective and theoretical orientation informed our deployment of the IDI methodology, data collection, data analysis, and ethical procedures implemented in our study. These spectra of study tools deeply probed into questions that identified and highlighted specific strategies engaged by employers to address the needs of PWDs working in their organizations. IDIs are veritable qualitative tools for direct, one-on-one engagement with principal actors in a study. Specifically, in our case, IDIs pinpoint not only the social support needed but also the associated challenges in their implementation as well as how to sustain such supports in the service of unmet needs of their employees with disabilities.

2.2. Study setting

From a population of 350,000 in the 1962 census to 4,397,073 in the 2019 census, Nairobi typifies the rapid urbanization and population explosion in sub-Saharan Africa (34). As the capital and largest city of Kenya, Nairobi has always been the major attraction of various segments of the Kenyan population—in search of better livelihood opportunities, including the marginalized and vulnerable groups such as persons with disability (16). The consequence of the rapid and uncontrolled population explosion is the proliferation of informal settlements in Nairobi, with upwards of 60% of Nairobi residents estimated to be living in slums and contributing to increasing urbanization and the need for employment opportunities. Our study covered two informal settlements of Korogocho and Viwandani informal settlements in Nairobi, in the regions covered by Nairobi Urban Health and Demographic Surveillance System (NUHDSS) initiated in 2002 by the African Population and Health Research Center (APHRC) (35) (**Figure 2**). Informal settlements of Korogocho have a more steady population, and multi-generational inhabitants reside in the region for several years (36). On the other hand, Viwandani is situated nearby an industrial zone with many vastly traveling and more educated occupants who labor or look out for better jobs outside the informal settlements (36).

2.3. Target population, sampling, and sample size

The population of interest were service providers in five sectors that were identified and described in the governance diaries as priority basic needs (16). The sectors included education, health, water, sanitation, and solid waste management. Through a stakeholder mapping exercise, we developed a stakeholder database that depicts actors/service providers with employed PWDs and were re-defined and confirmed by PWDs interviewed during governance diaries data collection process (13) and during community advisory study consultation (10). From the service providers identified, we purposively selected four education providers, two healthcare providers, four water providers, four sanitation providers, and four solid waste management providers in each of the study sites. Two sub-county officials in each study site were also purposively selected if they had experiences in offering social support to employed PWDs in the sub-county. This enabled us to understand the social support offered to employed PWDs, challenges faced in social support, and how to maintain the support.

2.4. Data collection process

We collected data from March to May 2022. We selected Research Assistants with support from community advisory committees (10), if they were endorsed by community leaders in the study sites and if they had some experience in qualitative research. We opted for Research Assistants from the community who are insiders. Insider researchers are native to the setting and are usually perceived to be too close, thereby not attaining the distance and objectivity necessary for valid research (37). Notably, we challenged the limitations of using insider Research Assistants in this study. Insider knowledge in whatever research tradition is not only valid and useful but also provides important knowledge, in which approaches used by outsiders may not be able to uncover (38). In our view, insider research is not problematic in itself and is a respectable research in whatever paradigm it is undertaken. Data were collected through IDIs (33), using an IDI guide which had questions on social support

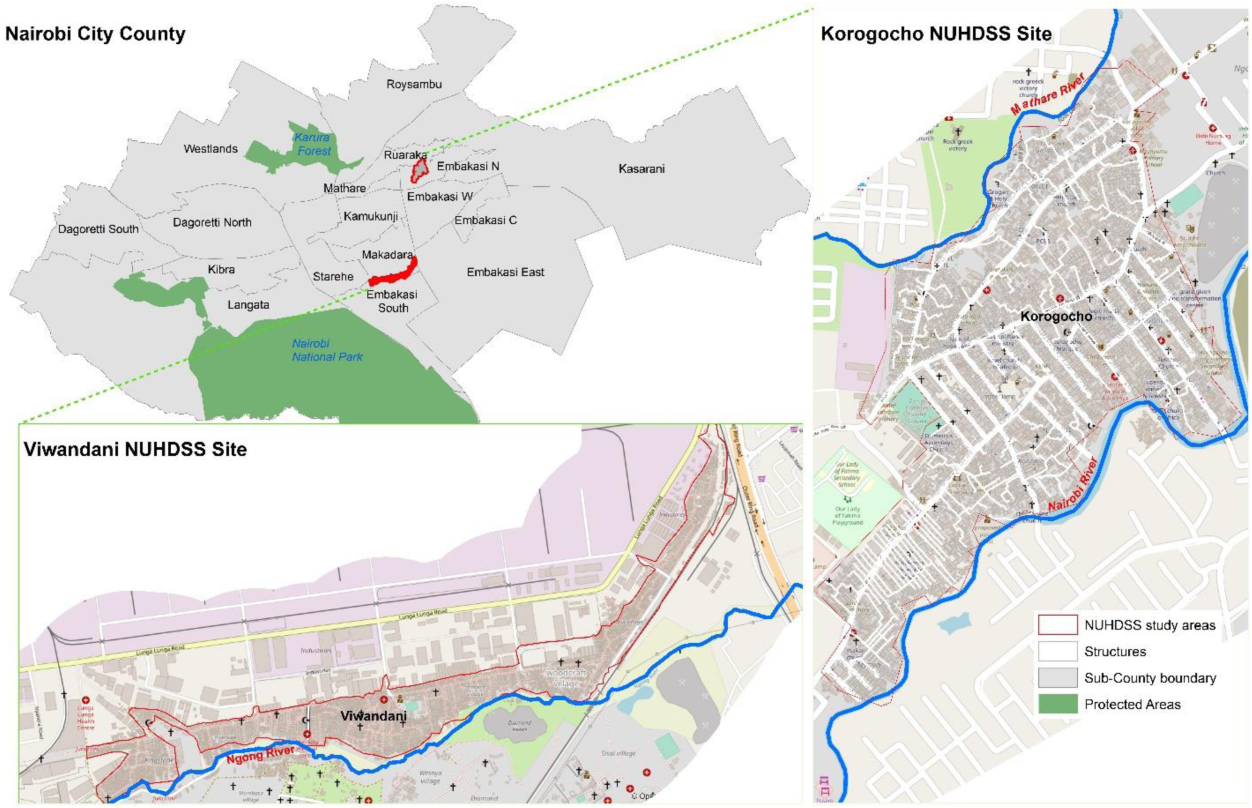

FIGURE 2
Study sites (source: authors 2022).

available for employed PWDs at the workplace. We conducted face-to-face interviews in English or in Swahili, at a quiet location convenient to the participants which were mainly at their workplace and in convenience of the study participants. Research Assistants recorded the interviews using a digital recorder and backed up with handwritten records. These interviews lasted for approximately 1 h. The sampling of study participants for the interviews continued until no new information was forthcoming.

2.5. Data quality control

Project Researchers reviewed all audio files on real time to ensure completeness and depth of the interviews and provided feedback to the Research Assistants, who were trained for 5 days on study aims, data collection procedures, study tools, and study ethics. Researchers and Research Assistants held debriefing sessions every day to determine the key emerging themes, probing techniques, and general progress.

2.6. Data management and analysis

Recorded audios from IDIs were translated and transcribed from Swahili to English and saved as individual Microsoft Word documents. Outputs were assigned number codes to prepare for analysis and to ensure confidentiality. Thereafter, transcripts were imported into NVivo 12 software (QSR International, Australia) for coding and analysis. Each transcript had a unique identifier comprising participant category, study site, and sex to enhance anonymity and facilitate informed analysis.

We used a framework analysis (39), informed by the social support theory (28) (**Figure 1**). Framework analysis is adopted for research that has specific questions, a pre-designed sample, and priory issues (39)· The first step of framework analysis was listening to the recordings to familiarize the researchers with the information related to social support, challenges, and maintenance of social support. To ensure reliability, two researchers (an experienced qualitative researcher with experience in labor markets and an anthropologist) and five co-researchers, who collected the data participated in the development of a coding framework by reading the outputs imported in NVivo 12 software independently to establish an inter-coder agreement. Once the initial coding framework was completed, the team met to discuss the themes generated and to reach an agreement on themes (**Table 2**). Two researchers proceeded with coding, charting, mapping, and interpretation of transcripts.

2.7. Ethical considerations

AMREF Health Africa's Ethics & Scientific Review Committee (ESRC) (REF: AMREF-ESRC P747/2020) approved the study. We obtained a research permit from the National Commission for Science, Technology and Innovation (NACOSTI) (REF: NACOSTI/P/20/7726). Approval was also sought from the Liverpool School of Tropical Medicine (LSTM) and the APHRC internal ethical review committees as part of the larger Accountability and Responsiveness in Informal Settlements for Equity (ARISE) Hub funded by the UK Research and Innovation (UKRI). Before participating in an interview, all participants provided an informed written consent. The interviews were conducted in quiet spaces for privacy and confidentiality and for the quality of the audio files.

3. Results

We present findings on social support for PWDs, challenges faced by social support, and maintenance of support. Study participants included employers or service providers who had recruited PWDs in the workplaces and sub-county officials with lived experiences on employment of PWDs in the two study sites. Specifically, four education providers, two healthcare providers, four water providers, four sanitation providers, four solid waste management providers, and two sub-county officials in each of the study sites took part in our study (**Table 1**).

The study themes and sub-themes were anchored on social support theory (**Table 2**). In addition, we reported emerging themes on challenges and maintenance of support.

3.1. Theme 1: social support

Social support is commonly conceptualized as the social resources on which an individual can rely when dealing with life problems and stressors. Three important theoretical perspectives on social support research are (a) the stress and coping perspective, (b) the social constructionist perspective, and (c) the relationship perspective (**Figure 1**). We identified social support approaches that include a PWD being listened to with a concern; identifying strengths of a PWD and the obstacles they face; planning for the PWD based on qualities, knowledge, and experience and linking them with existing opportunities; creating targeted opportunities and facilitating access to the opportunities; the gradual withdrawal of support by the employee support team; and lastly compromise by the employer and employees as discussed below.

TABLE 1 Summary of the study's sample coverage.

Study participants	Korogocho	Viwandani
Education service providers	4	4
Health service providers	2	2
Water service providers	4	4
Sanitation service providers	4	4
Solid waste management service providers	4	4
Sub-county official	2	2
Sub-total	20	20
Total	40	

TABLE 2 Themes of the study.

Major themes	Sub-themes
Social support	a) Stress and coping perspective • Listening with a concern • Gradual withdraw of support offered to PWDs b) Social constructionist perspective • Identifying strengths and obstacles for PWDs • Compromising of principles by support members for the benefit of PWDs c) Relationship perspective • Planning for PWDs based on their experiences • Linking PWDs with existing opportunities and creating opportunities at work
Challenges in social support	• Misdirected and inadequate resources • Dissatisfaction and unhappiness • Conflicts
Maintenance of the social support	• Communicating information • Coordinating the network • Sharing the workload • Supporting individual members

3.1.1. Stress and coping perspective

Stress and coping perspectives include listening with a concern and gradual withdraw of support offered to PWDs, as the two strategies reduce stress.

3.1.1.1. Listening to PWDs with a concern

Employers and employees without disability acted as support team/group to employed PWDs. The support groups consulted with PWDs to identify choices, roles, interests, and needs on which planning could be based. Careful listening clarified the person's choices and reasons behind choices. Communication could take place within a formal meeting or as an exchange between two people during a chance social encounter. The question may have concerned a decision as major as relocating a water point or as minor as a choice of time to arrive and leave the workplace.

> *During a discussion about a person with disability attempts of relocating a water point, other employees suddenly turned to her and asked, 'is this really what you want to do?' Another member added 'just be open'. The person thought for a while and then said it was what she wanted to do but didn't know how to go about it.* (IDI, Male Water Provider, Viwandani)

The support team of employees with support from employers noticed a growth in assertiveness and confidence of employed PWDs who were listened to with a concern. Gaining input from a PWD continued to be a top priority in planning to support employees, who were always keen and alert on signs that indicated meaning and choices for PWDs.

> *Despite her disability, the person has always contributed a lot to the group. We are very observant of non-verbal cues to pick on aspects to help the person work independently … we are interested in empowering them on the same.* (IDI, Female Healthcare Provider, Korogocho)

3.1.1.2. Support team getting out of the way and gradual withdrawal of support

Support employee team "got out of the way" when it became obvious that the PWD was becoming more autonomous. In many cases the support team often seemed surprised and delighted at the speed and confidence with which the PWD adapted to new situations and revealed previously unnoticed strengths. Support members would then adjust and change their actions accordingly, and overtime withdraw support, as the PWD became proficient. This strategy eased transition and increased success, making participation more comfortable for the person.

> *When a support group in the employment space thought the PWD is confident to execute their tasks, the support group move aside for them to work independently.* (IDI, Female Solid Waste Management Provider, Korogocho)

> *When the PWD began attending soccer and counselling sessions, a support employee talked to the staff and accompanied them for support … bit by bit we wean off to a point where the PWD would book their appointment and go on their own.* (IDI, Female Education Provider, Viwandani)

3.1.2. Social constructionist perspective

Social constructionist perspectives include identifying strengths and obstacles for PWDs and compromising of principles by support members for the benefit of PWDs, as the strategies enhance self-esteem of PWDs.

3.1.2.1. Identifying strengths and recognizing obstacles

Employers worked on identifying the skills, talents, and personal qualities of PWDs. On some occasions where the employers and employee support groups identified a PWD as an excellent social organizer and able to connect peers to social groups and supply information about social activities, she/he was nominated as a team leader. This boosted their self-esteem as they felt recognized and supported from support group members or the employer. As such, at the time of study, an individual with disability was working with the communication team, and the communication coordinator had complemented their excellent job on packaging inclusive messages. In some cases, former life experiences such as vilification or abuse, or communication barriers, created obstacles to participation for the PWD, and the employee support teams did their best to identify and troubleshoot the obstacles.

> *She loves organizing things. As such she was appointed as a team leader for an event. The members also supported her in some ways during the event … But the key thing here is that she was leading the role and her self-esteem was boosted.* (IDI, Male Education Provider, Viwandani)

> *At the session, attendees include people with hearing impairments. The PWD helped with developing inclusive messages… You also find that the PWD has gone through many other painful life experiences and you have to pinpoint the challenges as you would not want to add more pain at the workplace.* (IDI, Male Healthcare Provider, Viwandani)

3.1.2.2. Compromise by employers or by PWD support group

Occasionally the person and the employer or support networks held differing views. The employer or support staff may have felt that a goal was out of reach, or saw another goal as crucial, but the person held the opposite view. Discussion and compromise were required when these dilemmas were portrayed. This could be stressful for some employers or support staff. Support networks at work felt strongly enough to hold out against criticism from outside and were convinced that in specific situations they knew what was right for the person despite resistance. One person liked to dress casually even during official meetings. A network member felt that this was not appropriate, consulted with the person, and persuaded her to change into suitable attire; however, instead the person accepted but brought along her preferred attire, where she ultimately wore as per her likes.

> *We had an official meeting and on those days, there is a dress code. So I consulted with the person so that she could dress officially. The person went and changed but carried her preferred attire and to my surprise, during the event, she was dressed in her preferred attire. I had nothing to say.* (IDI, Male Solid Waste Management Provider, Korogocho)

3.1.3. Relationship perspective

Relationship perspectives include planning for PWDs based on their experiences, linking them with existing opportunities, and creating opportunities for PWDs at work, as the strategies enhance linkages and networking, hence low social conflict.

3.1.3.1. Planning based on qualities, knowledge, and experience and linking with existing opportunities

Having asked questions and identified strengths, interests and choices, skills and qualities, and possible obstacles, the support network/staff members planned for participation by the PWD. Employers and support employees also researched opportunities in the wider community and included groups, facilities, businesses, or programs, and as such they remained alert for useful contacts, encounters, or information that may lead to suitable options for PWDs. Planning and linking with opportunities informed each other and often happened simultaneously; on the other hand, sometimes opportunities occurred spontaneously and became a basis for further planning. These were for additional skills that could not be offered by the employer and support groups on the job. There were also reports relating to lessons learnt by PWDs from a certain program on how to deal with unexpected everyday situations, but the program only run for a very short period. Despite that the employers offered on-the-job skills on how to deal with unexpected situations, they acknowledged the need of not abruptly disconnecting the employed person with their previous support, until the PWD was comfortable. As such they allowed the person to continue with their previous programs (i.e., programs before they joined the employer) on some days of the week, until the person considered the support from work as adequate.

> *One person came to me very early at my office to report a program which was closed that helped deal with unexpected life situations. I had to call other employees who were supporting the PWD at work and we thought about how to connect the person with other programs. We connected the PWD to a program and he did not benefit … we then referred him to a community program, where they could attend for two hours in a week and he benefitted … but with time, the person realized the support at work is adequate for them.* (IDI, Female Education Provider, Korogocho)

Employers and employee support teams evaluated opportunities by considering factors such as geography, public transport, cost, and accessibility. Complex obstacles were worked through with a thought, persistence, and creativity. Risk came with independence, and this was a concern for network members balancing participation and protection. As such, there was a need for complex obstacles to be addressed by affirmative action office at the county. The initiatives were personal to employers and management teams of the different sectors in the attempt to support the most vulnerable in the community and sometimes in the attempt to meet the policy action of inclusivity at the workplace.

> *We do all we can to resolve issues that affect persons with disability at work.* (IDI, Male Sub-county official, Korogocho)

3.1.3.2. Creating targeted opportunities and facilitating access to opportunities

Employers and support groups established programs, groups, organizations, and facilities or sometimes expanded an existing opportunity for fitness to all including fitness to employed PWDs. Opportunities created by employers included soccer days, netball competitions, vocational education, exhibitions, book clubs, personal care support, securing furniture and appliances, health review, and community gardening, among other opportunities.

> *We used to send the persons to* {Name of a program} *but it was not convenient. We started our own safe space where we have sports, care services, art, competitions, clubs and all sorts of opportunities. It is a small space but it has done wonders in supporting the disadvantaged people in the community … We talked to everyone to support our safe space so that everyone can access it. We've got churches on the side, clubs, local government, you name it … nothing ever in isolation and our groups have benefitted.* (IDI, Male Education Provider, Viwandani)

3.2. Theme 2: challenges in social support

Study participants described how misdirected and inadequate resources, dissatisfaction and unhappiness, and conflicts were constraints to social support to PWDs in the workplace.

3.2.1. Misdirected and inadequate resources

The most commonly reported reason for the failure of support was the inadequate and often misdirected contribution of some support groups. Some groups frequently failed to identify what was meaningful to the person as well as opportunities and suitable strategies to enhance participation, taking a "one-size-fits-all" approach. Some support services seemed hampered by a lack of funding and staffing, hence the need to address most pressing needs, inaccurate beliefs, and inflexibility of policy both at a personal level and an organizational level, resulting in an inefficient use of resources to support PWDs.

> *Due to inadequate funding or few qualified workers, employers find themselves in a situation where there is no real support for PWD or the support is channeled to most pressing issues and individualized support is lost.* (IDI, Female Sub-county official, Viwandani)

3.2.2. Dissatisfaction and unhappiness

Sometimes the PWD communicated unhappiness to their job support group, or support groups reported dissatisfaction in the way the PWD performs their role. Notably, sometimes the support collapsed altogether. One person lost a job when a support group was not satisfied and unhappy because they were afraid that the person might jump out of the lorry without warning and hurt themselves.

> *Feedback is key. One time a driver reported that the person he was supporting was about to jump from the lorry several times while transporting solid waste to the dumping site. The person lost the prestigious job because the driver was not happy and did not want him to lose his life while at work.* (IDI, Male Solid waste management Provider, Korogocho)

3.2.3. Conflicts

Sometimes, employers and employees were in conflicts. Some conflicts stemmed from the disagreement, anger, closeness, and persistence in the workplace by the employed PWD with the employees in a support group. Remarkably, this could result in anger by the support group and a lack of willingness to offer maximum support. When conflicts had not always been anticipated, it could take months or years to negotiate, thus affecting social support offered to PWDs by the employee's or employer's network.

> *There are conflicts of course between the support group of employees with the employed person with disability and this mostly results in anger and unwillingness to support … the conflicts could take long to be resolved if they are not anticipated.* (IDI, Male Sanitation Provider, Viwandani)

3.3. Theme 3: maintenance of the social support

From the employers' perspectives, essential to the functioning and an enabling environment for PWDs were communication, coordination, sharing of the workload, and support by a network/support group. Employers did not randomly hire PWDs to make their life better; for some, there was a deliberate policy and action plan that necessitated the actions of engaging and supporting PWDs. For many, they employed PWDs to utilize their talents.

3.3.1. Communication

Employers pooled information about PWDs and available opportunities. Information was made accessible, and all leads were followed to arrive at successful support strategies. This was often established at the beginning of work engagement and continued as the PWD was already involved at work.

> *The PWD who was employed was introduced to diarizing progress by the employer. Employers could then produce a weekly or monthly summary of the changes in person. A close employer working with the PWD also summarized and shared on the progress report of the PWD.* (IDI, Male Education Provider, Korogocho)

3.3.2. Coordination at work

Employees coordinated times and dates for meetings when extra support would be required by any employee, with a focus on PWDs. Records were kept, for example, meeting minutes or a goal chart for supporting PWDs.

> *There are meetings coordinated to support employee in need, more so PWD. Minutes, action plans, and any emerging issues were used to resolve work related challenges.* (IDI, Male Solid Waste Management Provider, Viwandani)

3.3.3. Sharing the workload

Support tasks and roles involved time and hard work, and as such support for PWDs was deliberately delegated. This was overwhelming for some network members; therefore, the employers were supportive in ensuring the PWD finds the right support when needed.

> *'The management supports a PWD achieve their goals … .It is usually who can help the person best. When? How? So we are deliberate with support, otherwise, it all becomes very wishy-washy and nobody knows who is going to do what.* (IDI, Male Education Provider, Korogocho)

3.3.4. Supporting individual members

All employees inclusive of those without disability were appreciative of each other's time and input, were aware of personal circumstances, and offered support and understanding to each other when needed. When circumstances affected employees "contribution, avenues of communication remained open in the hope that support would be provided to anyone in need."

> *The employees without disability are dedicated to support PWD when needed. There are open avenues for communication when one needs support. Sometimes they think about it as if it were their family members.* (IDI, Female Water Provider, Korogocho)

4. Discussion

Social support identified in the study was in the form of listening to PWDs with a concern; identifying strengths and obstacles of the person; planning for the person based on qualities, knowledge, and experience and linking them with existing opportunities; creating opportunities and facilitating access to opportunities; gradual withdrawal of support by a support team; and compromise by a support team. This could be attributed to the fact that the National Council for Persons with Disabilities of Kenya has an array of commitments for PWDs and their environs, with concerns on way, drive, and engagement compared to other counties in LMICs (9). More often than not, employers seek to hire people who are highly productive, competent, and skillful at work. However, a few employers have gone beyond work centeredness to employ and provide social support for PWDs to enhance their productivity and capabilities. This is contrary to the traditional beliefs and perceptions that associate disability with ill health and depict PWDs as "sickly" and entities of misfortune, who should rely on handouts (18). Despite that for-profit firms–service providers may have additional pressures that may influence their attitudes and willingness to offer support for PWDs, employers who were interviewed capitalized on strengths and talents of PWDs for mutual benefits. We add to the literature that "begging" is the only available work option to PWDs, due to lack of willingness and ready employers, especially at the lower rungs of the employment spectrum. Our findings sought to add to the existing literature on PWDs in the labor market from the perspectives of employers. A review to explore studies on the employment of PWDs by the Organisation Economic Cooperation and Development (OECD) and other key actors discloses a worthy research on involvement (or lack thereof) of PWDs, with studies primarily concentrated on employees, and to the best of our knowledge, no specific studies in informal settlements approached the employment and inclusion matters from employers' perspective (24, 40). Worthy to note is that Kenya has made some strides and has been portrayed in this study with employers and entrepreneurs offering social support to employed PWDs.

Beyond reported challenges faced by PWDs relating to negative treatment and associated psychological problems of self-esteem and other stressors in the community and at work, our study, guided by the social support theory, especially the postulation that social resources can be relied upon by individuals when dealing with lived challenges, realities, and stressors (27), builds on the need to understand the pathways through which PWDs will obtain the social resources they need for their effective functioning in their workplace. We sought to document what it will take to socially support an employed PWD from the perspectives of employers and entrepreneurs. Our study highlighted the best practices in the employment of PWDs, adding to an understanding of social support for PWDs in the labor market. There is evidence that not all employers and entrepreneurs have invested in the vision of inclusion of PWDs in the labor market (7, 41), despite the significant number of commitments made around social protection (4). This could be ascribed to many commitments relating to inclusion of PWDs that are fairly not precise and often broad (40). Thus, the commitments possibly engender reservations regarding what precisely is needed or a possibility that there is more evidence needed before such commitments are implemented (9). Particularly, employers and entrepreneurs could learn from the social support approaches identified and take precautions against the challenges pointed out in this study. Notwithstanding the scanty literature on social support for employed PWDs in low-income areas and the need to advocate for support, the commitments are broad and non-specific (9, 24), calling for more champions to support PWDs in the workplace. Further, results depict how disability is no longer relegated to charity in low-income areas but an inclusion issue, and some employers are championing this movement in Kenya by going beyond what the government expects in terms of quotas and incentives, by enhancing social support of PWDs, which is beyond the targets set by the government (20). The findings substantially differ from those of many previous studies (5, 42) describing how employers are reluctant in employing PWDs (41), in that the study paints a more realistic picture of the concerns and social support of employers toward employed PWDs in low-income areas.

5. Implications

Our results have implications on employment policies for PWDs and practice related to social support concerning PWDs in Kenya, more so in the informal settlements. Actors and institutions focusing on the welfare of PWDs could campaign for the execution and administration of disability laws documented in the Persons with Disabilities Act (43). The act forbids discrimination and necessitates that 5% of the contractual and spontaneous jobs be earmarked for PWDs and should be obligatory. This could be built on our findings that advance documenting best practices for enabling and inclusive work environments to maximize the productivity of people with disability in the workplace. Our study was driven beyond the "supply side" of the employment equation, to cover the "demand side" of the employment equation. Our intention here is to add value to the demand side of the employment of PWD equation by engaging a dominant missing link from the voices of employers and entrepreneurs themselves. Social support strategies are substantial for policy strategies that could reduce employer concerns about lawsuits or discrimination complaints after hiring workers with disabilities. Notably, social support strategies may slightly differ for employees with disability in other formal settings.

The findings have concrete implications for managing PWDs in the labor market. First, it is important to socially support workers with disabilities. As such, employers, employees without disability, and other actors should consider calls for support from workers with disabilities in each aspect of their tasks and at every instant of professional development. Second, organizations should design some support teams/groups at work according to definite levels of support required by workers with disabilities. Notably, establishing worker–organization feedback mechanisms would be key in building and fostering employer–employee work relations for suitable support of PWDs to fit into their tasks at work and offers the right balance between support demanded and support offered. Further, from our findings, distancing and withdrawal of some support to PWDs overtime could be a managing scheme for workers with disability to achieve independence, confidence, and sensitivity and be less vulnerable to work-related challenges (7, 18). Third, our findings could be beneficial to PWDs as it aids in designing and redesigning jobs to enable strengthening and inspiring of PWDs to self-sufficiency, personal growth, job empowerment, and reducing underemployment and discrimination in the workplace (24, 44). The findings also imply that PWDs will fit into their tasks at work, if social support at the workplace is designed to address their real needs as employees of normal organizations (18, 44).

The result might lead to a more diverse and accepting workplace for all employees: a more flexible approach to retaining skilled workers and hiring new employees, opportunities to increase productivity and take advantage of untapped talent, and a greater focus on job skills and performance rather than fear of potential future problems. Bringing in external experts to help with disability and accommodation issues could not only offer a broader range of solutions but also demonstrate good faith and ensure fair treatment and therefore potentially reduce legal liability. Employers could take a greater role in acquiring and centralizing the necessary information and expertise to better understand disability, appreciate workers' abilities, and solve accommodation problems. They could also create company-wide procedures, policies, and mechanisms to place less responsibility and burden on the individual.

Our findings do not map the experiences of PWDs entering the workforce and in the workplace. However, the results captured perspectives of social support that might be expanded in future research to uncover the processes of joining workforce by PWDs.

6. Conclusion

Inclusion of PWDs includes crafting an all-encompassing workstation, where employed persons with disability are contented, appreciated, respected, and treasured at all times without judgement. Nobody wishes to be endured at work, and like those without disabilities, PWDs need to be acknowledged for their actions. Often, there is some skepticism and reservation that comes with a resolution to employ a PWD, as they are reflected to be a liability by many employers. Therefore, the primary objective of inclusion is to embrace competencies, skills, capabilities, and strengths of all, in diverse work settings without judgement. These will ensure that workplaces align to building an all-inclusive work environment for all. Notably, in the absence of jobs for everyone and high unemployment rates among every segment of the population, there is a need for a thorough national awareness operation in Kenya to mobilize and sensitize employers and investors around the competencies of PWDs and their need to socially support on an impartial basis. On the other hand, employment centers may consider setting up at various locations to advise and support PWDs on the job and career opportunities that are disability-friendly. Additionally, vocational centers should partner with employers and avail information about capabilities and skills of PWDs. On the other hand, the government should provide tax-related benefits to employers to upsurge employer incentives for hiring PWDs. Employment matters affecting PWDs are complex and require multi-pronged context-specific approaches. Thus, employers of PWDs and their supporters may need to be hands-on and involve diverse stakeholders to implement current policies, frameworks, and guidelines in different work contexts across the country and beyond. Worthy to note is that some PWDs have already internalized misconstructions and misapprehensions regarding their capabilities. As such, actions may be required to upsurge self-confidence and self-esteem in them.

The big challenge in labor market is how to get employers interested in social support, by being committed to changing their culture of taking employed PWDs as a liability. If the employment prospects of PWDs are to be significantly improved, key actors in the labor must pay attention to the ways in which corporate culture creates or reinforces obstacles for employees with disabilities and how those obstacles can be removed or overcome. The removal of barriers has significant benefits not just for PWDs but also for other employees and the organization as a whole. Experts in law, economics, human resources, regulatory compliance, corporate anthropology, disability studies and policy, and PWDs themselves need to collaborate in formulating a blueprint for the future study of disability and corporate culture. These results also point to the value of further research into employer behavior regarding employees with disability. It would be valuable to extend this research in the future, particularly because unlike the profiles constructed here, many PWDs in low-income areas are not employed, and when employed, they usually lack some social support. Further research could also assess the types of social information in hiring behavior, which can shed light on the reasons for lower interest in applicants with disabilities along with specific policies or practices that can reduce this problem. For example, how do employers react when they are confronted with an application from a PWD, what are the steps in their reaction, and what are the beliefs, attitudes, and hiring behaviors? What is the role of written disability policies, training, and support from management? Such research can help identify the most effective policies and practices to increase their employment opportunities and social support for employed PWDs.

PWDs, employers with PWDs, and labor activists should endeavor to engage in policy dialog to raise awareness of the barriers faced by people with disabilities and the opportunities to strengthen their social support in employment; support employers in implementing disability-inclusive policies, practices, and services; and support research and data collection in low-income areas to understand the key needs of and barriers faced by PWDs regarding employment, so as to establish examples of good practice and lead by example in providing support to employees with disabilities. Policymakers should endeavor to review national labor laws to ensure that they do not create unintended disincentives to the employment of people with disabilities; codify minimum standards for accessibility in law, while allowing for flexible and incremental implementation of guidelines supporting employed PWDs; offer positive incentives for employers to employ people with disabilities; and equip public employment services to support jobseekers with disabilities. On the other hand, private sectors should introduce targeted recruitment and in-work support for PWDs, give PWDs opportunities to enhance their skills, and adopt or promote the best practice in the universal design of products and services for employed PWDs.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. The request can be made through https://aphrc.org/microdata-portal/.

Ethics statement

The studies involving human participants were reviewed and approved by AMREF Health Africa's Ethics & Scientific Review Committee (ESRC) (REF: AMREF-ESRC P747/2020). We also obtained approvals from the National Commission for Science, Technology and Innovation (NACOSTI) (REF: NACOSTI/P/20/7726). Approval was also obtained from the Liverpool School of

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Author contributions

IC: conceptualization, data curation and analysis, methodology, project administration, and first draft. IC, CK, and BM: validation, review, and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Disability doesn't discriminate: health inequities at the intersection of race and disability

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Objectives: Given the prevalence of discrimination experienced by racial and ethnic minorities living with disabilities, it is likely that racism experienced by Black, Indigenous, and people of color (BIPOC) is compounded by the ableism experienced by people with disabilities, widening disparities in health and healthcare outcomes. To address this, we described unmet healthcare needs of a sample of Black, non-Hispanic, and Hispanic adults with and without disabilities. The following research question was examined exploratively: Are Black and Hispanic adults with disabilities at increased risk of unmet healthcare needs compared to Black and Hispanic adults without disabilities according to the 2018 National Health Interview Survey?
Methods: Survey data was examined from the 2018 National Health Interview Survey (NHIS), a nationally representative survey of community-dwelling adults in the United States.
Results: Black and non-Hispanic adults most commonly reported mobility only disabilities. People with disabilities were significantly more likely to delay or forego care than their peers without disabilities within each racial/ethnic group. Among non-Hispanic Black and Hispanic adults, nearly 30% of people with disabilities forewent services due to cost compared to persons without disabilities.
Conclusions: Black and Hispanic adults with disabilities experience greater disparities in access to healthcare than Black and Hispanic adults without disabilities. Therefore, health disparities experienced by racial and ethnic minorities living with disabilities is likely influenced by the dual systemic factors of racism and ableism.

KEYWORDS
disability, discrimination, BIPOC, disparities (health, racial), survey data

Introduction

Recent estimates indicate that 26% of US adults experience disability (1), with higher rates of disabilities in Black, Indigenous, and people of color (BIPOC) communities. For example, compared to 26.6% of white persons with disabilities (PwD) ages 45–64, 35.5% of Black and Hispanic adults in that same age group are living with a disability in the US (2). Moreover, research shows that both BIPOC and disability communities experience disparities in the receipt of equitable care (3–5). For example, each report unmet needs for healthcare at disproportionately higher levels than their white, non-Hispanic and non-disabled counterparts, respectively (2, 6, 7). Both groups face insurance, cost, and provider-patient communication barriers to high-quality care and problems receiving culturally appropriate care.

Despite the overlap in both prevalence and similar inequities experienced by both groups, little research has examined the health and health care outcomes at the intersection of BIPOC and PwD. Given the prevalence of discrimination, it is likely that racism experienced by BIPOC is compounded by the ableism experienced by PwD, potentially amplifying disparities in health and healthcare outcomes (8–10). Studies have demonstrated in specific disability populations, namely individuals with intellectual and developmental disabilities, who belong to racial and ethnic marginalized communities have worse health and health care outcomes as compared to white individuals with intellectual and developmental disabilities (11–15). Additionally, several studies demonstrate disparities in health care utilization for women who live at the intersection of disability and race/ethnicity (16, 17). However, a dearth of evidence on the health care outcomes of the population of persons with disabilities who belong to ethnic and racial minority communities exists. To address this, we described unmet healthcare needs of a sample of Black and Hispanic adults with and without disabilities. The following research question was examined exploratively: Are Black and Hispanic adults with disabilities at increased risk of unmet healthcare needs compared to Black and Hispanic adults without disabilities according to the 2018 National Health Interview Survey?

Methods

We examined data from the 2018 National Health Interview Survey (NHIS), a nationally representative survey of community-dwelling adults in the US (18). The NHIS is a longstanding in-person federal survey of health and healthcare; it is publicly available from the National Center for Health Statistics and is, therefore, exempt from review. All persons in 30,000 households were interviewed; a single adult was randomly selected for more extensive questions on the Sample Adult file ($n = 25{,}417$). The response rate on this file was 83.9% (18).

Sample

We focus our analysis on Black, non-Hispanic adults and Hispanic adults with and without disabilities, due to the small racial/ethnic sample sizes for other BIPOC. Our retrospective cohort study includes 2 analytic samples (≥18 years old): Black, non-Hispanic adults ($n = 2{,}822$) and Hispanic adults of any race ($n = 3{,}069$).

Respondents were categorized as having a disability if they reported a lot of difficulty in any of the following areas: seeing with glasses; hearing with a hearing aid; walking or climbing steps; communicating in their "usual language"; "remembering or concentrating"; or self-care activities. Combining disability types into a single catch-all category is not ideal, because of how types of disability interact differently with the environment (19). However, the NHIS first asked these questions of all sample adults in 2018 and the sample sizes of each disability type were too small to be examined reliably. When possible, we describe some preliminary differences by disability type.

Measures

Outcome measures included self-reported usual source of care (USC) for sick and routine care. Respondents reported 4 separate measures of unmet need: (1 and 2) delayed/forewent care due to cost, (3) delayed care due to availability (e.g., could not get through on the phone, wait was too long), and (4) forewent services (e.g., prescription medication, mental healthcare) due to cost.

Analysis

Pearson's χ^2 and multivariate logistic regression were used to examine outcomes by disability within each race/ethnicity group, controlling for age, sex, marital status, employment, education, imputed poverty status, health insurance, and number of chronic conditions. We report predicted proportions and odds ratios (95% confidence intervals) from regression. Analyses were

TABLE 1 Characteristics of black, non-Hispanic and Hispanic adults in the sample.

	Black, non-Hispanic		Hispanic	
	%	(*n*)	%	(*n*)
Total		(2,822)		(3,069)
Age				
18–34	35.1	(702)	39.4	(1,033)
35–64	49.3	(1,396)	49.5	(1,528)
>64	15.6	(724)	11.0	(508)
Female	54.1	(1,672)	50.6	(1,757)
Married	32.9	(728)	49.1	(1,354)
Employed	61.9	(1,579)	66.5	(1,954)
Education				
Less than high school	13.2	(446)	27.7	(881)
High school graduate/GED	28.7	(785)	27.1	(797)
Some college	22.4	(605)	17.4	(482)
College degree	35.7	(986)	27.7	(909)
Poverty status[a]				
<100% FPL[b]	20.6	(581)	18.0	(542)
100%–199% FPL	23.5	(537)	28.6	(708)
200%–399% FPL	28.7	(658)	30.5	(743)
≥400% FPL	27.2	(558)	22.9	(586)
Health insurance				
None	11.7	(300)	23.6	(677)
Public only	28.1	(922)	24.4	(844)
Any private	60.2	(1,600)	52.0	(1,548)
Chronic conditions				
None	43.6	(1,031)	58.4	(1,659)
1	28.2	(745)	23.1	(713)
≥2	28.2	(1,046)	18.6	(697)

[a] Poverty Status was imputed by the National Center for Health Statistics. Cell sizes reflect unimputed frequencies.

[b] *FPL*, Federal Poverty Level.

conducted in Stata 15, accounting for NHIS weights and complex sampling design. We used $p < 0.017$ to account for the examination of multiple outcomes within each racial/ethnic group (20).

Results

Sociodemographic characteristics of our sample are contained in **Table 1**. Fifty percent of adults were ages 35–64 and female; most had private health insurance, graduated high school or earned a GED, and were employed. Approximately 20% of adults reported living in poverty. Most had no chronic conditions.

Approximately 11.5% ($n = 402$) of Black, non-Hispanic adults reported a disability; the most common disabilities were mobility only disabilities [4.7% ($n = 197$)] and multiple disabilities, including mobility disability [3.0% ($n = 100$)]. Among Hispanic adults, 8.1% reported a disability, most commonly mobility only disabilities [2.8% ($n = 119$)].

The predicted proportions of access to care outcomes by race/ethnicity and disability are shown in **Figure 1**. Within each racial/ethnic group, PwD were significantly more likely to delay or forego care than their peers without disabilities. Nearly 30% of PwD forewent services due to cost (Black, non-Hispanic: 28.2%;

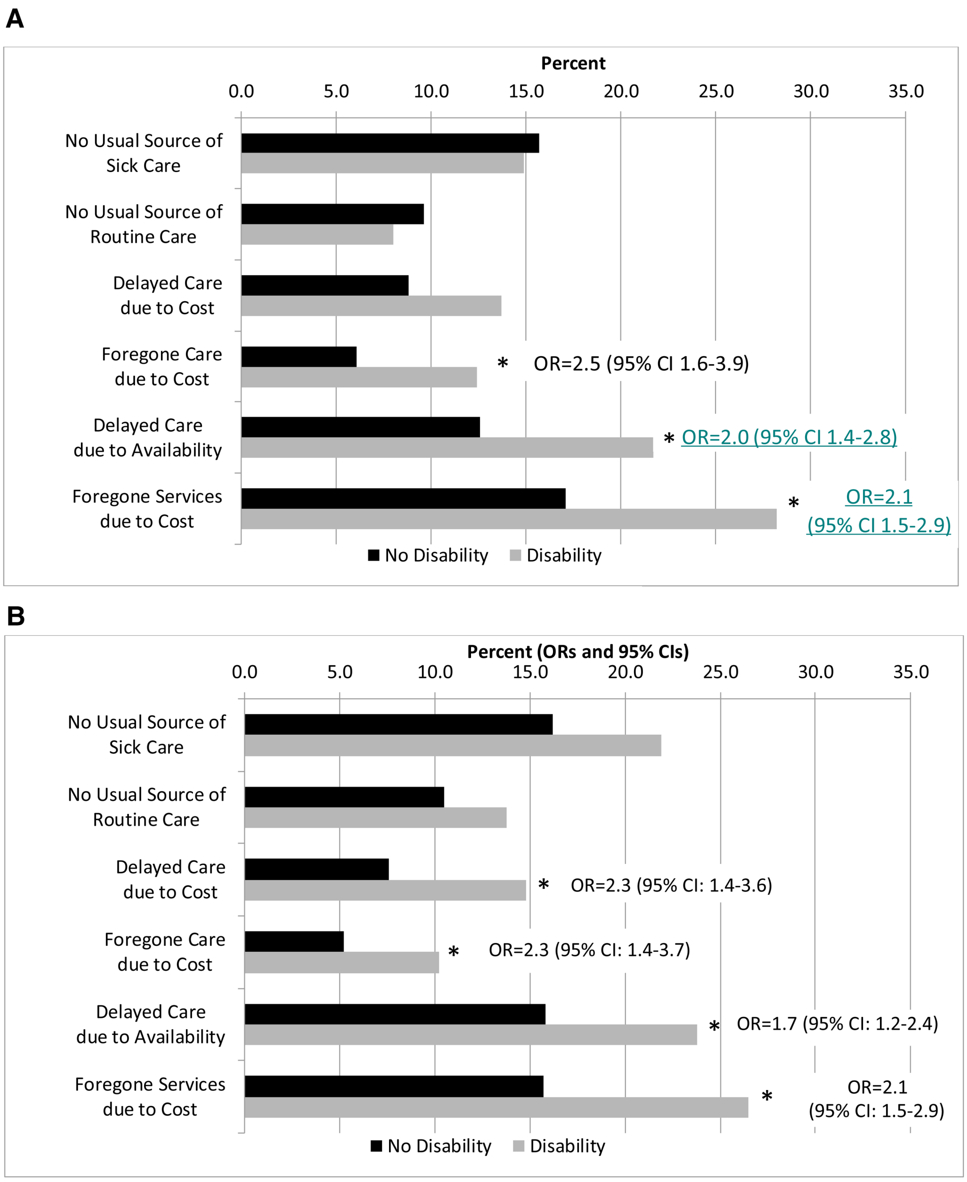

FIGURE 1
Predicted probabilities of access to healthcare by race/ethnicity and disability Status. (A) Black, non-Hispanic Adults. (B) Hispanic Adults. $*p < 0.017$, Indicates that the Odds ratios (OR) and 95% confidence intervals (CI) from logistic regression controlling for age, sex, marital status, employment status, educational attainment, poverty ratio, chronic conditions, and health insurance type. The ORs represent the disability group in reference to the no disability group.

Hispanic: 26.5%) compared to persons without disabilities (Black, non-Hispanic: 17.1%; Hispanic: 15.7%, both $p < 0.001$). There were no significant differences in access to usual source of care by disability group for either racial/ethnic group or for delaying care due to cost among Black, non-Hispanic adults.

Discussion

We found that Black and Hispanic adults with disabilities were significantly more likely to forego or delay care due to reasons such as cost as compared to Black and Hispanic adults without disabilities. This suggests that BIPOC with disabilities experience greater disparities in access to healthcare than those without disabilities. This may reflect the systemic economic barriers experience by both BIPOC and disability communities, as well as those who experience intersectionality (10, 21). Policies and programs are needed to reduce costs whenever possible to ensure that BIPOC with disabilities (and BIPOC and PwD more generally) receive timely access to appropriate healthcare.

We found that across both Black and Hispanic populations, there was no difference in reporting a usual source of care by disability status. This is similar to the findings of a study using Medicare Expenditure Panel Survey data from 2002 to 2010 (22). This study found that Hispanics with basic activity limitations were the only group to be more likely to report lacking a usual source of care, as compared to other disability groups who are Hispanic.

Racism and ableism are often thought of as parallel systems of oppression that work separately, yet this notion ignores experiences at the intersection of BIPOC and PwD (8, 9). Our findings bring together separate bodies of scholarship that show that PwD and racial/ethnic minority populations experience disparities compared to their non-disabled and non-Hispanic white peers. Moreover, our findings highlight the need to account for the intersection of these identities in future analyses to appropriately tailor programs and policies. The health care disparities experienced by racial and ethnic minorities living with disabilities is likely influenced by systemic racism and systemic ableism factors.

There are limitations to our findings. We focused our analysis on Black, non-Hispanic adults and Hispanic adults with and without disabilities. Additional research should be conducted to investigate Asian and Indigenous populations. Additionally, due to sample size, we collapsed disability types. Differences may exist based on type of disability. Another limitation is the fact the findings are descriptive and do not consider longitudinal data or related contextual factors. Health disparities research is often examined through risk and not indicative of a strength-based approach. Finally, the term BIPOC does not account for or reflect the breadth of diversity among BIPOC individuals. More research should be done to acknowledge and examine the diversity across and within BIPOC PwD.

Future research should examine the intersection of social stressors such as racism and ableism and how they uniquely impact the health outcomes of BIPOC individuals. The disparity at the intersection of BIPOC and disability suggests disability access issues faced by BIPOC with disabilities cannot be solved without systemic reform of the healthcare delivery system. With respect to systemic challenges faced by BIPOC PwD and in line with other initiatives and recommendations to increase health equity for other marginalized groups, it is likely that systemic changes such as reducing costs associated with quality health care, increasing accessibility to health care, and building provider competency in the unique needs of racial and ethnic minority PwD may meaningfully improve health outcomes for this community. However, further qualitative examination of health needs from the perspective of members of this community is needed.

Meeting the health needs of BIPOC with disabilities is a matter of quality as much as it is equity. BIPOC with disabilities are likely to experience additional barriers such as racism, compounded by what is often an urgent or chronic need to maintain frequent consistent use of the healthcare system. Understanding health outcomes experienced by those who are members of both groups is critical to developing successful interventions aimed at improving health outcomes for this marginalized group.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found below: https://www.cdc.gov/nchs/nhis/nhis_2018_data_release.htm.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

The authors confirm contribution to the paper as follows: study conception and design: BD and MM; data collection: MS; analysis and interpretation of results: BD, ND and MS; draft manuscript preparation: all authors. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Do we react differently toward bionic devices vs. cochlear implants and wheelchairs? Possible links with personality traits

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The present study explored the attitudes toward individuals with bionic eyes and limbs, cochlear implants, and people with disabilities that imply using a wheelchair. Our sample consisted of 474 Romanian adults aged 18–61 ($M = 27.56$, $SD = 11.80$). Participants were randomly divided into five groups. They all filled scales related to personality characteristics, i.e., agreeableness, neuroticism, openness to experience, comprehension/intellectual efficiency, and previous contact with disability. Then, each group was presented with a vignette describing a character (wheelchair/bionic eye/bionic leg/cochlear implant/control group). Finally, they answered questions about their emotions, cognitions, and behaviors related to that context. Overall, our results suggested that higher agreeability, extraversion, openness to experience, intellectual complexity, and lower neuroticism were generally associated with more positive attitudes toward disability. When examining the differences in participants' emotions, cognitions, and behaviors depending on the target's characteristics, our results generally suggested that the most negative reactions were toward the character with a bionic eye. We discuss these findings considering their importance for shaping positive attitudes related to disability, especially related to the future technological advances in bionic devices.

KEYWORDS

disability, personality, bionic eye, bionic limb, attitudes

Introduction

As a result of an increasing elderly population and shifts in the demographic makeup of various cultures (1), disability has evolved into an inevitable facet of the human experience in multiple parts of the world. According to the World Health Organization (2), the development of a disability, which can take on a wide variety of forms, is the result of the interaction between people with a health condition and the personal and environmental elements they are exposed to. More than one billion individuals, which accounts for fifteen percent of the world's population, are living with a variety of disabilities, which results in a significant economic, societal, and medical burden around the globe (3). As a result, it encourages the general public to contemplate effective solutions for incorporating and supporting those with disabilities. In recent years, several countries have begun to construct social and rehabilitative plans to alleviate the burden and improve the well-being of persons with mental and physical impairments who live in their communities (4).

Appraising a person's attitudes regarding their disability can be multifaceted—either positive or negative, or a mixture of the two (5). Several studies have investigated the effects of various attitudes. For instance, positive social attitudes could make it easier for people to be accepted by their families, friends, and employers (6). In contrast, negative attitudes could result in low expectations, discrimination, and marginalization (7). More specifically, research demonstrated that negative attitudes of healthcare providers had been indicated as a barrier to the involvement of individuals with disabilities in activities such as physical and educational contexts (8). In light of the current state of affairs and the significance of one's mentality, the general public needs to be encouraged to reevaluate and improve their perspectives on individuals with disabilities to create a more accepting society.

Individualistic societies, which emphasize personal identity and aspirations, have more favorable attitudes toward people with disabilities than collectivistic societies [e.g., (9)]. However, prostheses alter social lives, according to previous studies. Westbrook et al. (10), for example, studied six Australian communities (Chinese, Italians, Greeks, Germans, Arabic speaking, and Anglo-Australians) and found that Germans (individualists) were the most accepting of amputees, while Greeks and Arabs (collectivists) were the least, most likely due to the associated cultural features. At the same time, in the past years, globalization increased cultural uniformity, making cultures less collectivistic (11).

Technological evolution and bionic prosthetics

In recent years, technology has rapidly advanced to assist people with physical limitations. Prostheses and bionic hands gained widespread media and public attention. However, in Romania, the public health system does not cover the full costs of such protheses, which can be challenging for prospective users (12). Nevertheless, new questions mark specific research directions as the world progresses and people become increasingly familiar with the expanding technology for assisting people with different disabilities. These questions include: how and to what extent does artificial intelligence (AI) in bionic devices impact persons with disabilities? Is it possible that it also brings drawbacks besides the great benefits of specific devices such as cochlear implants or bionic hands and limbs? Kaplan (13) researched the cultural differences in AI perception and found that eastern cultures, such as the Japanese, respond more positively to various forms of AI than Western cultures. On the other hand, according to Hirai and Dautenhahn (14), people who live in western cultures tend to view AI as a competitor, as the function of technology is still regarded with suspicion and fear. Similarly, the Frankenstein Syndrome refers to these concerns triggered by the use of AI, including bionic prosthetics (15).

Jack E. Steele, the creator of the American television show "The Six Million Dollar Man and Bionic Woman," is credited with being the first person to use the term *bionics*. The characters of the show were given superpowers using electromechanical implants. After that, this term became popular in various contexts, including television and literature (16). However, in the context of the terminology currently in use, it primarily refers to medical equipment that directly connects with the disabled individuals' remaining neurological or muscle systems (17). In other words, a bionic prosthetic includes a mechanical or electric part that directly stimulates a nerve or muscle, obtaining the same results as a functional anatomic organ or limb, in most cases replacing it.

Only a few studies explore the attitudes toward people with bionic prosthetics, especially within the Romanian culture. For example, Maftei and Oancea-Matei (18) investigated whether a bionic target would generate different reactions in sacrificial dilemmas compared to other targets. Their results suggested that children were more willing to sacrifice the bionic targets compared to non-disabled and or targets with a disability. Meyer and Asbrock (19) also explored how stereotypical attitudes toward people with disabilities are affected by bionic prostheses. According to their results, using technology can alter the negative stereotypes associated with persons with disabilities (e.g., people with disability are warm but incompetent). As Meyer and Asbrock (19) suggested, people might see individuals using these bionic devices (i.e., bionic arm and leg prostheses, exoskeletons, or retina implants) as more competent than those with physical disabilities in general. Additionally, those who use bionic prostheses are thought to have a warmer disposition than able-bodied people. However, when the term "cyborg" was used instead of "bionic prostheses," people had the impression that cyborgs were intelligent but unfeeling, which made them appear menacing (19).

Target characteristics, contact, personality, and the attitudes toward disability

Examining people's views toward disability is crucial for addressing issues of equity, acceptance, and inclusion of people with disabilities. Various scholars explored this subject, and their conclusions are quite similar. For example, in the comprehensive review of Freer (20), the results suggested that, generally, females hold more favorable attitudes than males, and knowing a friend or a family member with a disability increases the chances of having more positive attitudes, as well [a result also confirmed within the Romanian population by Maftei and Gherguț (21)]. Also, inclusive education seems to be associated with students' more positive attitudes toward disabilities [e.g., (22)].

When it comes to age, however, the findings are mixed. Some studies suggested that younger individuals have more positive attitudes toward disability [e.g., (23, 24)], while others suggested the opposite (25). Also, other scholars found no significant differences in this regard [e.g., (26)].

The finding that concerns the association between the previous contact with disability and attitudes is the one that has been spoken about the most frequently among all of the components that have been discussed. The length of time spent in contact with disabled persons, the regularity and quality of that contact, and having disabled friends, family members, or coworkers are all examples of the manifestations of contact. In the vast majority of studies [e.g., (27, 28)], researchers concluded that interacting with persons who have disabilities could result in more favorable attitudes about those individuals. This finding may be because more contact could assist in reducing fear and anxiety and produce a more balanced and realistic perspective of the functional capacity and ability of persons with disabilities (27).

Evidence also suggests that persons who interact with disabled people will view themselves as more valued in social life and therefore be less likely to approach disabled people in a hostile manner (29). On the other hand, it is important to point out that a negative attitude toward disabled individuals would prevail in the absence of any controls over the demographic characteristics and the level of contact. For example, when the contact quality is not particularly examined, increased exposure may suddenly lead to uncomfortable or unpleasant sentiments, and people may associate these negative experiences with the disabled persons themselves (30). Therefore, it is also essential to consider the contact's number and quality rather than focusing solely on the frequency of the interactions. Even if some scholars [e.g., (31)] have found no substantial difference between attitude and contact, the causes that lead to those findings are still explicable (i.e., the lack of planned relationships between students and disabled people or the low frequency of such relationships). As a result, prior knowledge of the disabled individual's condition may be required under specific contact situations to foster a more positive attitude toward impairment. The decreasing tension between groups and the establishment of an atmosphere that could not only diminish prejudice but also encourage constructive relationships in a more pleasurable manner hints at the existence of a virtuous cycle of beneficial outcomes (32).

In addition to the elements mentioned up until this point, it has been suggested that public opinion also relies on individual aspects of the disabled person, such as the type of disability (33). For example, people tend to have less of a positive attitude toward individuals with a more evident physical disability (34). Also, people tend to have more positive attitudes toward people who are blind and deaf compared to those who are paralyzed and intellectually disabled (35). In addition, people with facial anomalies are likely to be perceived less favorably than people with other types of physical disabilities (32). Finally, a series of psychological factors have also been examined by previous studies regarding attitudes toward disability. For example, Hellmich and Loeper (36) suggested a positive correlation between self-efficacy and disability views. Armstrong et al. (23) suggested that reduced contact anxiety and high empathy scores were associated with positive disability attitudes. Also, self-esteem predicts more positive attitudes toward sensory impairments but not physical limitations, according to de Laat et al. (35).

However, regarding personality characteristics and variables such as agreeability, extraversion, neuroticism, openness to experience (i.e., some of the big Five dimensions), and intellectual efficiency, the findings are scarce when exploring the attitudes toward disability. For example, Ekehammar et al. (37) suggested that generalized prejudice (racism, sexism, prejudice toward homosexuals, and intellectual disability) was indirectly affected by extraversion, openness to experience, and conscientiousness through right-wing authoritarianism, and by agreeableness through social dominance orientation, whereas neuroticism had no significant effect. Page et al. (38) suggested that higher levels of openness and agreeableness were significantly associated with positive attitudes toward intellectual disability. Similar findings were reported by more recent research, e.g., Himmelberger et al. (39), generally highlighting that high levels of openness, agreeableness, and extraversion, and low levels of neuroticism usually predict more positive attitudes toward disability.

Finally, the research regarding the link between comprehension/intellectual efficiency and attitudes toward disability is scarce. Some previous studies explored the link between emotional intelligence and prejudice (not specifically toward disability) and suggested a negative link between them [e.g., (40)]. Other studies suggested that (cognitive) intelligence test scores seem to be negatively related to racial prejudice, while self-perceived intelligence is positively related, highlighting the need to explore various mediating mechanisms (41). The meta-analysis conducted by Onraet et al. (42) also concluded that higher scores on intelligence tests predict lower levels of prejudice. One possible explanation in this regard is that individuals with lower intelligence are more inclined to adopt essentialist thinking (41), i.e., “the belief that members of a particular social category share a fixed underlying nature, or essence” (43).

The present study

In the present study, we aimed to explore the attitudes toward individuals with bionic eyes and limbs, cochlear implants, and people with disabilities that imply using a wheelchair. Though previous scholars researched similar topics, the novelty of our approach is that (1) we used an experimental approach, addressing the related limitation mentioned by previous work, (2) we used vignettes depicting various impairments, including some that implied the use of bionic devices, and (3) we explored the role played by personality traits since the evidence in the area is scarce.

Based on the previous literature regarding the attitudes toward disability, bionic prosthethes, and the underlying psychological mechanisms, we assumed the following:

H1. The *bionic* targets would generate more negative attitudes compared to the non-bionic targets [e.g., (18, 19)].

H2. Higher agreeability, extraversion, openness to experience, comprehension/intellectual efficiency, and lower neuroticism would be significantly linked to more positive attitudes toward disability [e.g., (39)].

H3. More frequent previous contact with a disability would be significantly linked to more positive attitudes toward disability [e.g., (27, 28, 30)].

Method

Participants and procedure

Our sample was formed of 474 participants aged 18–61 (M = 27.56, SD = 11.80). Most participants were females (94.9%) with a high-school diploma (48.3%). **Table 1** details the sample's characteristics. The only inclusion criterion was related to age (i.e., all participants had to be over 18).

Data were collected through an online questionnaire and distributed via social media platforms and communication groups (Facebook, Instagram, Messenger, and WhatsApp), using the snowball technique (44), at the beginning of 2022. Many of the participants who filled out the form were students from the faculty where the authors were affiliated, who received course credits for their participation. All participants voluntarily participated in this study, and they were informed that the information they provided would remain anonymous and confidential and that they could retire from this study at any time. The time needed to complete the questionnaire was around 20 min. The research was conducted following the Helsinki Declaration ethical criteria and the ethical research requirements approved by the institutional board of the authors' institution.

Measures

Interaction

We asked participants to assess the frequency of interaction with individuals with physical or intellectual disabilities in the past 12 months. The exact question was, *How often did you interact, in the past 12 months, with someone with a physical/ intellectual disability?*. We used a 5-point Likert scale ranging from 1 (not at all) to 5 (very often).

Attitude toward disability

We used the 34-item Multidimensional Attitudes Scale Toward Persons With Disabilities [MAS scale; (6)]. The instrument comprises three factors (emotions, cognitions, and behaviors). Participants were presented with a vignette describing the situation. They were randomly assigned to one of the five groups based on the character's description. In these vignettes, a woman called Maria (the character from the vignette) "went to a coffee shop for lunch with some friends. A woman in a wheelchair (**Group 1**)/with a bionic eye, i.e., an electronic visual prosthesis (**Group 2**)/with a prosthetic bionic leg (**Group 3**)/with a cochlear implant (**Group 4**)/with no specific characteristics (i.e., **Group 5**—'a woman'—control group), with whom Maria is not acquainted, enters the coffee shop and joins the group. Maria is introduced to this person, and shortly thereafter, everyone else leaves, with only Maria and the woman in the wheelchair remaining alone together at the table. Maria has 15 min to wait for her ride. Try to imagine the situation." For groups 2, 3, and 4 (bionic eye/bionic leg/cochlear implant), the participants read a short description of these devices to ensure that everybody knew exactly what they meant. Then, they read the 34 items describing the emotions (e.g., tension/stress/pity/disgust), thoughts (e.g., She seems to be an interesting guy/girl/She looks like an OK person), and behaviors (Move away/Find an excuse to leave) that Maria might have expressed. Each dimension had questions that participants answered on a scale ranging from 1 (not at all) to 5 (very much). Cronbach's alpha-s (regardless of the experimental group) was 0.90 for the Emotions dimension, 0.92 for the Cognition factor, and 0.82 for the Behavioral dimension. Higher scores suggested more negative attitudes toward disability.

TABLE 1 Sample characteristics (N = 474).

	N (%)
Gender (self-reported)	
Male	24 (5.1)
Female	450 (94.9)
Age distribution (Mdn = 20)	
>20	239 (50.4)
<20	235 (49.6)
Education	
High-school	229 (48.3)
Bachelor's degree	152 (32.1)
Master's degree	89 (18.8)
PhD	4 (0.8)

Agreeability

We used the 10-item Agreeability scale developed by Goldberg et al. (45) to measure agreeability. Example items included "I am interested in people" and "I take time out for others." Higher scores suggested higher agreeability. Cronbach's alpha was 0.80.

Extraversion

We used the 10-item Extraversion scale developed by Goldberg et al. (45). Example items included "I am the life of the party" and "I feel comfortable around people." Higher scores suggested higher extraversion. Cronbach's alpha was 0.78.

Neuroticism

We used the 10-item Neuroticism scale developed by Goldberg et al. (45). Example items included "I get upset easily" and "I become overwhelmed by events." Higher scores suggested higher neuroticism. Cronbach's alpha was 0.91.

Openness to experience

We used the 10-item Openness to experience scale developed by Goldberg et al. (45). Example items included "I carry the conversation to a higher level." and "I enjoy hearing new ideas." Higher scores suggested higher Openness to experience. Cronbach's alpha was 0.72.

Intellectual efficiency

Finally, we used the 10-item Comprehension/Intellectual Efficiency scale developed by Goldberg et al. (45). Example items included "I have a rich vocabulary" and "I know the answers to many questions." Higher scores suggested higher intellectual efficiency. Cronbach's alpha was 0.85.

A demographic scale assessed participants' age, gender, and education level.

Results

Preliminary analyses

We used the SPSS 26.0 program to analyze our data. We first computed the Skewness and Kurtosis values for the main variables to assess the normality of the distributions (46), and we further used parametric tests (see **Table 2** for the descriptive statistics of the variables). We also computed the means and standard deviations for the main variables.

Correlation analyses

Next, we examined the associations between the main variables, considering the experimental group participants were distributed in (see **Table 3**).

a. **Group 1** (i.e., the character in a wheelchair)

In Group 1, where participants were presented with the scenario involving a person in a wheelchair, we found significant associations between the overall attitudes toward disability and agreeability ($r = -.30$, $p = .005$), extraversion ($r = -.26$, $p = .01$), neuroticism ($r = .25$, $p = .01$), and the interaction with people with intellectual disabilities ($r = .24$, $p = .02$). Since higher scores on the MAS scale (i.e., attitudes toward disability) suggested more negative attitudes toward disability, our results suggested that the higher the agreeability, extraversion, and the lower the neuroticism, the more positive overall attitudes toward disability.

b. **Group 2** (i.e., the character with a bionic eye)

In Group 2, where participants were presented with the scenario involving a person with a bionic eye, we found a significant association between the overall attitudes toward disability and agreeability ($r = -.27$, $p = .01$). The other associations between the overall attitudes toward disability and the primary variables were non-significant. However, results also suggested that the cognitions dimension of the attitude toward disability was significantly associated with agreeability ($r = -.41$, $p < .001$), openness to experiences ($r = -.37$, $p = .001$), and intellectual efficiency ($r = -.36$, $p = .001$). Thus, our results suggested that the higher the agreeability, the more positive overall attitudes. Also, the higher the agreeability, Openness to experiences, and intellectual efficiency, the more positive cognitions related to disability.

c. **Group 3** (i.e., the character with a bionic leg)

In Group 3, where participants were presented with the scenario involving a person with a bionic leg, we found a significant association between the overall attitudes toward disability and agreeability ($r = -.25$, $p = .02$). The other associations between the overall attitudes toward disability and the primary variables were non-significant. However, results also suggested that the cognitions dimension of the attitude toward disability was significantly associated with agreeability ($r = -.35$, $p = .002$) and extraversion ($r = -.24$, $p = .03$). Thus, the higher the agreeability and extraversion, the more positive cognitions related to disability.

d. **Group 4** (i.e., the character with a cochlear implant)

In Group 4, where participants were presented with the scenario involving a person with a cochlear implant, we found a significant association between the overall attitudes toward disability and agreeability ($r = -.27$, $p = .01$). The other associations between the overall attitudes toward disability and the primary variables were non-significant. However, results also suggested that the cognitions dimension of the attitude toward disability was significantly associated with agreeability ($r = -.43$, $p < .001$) and Openness to experience ($r = -.33$, $p = .002$). Thus, the higher the agreeability and Openness to experience, the more positive cognitions related to disability.

e. **Group 5** (i.e., control group)

In Group 5, where participants were presented with a scenario involving a person with no specific characteristics, we found a significant association between the overall attitudes toward that specific character/situation and agreeability ($r = -.29$, $p < .001$), extraversion ($r = -.33$, $p < .001$), neuroticism ($r = -.40$, $p < .001$), openness to experiences ($r = -.38$, $p < .001$), and intellectual efficiency ($r = -.23$, $p = .004$). Similar patterns were observed for all the three dimensions explored (i.e., emotions, cognitions, behaviors) (see **Table 3**).

TABLE 2 Descriptive statistics for the main variables (overall sample, *N* = 474).

Variable	*M*	SD	Min	Max	Skewness	Kurtosis
Agreeability	43.66	5.18	22	50	−1.03	.91
Extraversion	32.02	6.85	12	48	−.02	−.32
Neuroticism	52.63	14.35	19	86	−.01	−.55
Openness to experience	39.86	5.34	25	50	−.48	−.33
Intellectual efficiency	38.95	6.22	20	50	−.31	−.28
Interaction (physical disability)	3.02	1.50	1	5	.07	−1.42
Interaction (intellectual disability)	3.06	1.57	1	5	−.02	−1.55
Attitude (MAS scale)	79.18	18.82	34	125	.16	−.59

TABLE 3 Zero-order correlations between the main variables (depending on the experimental group).

Variable	1	2	3	4	5	6	7	8	9	10
A Group 1 (wheelchair, $N = 84$)										
1. Agreeability	-			.						
2. Extraversion	.10	-								
3. Neuroticism	−.18	−.16	-							
4. Openness to experience	.32*	.40**	−.22*	-						
5. Intellectual efficiency	35*	.43**	−.28*	.54**	-					
6. Interaction (physical disability)	.06	.20	.08	.26*	.21*	-				
7. Interaction (intellectual disability)	−.03	−.07	.05	.08	−.05	.47**	-			
8. MAS—emotions	−.15	−.07	.25*	−.06	−.09	−.04	.15	-		
9. MAS—cognitions	−.27*	−.31*	.01	−.19	−.24*	−.13	.10	.25*	-	
10. MAS—behavior	−.32*	−.33*	.25*	−.20	−.18	.18	.32*	.38**	.27*	-
11. MAS—overall	−.30*	−.26*	.25*	−.17	−.20	−.01	.24*	.86**	.60**	.67**
B Group 2 (bionic eye, $N = 75$)										
1. Agreeability	-			.						
2. Extraversion	.18	-								
3. Neuroticism	.05	−.21	-							
4. Openness to experience	.50**	.18	−.05	-						
5. Intellectual efficiency	.31*	.18	−.25*	.46**	-					
6. Interaction (physical disability)	.07	.19	−.03	.14	.07	-				
7. Interaction (intellectual disability)	.23*	.31*	−.16	.08	.21	.56**	-			
8. MAS—emotions	−.12	.06	.14	−.09	−.14	−.04	−.14	-		
9. MAS—cognitions	−.41**	−.01	.12	−.37**	−.36**	.01	−.06	.22	-	
10. MAS—behavior	−.10	.07	.13	.01	.02	.08	.14	.34*	.20	-
11. MAS—overall	−.27*	.06	.18	−.19	−.22	.00	−.06	.84**	.59**	.64**
C Group 3 (bionic leg, $N = 78$)										
1. Agreeability	-									
2. Extraversion	.48**	-								
3. Neuroticism	−.20	−.39**	-							
4. Openness to experience	.50**	.20	−.18	-						
5. Intellectual efficiency	.54**	.49**	−.49**	.32*	-					
6. Interaction (physical disability)	.03	.18	−.27*	.08	.24*	-				
7. Interaction (intellectual disability)	.08	.16	.06	.17	.11	.36**	-			
8. MAS—emotions	−.07	−.05	.10	−.10	.14	.05	.14	-		
9. MAS—cognitions	.35*	−.24*	.05	−.19	−.20	−.06	−.21	.17	-	
10. MAS—behavior	−.20	.09	.04	−.15	.05	.13	.05	.41**	.28*	-
11. MAS—overall	−.25*	−.09	.10	−.19	.02	.05	.02	.82**	.59**	.72**
D Group 4 (cochlear implant, $N = 82$)										
1. Agreeability	-									
2. Extraversion	.26*	-								
3. Neuroticism	−.20	−.18	-							
4. Openness to experience	.36**	.22*	−.42**	-						
5. Intellectual efficiency	.39**	.21*	−.45**	.43**	-					
6. Interaction (physical disability)	.14	.29*	−.07	.23*	.30*	-				
7. Interaction (intellectual disability)	−.04	.17	.12	.11	.04	.45**	-			
8. MAS—emotions	−.06	−.05	.18	−.08	.09	−.02	−.00	-		
9. MAS—cognitions	−.43**	−.07	−.02	−.33**	−.19	−.19	−.15	.11	-	
10. MAS—behavior	−.13	.12	−.05	−.00	.03	−.23*	−.06	.24*	.10	-
11. MAS—overall	−.27*	−.01	.09	−.19	−.00	−.18	−.09	.82**	.53**	.58**
E Group 5 (control group, $N = 155$)										
1. Agreeability	-									
2. Extraversion	.41**	-								
3. Neuroticism	−.32**	−.37**	-							
4. Openness to experience	.37**	.41**	−.46**	-						
5. Intellectual efficiency	.34**	.41**	−.52**	.58**	-					
6. Interaction (physical disability)	.05	.13	−.14	.09	.14	-				
7. Interaction (intellectual disability)	.02	.07	−.11	.03	.19*	.55**	-			
8. MAS—emotions	−.08	−.25**	.29**	−.30**	−.10	.04	.04	-		

(*Continued*)

TABLE 3 Continued

Variable	1	2	3	4	5	6	7	8	9	10
9. MAS—cognitions	−.41**	−.26**	.32**	−.31**	−.30**	−.05	−.11	.09	-	
10. MAS—behavior	−.25*	−.20**	.25**	−.19	−.15	.00	.15	.44**	.21*	-
11. MAS—overall	−.29**	−.33**	.40**	−.38**	−.23**	.01	.03	.86**	.50**	.69**

*$p < .05$.
**$p < .001$.

Differences depending on the experimental group

Next, we explored the potential differences related to participants' overall attitudes toward disability depending on the experimental groups. We performed Anova One Way tests, and we used Bonferroni correction to control for the probability of committing a type I error. The results suggested significant differences, F (4; 469) = 2.47, $p = .04$. However, the only significant difference was found between the second (i.e., bionic eye) and the last group (control group), M dif = 7.94, $p = .02$. More specifically, participants from the control group (M = 76.40) reported significantly more positive attitudes than those from the bionic eye group (M = 84.34). When examining these means, we also observed that these were the groups with the most positive (Group 5) and most negative (Group 2) attitudes.

For a more comprehensive view of the emotions, cognitions, and behaviors related to disability, we repeated the Anova One Ways analyses for each of these three dimensions.

Emotions

Anova One Way test results suggested significant differences, F (4; 469) = 7.60, $p < .001$. We found a significant difference between the first (i.e., wheelchair) and the last group (control group), M dif = 6.03, $p = .004$. More specifically, participants from the control group (M = 35.60) reported significantly more positive emotions than those from the first group (M = 41.64). Also, we found significant differences between the bionic eye group (Group 2, M = 43.40) and the control group, M dif = 7.79, $p < .001$. More specifically, participants from the control group reported significantly more positive emotions than those from the bionic eye group. Similar patterns were observed between the bionic leg group (Group 3, M = 42.65) and the control group, M dif = 7.04, $p = .001$), and the participants from the fourth group (cochlear implant, M = 40.89) and the control group. In all cases, the more positive emotions were reported in the case of participants from the control group. Finally, when examining these means, we observed that the bionic eye group, Group 2, reported the most negative emotions (M = 43.40), and the control group was the most positive.

Cognitions

Anova One Way test results suggested no significant differences between the groups, F (4; 469) = 2.26, $p = .06$. However, when examining the means of the groups, we observed the group with the most positive cognitions was the cochlear implant group (M = 18.15), and the most negative was the control group (M = 20.80).

Behaviors

Anova One Way test results suggested significant differences, F (4; 469) = 3.96, $p = .004$. We found a significant difference between the first (i.e., wheelchair) and second groups (i.e., bionic eye group), M dif = −3.85, $p = .001$. More specifically, participants from the control group (M = 20.00) reported significantly more positive behaviors than those from the first group (M = 21.85). When examining the means of each group, we observed that the bionic eye group reported the most negative behaviors and the first group (i.e., wheelchair) the most positive behaviors (M = 18.00).

Discussion

Our study investigated the attitudes toward people with bionic eyes and limbs, cochlear implants, and people with disabilities that imply using a wheelchair. Overall, our results suggested that higher agreeability, extraversion, openness to experience, intellectual complexity, and lower neuroticism were generally associated with more positive attitudes toward disability. However, when examining the differences in participants' emotions, cognitions, and behaviors depending on the target's characteristics, our results generally suggested that the most negative reactions were toward the character with a bionic eye. Thus, our primary assumptions were confirmed, highlighting the critical role of personality traits when discussing attitudes toward disability.

One of the interesting results of our study is related to the fact that intellectual complexity was associated with more positive attitudes toward disability. Previous studies also suggested that high intelligence test scores predicted lower prejudicial attitudes, though these studies did not specifically refer to disability [e.g., (40, 42)]. Thus, our study adds to the current literature exploring the link between intelligence and people's attitudes toward disability. Also, other scholars suggested that self-perceived intelligence was positively related to prejudice (41). In the present study, we did not measure participants' intelligence, as (40), but we asked participants to self-report their comprehension/intellectual complexity level. The different results that we obtained compared to those of De Keersmaecker et al. (41) might be related to the various psychological mechanisms that might also determine the attitudes toward disability, including cultural influences (47), peer norms (48), parental and social influences (49), moral values (50), or other related variables. Also, our measurements were different; we did not use the same scales, though the concepts share many similarities (51). Nevertheless, these findings highlight the need for further research in this area.

Another important finding in our study relates to the significant differences in participants' attitudes depending on the target's characteristics. We assumed that the *bionic* targets would be the ones toward which our participants would have the least positive attitudes, and our assumption was confirmed. This specific result aligns with previous findings in the area [e.g., (18)], highlighting the need for further programs to inform and explain bionic prosthethis and how they work, given that information is essential for shaping positive attitudes toward various disability and, implicitly, toward bionic devices and assistive technology, in general (52).

It is also important to acknowledge that, among the five experimental conditions, i.e., wheelchair/bionic eye/bionic leg/cochlear implant/control groups, the most negative attitudes were expressed toward the bionic eye character. That also raises the need for further, more complex, and in-depth research concerning the different perceptions and attitudes toward people with bionic prosthetics, depending on the type of bionic device used. Our results suggested that bionic eyes seem to be perceived more negatively than bionic legs, and this might be explained by the importance of perceived eye contact and facial expression (53). Nevertheless, future studies are needed to clarify the underlying psychological mechanisms better. Finally, though personality traits are rather unchangeable constructs, factual knowledge might be prone to intervention. We already know from previous studies the benefits of positive contact and information regarding disability (54), and future interventions might build on the current findings to build effective awareness and intervention strategies aimed to foster more positive attitudes.

A series of limitations need to be accounted for when interpreting our results. First, though we used an experimental approach, which adds value to our study, we used a relatively small sample of participants in each group. Future studies might benefit from using more extensive samples, and more heterogeneous in terms of age, education, and even disability status: it would be interesting to compare and assess the possible differences between these experimental groups by also diving them depending on disability status (i.e., with or without disabilities). Also, future studies might benefit from extending the target group to a larger number of people from different fields of activity. Next, though we provided short descriptions for each condition (e.g., for the bionic eye/bionic leg/cochlear implant), future studies using images instead of text might come to different conclusions.

Also another limitation is related to the self-reported measures of personality traits and intellectual complexity, which might have increased the desirability of the answers that participants gave. Also, we only used vignettes describing a female agent, and this type of vignette was used regardless of participants' gender. Though our sample was formed by 94.9% female participants, we must acknowledge this limitation, as well. Future studies might benefit from using gender-similar characters, to avoid any gender-based bias. Finally, future studies might benefit from exploring other variables that might account for significant variability when discussing the attitudes toward disability, and related bionic devices, such as cultural representations (55), media exposure and representations (56), social cognition (57), as well as specific knowledge of biotechnology, beliefs and support for more traditional values, and right-Wing authoritarianism (58).

The theoretical implications relate to the study of personality traits and self-reported intellectual complexity, the use of a multifaced scale for measuring the attitudes toward disability, and the experimental approach that allowed us to compare different targeted groups, including characters using assistive technology devices, i.e., bionic prosthetics. The practical insight brought by the present study is mostly related to the disability awareness programs that might be shaped to promote inclusive attitudes and positive views upon assistive technology, accounting for personality traits—in addition to other variables, as previous research suggested [e.g., (59)]. To conclude, we believe that, despite their limitations, the findings of our study are important considering their value for shaping positive attitudes related to disability, especially related to the future technological advances in bionic devices.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Faculty of Psychology and Education Sciences. The patients/participants provided their written informed consent to participate in this study.

Author contributions

All authors equally contributed to the goal of the present paper. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Factors influencing initial implementation of an online community-based exercise intervention with adults living with HIV: a systems approach

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Introduction: Online community-based exercise (CBE) is a digital health intervention and rehabilitation strategy that promotes health among people living with HIV. Our aim was to describe the factors influencing initial implementation of a pilot online CBE intervention with adults living with HIV using a systems approach, as recommended by implementation science specialists.

Methods: We piloted the implementation of a 6-month online CBE intervention and 6-month independent exercise follow up, in partnership with the YMCA in Toronto, Canada. We recruited adults living with HIV who identified themselves as safe to engage in exercise. The intervention phase included personalized exercise sessions online with a personal trainer; exercise equipment; access to online exercise classes; and a wireless physical activity monitor. Two researchers documented implementation factors articulated by participants and the implementation team during early implementation, defined as recruitment, screening, equipment distribution, technology orientation, and baseline assessments. Data sources included communication with participants; daily team communication; weekly team discussions; and in-person meetings. We documented implementation factors in meeting minutes, recruitment screening notes, and email communication; and analyzed the data using a qualitative descriptive approach using a systems engineering method called Cognitive Work Analysis.

Results: Thirty-three adults living with HIV enrolled in the study (n = 33; median age: 52 years; cis-men: 22, cis-women: 10, non-binary: 1). Fifty-five factors influencing implementation, spanned five layers: (i) *Natural*, including weather and the COVID-19 virus; (ii) *Societal*, including COVID-19 impacts (e.g. public transit health risks impacting equipment pick-ups); (iii) *Organizational*, including information dissemination (e.g. tech support) and logistics (e.g. scheduling); (iv) Personal, including physical setting (e.g. space) and digital setting (e.g. device access); and (v) *Human*, including health (e.g. episodic illness) and disposition (e.g. motivation). The implementation team experienced heightened needs to respond rapidly; sustain engagement; and provide training and support. Additional organizational factors included a committed fitness training and research team with skills spanning administration and logistics, participant engagement, technology training, physical therapy, and research ethics.

Conclusion: Fifty-five factors spanning multiple layers illustrate the complexities of online CBE with adults living with HIV. Initial implementation required a dedicated, rehabilitation-centred, multi-skilled, multi-stakeholder team to address a diverse set of factors.

KEYWORDS

cognitive work analysis, systems engineering, implementation science, hiv/aids, physical activity, exercise. factors influencing initial implementation

Introduction

Physical activity and exercise are rehabilitation strategies that benefit medically stable individuals with HIV (1). One model involves Community-based Exercise (CBE). CBE features exercise interventions designed by accredited professionals to boost regular physical activity for those in the community (2–4). CBE is traditionally delivered in-person.

Interest in telerehabilitation (5) and other digital health technologies is increasing. Stakeholders in the HIV community, for instance, have expressed interest in CBE that is online (6), while rehabilitation researchers have continued to explore new devices, such as physical activity monitors that are “smart” (7). These technological explorations are occurring against a backdrop of already existing challenges regarding uptake of physical activity. Even in the absence of new technologies, physical activity amongst people with HIV is variable, influenced by “a range of complex factors” (8). In the presence of new technologies, such as online CBE and wireless physical activity monitors, the implications for implementation are even less clear.

A key implementation question that behaviour change researchers face as they study new and modified digital health interventions is, “What works for whom in what settings to change what behaviors, and how?” (9). Digital health interventions include online rehabilitation services that use information and communication technologies such as wearable devices, interactive websites, and videoconferencing software (9). In 2017, implementation science specialists presented recommendations to develop and evaluate digital health interventions, which included recognizing the complexity of digital health behaviour change; adopting a “transdisciplinary” outlook; and considering approaches from “systems engineering” and “systems science” (9).

A system is defined variously as a “group or set of related or associated things…thought of as a unity”, which may include “persons working together as parts of an interconnecting network”; “artificial objects organized for a particular purpose”; and “natural objects…forming a connected or complex whole” (10). However, despite the 2017 recommendations (9), health researchers maintain that system complexity remains “much talked about but sub-optimally studied” (11). One problem involves ill-defined accounts of what an *intervention* is (12) and what its *context* is (13), while a related problem involves characterizing the connections between the two (13). Consequently, there is a continued push for more holistic approaches to health research, specifically ones that adopt complex systems thinking (2), described by the United Kingdom’s Medical Research Council as, “focusing on the interactions between entities that comprise a system and between those entities and their environment, rather than assuming that a system can be understood by breaking it down into its individual entities and studying each part separately” (14).

Systems that are sociotechnical involve a mix of people, artifacts, and technologies (15). Digital health behaviour change interventions, such as those that use fitness trackers or apps, are sociotechnical in nature. For example, consider an intervention with adults living with HIV using exercise equipment and wireless physical activity monitors (WPAMs). This intervention functions within a constellation of contextual factors embedded within various environments or layers. These factors may include seasonal light levels (in a natural environment), external stigma (in a gym/social environment), device-app functionality (in a technological environment), and access to training shoes (in a personal environment). By understanding the various contextual factors that populate each environment or layer, researchers can better answer the key implementation question, “what works” (9).

Cognitive Work Analysis (CWA) is an engineering approach intended to study complex sociotechnical systems (15, 16). This approach offers researchers a conceptual modeling framework and analytical tools that zero in on the environmental factors that shape human behaviour. In CWA, complex sociotechnical systems include those with potentially numerous, “dynamic”, “diverse”, interconnected, and geographically dispersed components, with data that may be “uncertain”, and effects that may be “unanticipated” (15). In fact, CWA specifies 11 “characteristics” associated with sociotechnical complexity (see Methods). It also describes systems in terms of factors that can occur in different environments or, in CWA terminology, “layers” (see Methods). These layers are interwoven such that “All of the layers come together to shape the performance of the system as a whole” (15). Continuing with the WPAM example, the natural, social, technological, and personal layers must consequently come together for an adult living with HIV to produce a certain result. A holistic perspective that accounts for all of the layers is therefore crucial.

A CWA approach has been adopted for various healthcare applications (17), including health behaviour change studies that range from medication management to self-care management (e.g., 18–21). However, to our knowledge this approach has yet to be applied in the context of HIV.

In this article, we adopt a CWA perspective regarding an online community-based exercise (CBE) intervention among adults living with HIV. Collectively, this intervention and its context are regarded as the online CBE *system*. The purpose of this system is to improve or maintain health for adults living with HIV through exercise and physical activity.

Overall aims of this article involve describing and depicting an online CBE system; and identifying system factors influencing initial implementation. Specific objectives are as follows:

1. To describe and illustrate an online CBE system involving adults living with HIV in terms of (a) 11 characteristics of sociotechnical complexity and (b) 5 layers of sociotechnical complexity, in accordance with a CWA perspective; and
2. To identify factors that influence the initial implementation of an online CBE intervention with adults living with HIV, organized along the five CWA layers.

Initial implementation is important to study because obstacles in this phase can hamper full participation for some individuals, and thereby limit access. A systems approach may help researchers and clinicians better understand the context in which an intervention is situated and the conditions needed to support access.

Methods

We used a CWA perspective (15, 16) to describe the factors influencing the early implementation of an online exercise intervention with adults living with HIV. The aim of the overarching Tele-coaching Exercise (TEx) Study is to pilot the implementation of an online community-based exercise intervention (22). In this systems-based sub-study, we specifically focused on the initial implementation phase of the intervention.

Activities associated with initial implementation included: (i) Participant recruitment, screening for eligibility, and consent to participate (Jul-Oct 2021); (ii) Exercise equipment distribution to participants (Oct-Nov 2021); and (iii) TEx Study orientation, and baseline fitness and questionnaire assessment (Oct-Dec 2021).

The TEx Study was approved by the University of Toronto Research Ethics Board (Protocol #40410). Evaluation of the TEx Study will be published elsewhere.

Online community-based exercise intervention

The Tele-coaching Exercise (TEx) Study consists of a 6-month intervention phase and a 6-month follow-up phase, with adults living with HIV (**Figure 1**). The intervention phase included 13 bi-weekly personalized exercise sessions online with a personal trainer at the Toronto YMCA; 6 online group self-management educational sessions delivered monthly; home exercise and assessment equipment (resistance bands, a plyo box, and a smart scale); access to the YMCA online group exercise classes; and a wireless physical activity monitor (WPAM) to track physical activity (synced weekly), specifically the Fitbit® Inspire 2.

Personalized exercise sessions led by YMCA trainers involved aerobic, resistance, balance, and flexibility training (~60 min, biweekly for 24 weeks). Type and intensity of exercise varied, depending on participants' abilities, goals and preferences. Dosage varied with participants' level of health, given the potentially fluctuating nature of their condition (23). Fitness and questionnaire assessments were administered online, at baseline and bi-monthly thereafter. The intervention included goal setting, exercise instruction, monitoring exercise progression, and feedback. Technology orientation involved an instructional handbook, electronic learning modules (e-modules), and one-on-one online tech support. Details regarding the data collection, assessments, and analysis for the TEx Study are available in the study protocol (22). See **Figure 1** for an overview of the timeline of initial implementation.

Participants and recruitment

We recruited adults 18 years or older, living with HIV in Toronto, who considered themselves safe to participate in exercise as determined by the Physical Activity Readiness Questionnaire (PAR-Q) (24). To participate, individuals were required to have access to a device(s) (e.g., tablet, laptop or desktop computer, smartphone); access to Wi-Fi or a data internet plan; access to a webcam and willingness to activate it for group exercise classes, fitness sessions, assessments and educational sessions; access to a space in the home to exercise; and finally, willingness to participate in one year of the online exercise intervention, exercising thrice weekly in activities of their choice (~60 min each time). We recruited participants via community-based organizations, via the Ontario HIV Treatment Network Cohort Study (25) at the Maple Leaf Medical Clinic, and via word of mouth.

Implementation team

The implementation team comprised fitness personnel and staff from the Central Toronto YMCA (responsible for personal training sessions, YMCA online platforms, and bi-monthly fitness assessments); and the University of Toronto research team (responsible for recruitment, screening, baseline questionnaire assessments, group self-management educational sessions, TEx Study orientation, equipment distribution at the YMCA, administration, budgeting, and research project management). The full team consisted of the following personnel:

- Central Toronto YMCA Core Fitness Personnel Team (5): 4 personal trainers, two of which performed bi-monthly online fitness assessments; and 1 Acting General Manager.
- University of Toronto Core Research Team (5): 2 TEx Study Co-Investigators, of which one functioned as an instructional designer, 1 Research Coordinator; 1 Post-doctoral Researcher; and 1 Engagement/Technology Coordinator.

Since initial implementation depended on the activities and interactions of these 10 team members, they were also considered participants of this sub-study, together with the TEx Study participants. In adopting a systems approach, we

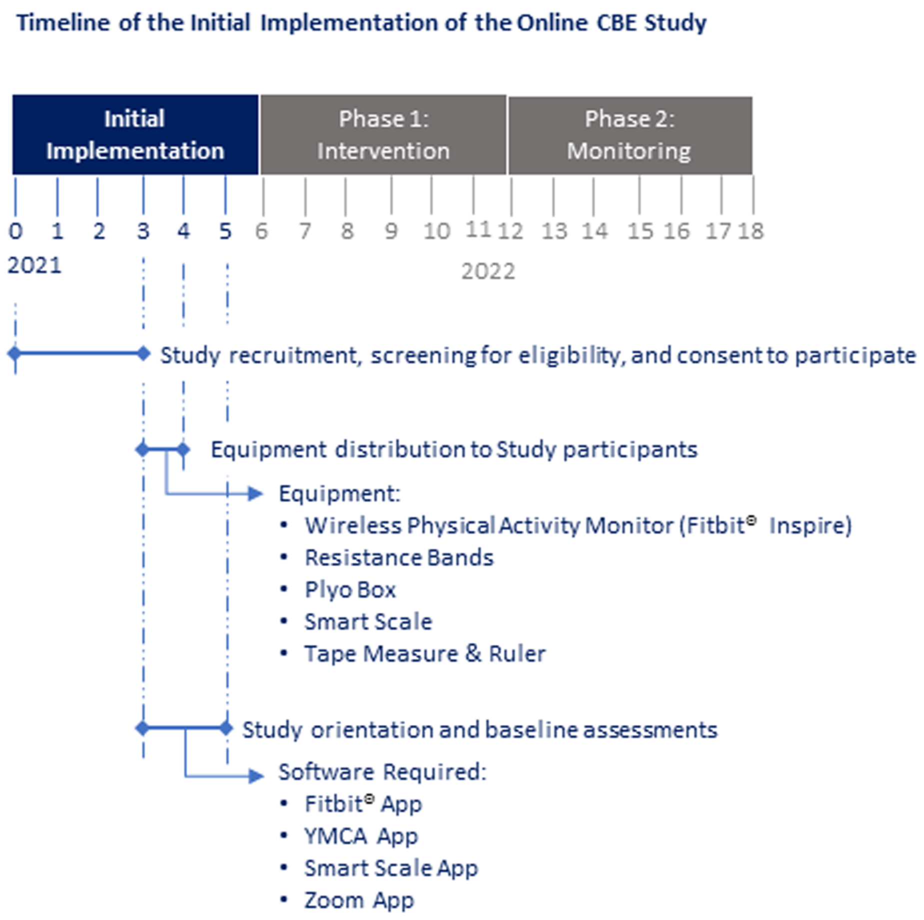

FIGURE 1
Overview of initial implementation of the online CBE intervention (details regarding phase 1 and phase 2 of the study are omitted for clarity).

recognized that implementation team members comprised part of the overall system (16).

Initial implementation data sources

We examined the following data sources for this sub-study: research protocol; and documentation (notes) from (i) screening meetings for TEx Study eligibility with potential participants, (ii) research team meetings (held weekly over Zoom), (iii) meetings with the YMCA team and IT representative (held twice over Zoom), (iv) orientation sessions with the YMCA trainers (held twice over Zoom), (v) communication between participants, the research team and YMCA team (via email, Zoom and phone), and (vi) one time in-person meetings between the research team, YMCA staff and each participant during exercise equipment distribution at the Toronto YMCA.

Cognitive work analysis approach

CWA comprises a perspective and tools to study mixed sociotechnical systems that are complex. This ecological perspective considers complexity in terms of various characteristics and layers (15).

Note that before applying formal CWA tools, a “knowledge elicitation” stage is required (15). This stage involves data collection using methods such as observation, interview, and document review. In this article, we describe knowledge elicitation using document reviews of the data sources (as listed above) pertaining to early implementation of the exercise intervention.

Eleven characteristics of sociotechnical complexity (objective 1a)

We applied the 11 characteristics of complex sociotechnical systems presented below (7) to the sub-study data sources to better understand the system in which the exercise intervention was embedded. The analysis was a subjective and pragmatic description of the system to identify components and their relations; and understand sources of complexity relevant to early implementation. The description was later reviewed by the research team. Note that the order of characteristics is not significant, and not all characteristics needed to be present for a system to be considered sociotechnically complex.

The 11 sociotechnical system characteristics are as follows: Large Problem Spaces (involving various “elements and forces"); Social (involving many individuals working in cooperation); Heterogeneous Perspectives (involving individuals with "potentially conflicting values"); Distributed (involving geographically distributed or dispersed individuals); Dynamic (involving changeable situations with potentially "long time constants" and delayed effects); Potentially High Hazards (involving negative effects on health, safety, finances or ecosystems); Many Coupled Subsystems (involving subsystems that are interconnected); Automated (involving automatic or algorithmic operations); Uncertain Data (involving "indicators" that may drift or fail); Mediated Interactions [involving "properties (that) cannot be directly observed by human perceptual systems", such as intentions]; and Subject to Disturbances' (involving "unanticipated events") (15).

System schematic (objective 1b)

To complete this objective, a core team researcher and systems specialist (TJ), who also met with individuals to screen for eligibility to participate in the TEx Study, undertook an in-depth review of the sub-study documents (see Data Sources above), and drafted a system schematic for review by the research team. To generate the schematic, we used the review of the 11 characteristics listed above (Objective 1a) to help identify the system components; and the 5 layers of sociotechnical complexity (see **Figure 2**) to organize the components within the schematic.

The system schematic illustrates the primary components of the system (coloured in black) and helps set the scope for an ensuing analysis. Note that some components relevant to the system were consciously depicted outside the system boundary (coloured in grey) indicating they fell outside scope of the analysis. These secondary components included those most active outside the initial implementation period (e.g., funders) or components with which there was little to no interaction involving implementation team members (e.g., healthcare clinics, participant workplaces). Also depicted were entities that flow between primary components, such as goods, money, information, and personal data. These entities show some of the relations between primary components. The schematic was iteratively refined after the initial draft was reviewed by the full research team.

Regarding the layers, labelling them is system-specific, based on consensus, and intended to be flexible and pragmatic. To establish the system schematic for the CBE intervention, we defined layers as *human*, *person* (i.e., proximate social, physical, and digital settings), *organization(s)* including policies and procedures related to an intervention, *society* including customs and laws, and finally, *nature* (**Figure 2**). These layers are adapted from the CWA theory (15).

Initial implementation factors (objective 2)

The lead author identified the initial implementation factors (TJ) based on the data sources listed above. Once the factors were compiled, they were reviewed by the core research team, refined, and presented to the broader research team for feedback and verification. We used the five CWA layers to classify the implementation factors.

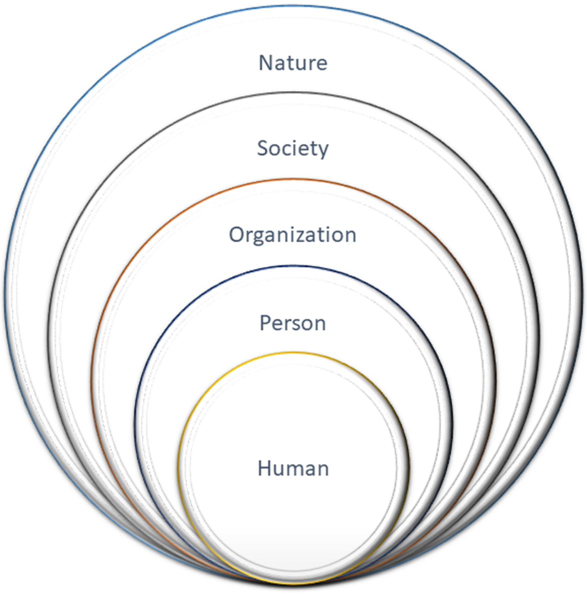

FIGURE 2
Five layers of sociotechnical complexity associated with an online community-based exercise system, adapted from vicente (15). Boundaries between layers are porous.

Results

Forty-three individuals participated in the initial implementation period, of which 33 were adults living with HIV enrolled in the TEx Study (**Table 1**) and ten were members of the implementation team.

Sixty-nine additional individuals communicated with the lead author (TJ) during recruitment and declined to participate. Of those 69 individuals, 18 expressed various concerns about the intervention and reasons for declining, which included the following: Lack of time/time commitment too high ($n = 3$); Lack of space ($n = 2$); Lack of motivation to exercise online ($n = 2$); Lack of privacy at home (re. disclosure) ($n = 1$); Not ready to commit to a one-year intervention ($n = 1$); Discomfort exercising in front of people (both in-person and online) ($n = 1$); Advised against participating by clinician ($n = 1$); Health reasons ($n = 1$); Technology issue (server problem) ($n = 1$); Lack of access to hardware (no webcam) ($n = 1$); Concerned about technological accessibility ($n = 1$); Has own personal trainer ($n = 1$); Belongs to a gym ($n = 1$); and Accepted employment out of town ($n = 1$).

Sociotechnical characteristics of a complex online CBE system (objective 1a)

The description below refers to initial implementation of the online CBE intervention as it pertains to the 11 characteristics of a complex sociotechnical system.

TABLE 1 Participant characteristics at study baseline in the online CBE intervention study ($n = 33$ participants).

Characteristic at study initiation	N (%)
Age, median	52 years
(Age range)	(33–71)
Gender	
Cis-Woman	10 (30%)
Cis-Man	22 (67%)
Non-binary	1 (3%)
Current marital or partnership status	
Single	12 (36%)
Married, common-law, partner or relationship	15 (46%)
Separated or Divorced	2 (6%)
Widowed	2 (6%)
Prefer not to answer	2 (6%)
Have children	9 (27%)
Live alone ($n = 32$)	13 (45%)
Average personal gross yearly income (CAD)	
Less than $30,000 CAD	15 (46%)
$30,000 to less than $60,000 CAD	10 (30%)
$60,000 to less than $100,000 CAD	6 (18%)
Greater than $100,000 CAD	2 (6%)
Main source of income	
Employment (full, part-time, or self)	12 (36%)
Income Support (e.g. Disability, Welfare, Worker's Compensation, Employment Insurance or Long Term Disability)	14 (42%)
Pension, Student Loans, or Savings	7 (21%)
Under the table work or Street-related work (e.g. pan-handling)	0 (0%)
Current employment status	
Employed (full time or part time)	15 (45%)
Student, Retired, or Volunteering	10 (30%)
Unemployed or on disability	8 (24%)
Highest level of education ($n = 31$)	
No formal education; secondary school completed	6 (19%)
Completed trade or technical training, or completed college	12 (39%)
Completed university or postgraduate education	13 (42%)
Race	
White	15 (46%)
Latin American, Hispanic or Latino (e.g. Mexican, Central/South American)	8 (24%)
Black or African American	8 (24%)
Asian (origins in far east, south east Asia, or Indian subcontinent including e.g. Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, Philippine Islands, Thailand, Vietnam)	8 (24%)
First Nation (Indigenous), Inuit, Métis	3 (9%)
Prefer not to answer	1 (3%)
Year of HIV diagnosis	
Median (25–75th percentile)	2002 (1992–2012)
Undetectable viral load (<50 copies/ml)	30 (91%)
Concurrent health conditions *(conditions $\geq$30% of sample)*	
Cognitive decline (e.g. memory loss, confusion, trouble thinking clearly or solving day-to-day problems)	10 (30%)
Mental health condition	13 (39%)
Gastrointestinal conditions	16 (48%)
Trouble Sleeping	11 (33%)
Number of concurrent health conditions in addition to HIV	
2 or more	24 (73%)

(*Continued*)

TABLE 1 Continued

Characteristic at study initiation	N (%)
Self-reported general health status	
Excellent	3 (9%)
Very good	12 (36%)
Good	10 (30%)
Fair	7 (21%)
Poor	1 (3%)
Health compared to previous year	
Much better	6 (18%)
Somewhat better	3 (9%)
About the same	15 (46%)
Somewhat worse	8 (24%)
Much worse	1 (3%)
Current state of exercise activity	
I currently do not exercise, do not intend to start	0
I currently do not exercise, but thinking of starting	8 (24%)
I currently exercise but not regularly	11 (33%)
I currently exercise regularly but only began in last 6 months	2 (6%)
I currently exercise regularly and have done so for >6 months	6 (18%)
I have exercised regularly in past but am not doing so currently	6 (18%)

Large problem space

The "many different elements and forces" as well as variables at play ranged from health situations to resource demands, technological challenges, and societal pressures (15). During screening interviews for eligibility and enrollment in the TEx Study, potential participants revealed a variety of health situations ranging from the impacts of HIV (e.g., fatigue, lipodystrophy) to the presence of comorbidities such as cardiovascular disease and depression and the impact of other health events, including a previous car accident and upcoming surgery. Potential participants raised other issues including access to technology (i.e., acquiring, using, and managing devices and peripheral hardware such as webcams), scheduling pressures (involving work and/or caregiving responsibilities), cost concerns (around internet data plans, future gyms memberships, and exercise equipment), pandemic restrictions (regarding gym closures), COVID-19 threats (considered "scary"), and finally, local weather conditions (specifically, wintry conditions).

Social

Of the 43 individuals involved in the initial implementation, 33 were participants who began the TEx Study at baseline. Ten individuals administered the intervention, working from two institutions (Central Toronto YMCA and University of Toronto). During initial implementation, we also planned self-management educational sessions, involving five subject matter experts who were invited to present various topics to participants online. Other stakeholders who met during initial implementation included the full research team, comprising 22 individuals operating from clinics, community-based organizations, and universities across the province and internationally (UK). Funding for the TEx Study (to implement the exercise intervention) came from a provincial organization.

Heterogeneous perspectives

Given the social nature of this intervention (see above), a variety of values, priorities and interests were conceivable. From potential participants, items raised during screening for eligibility to the TEx Study included privacy, motivation, and habit formation. From the implementation team, other concerns included intervention reach, budgeting, staff training, and TEx Study fidelity. Furthermore, the age range of participants was broad (between 33 and 71, see **Table 1**), contributing to the cohort's diversity of experience. Exercise histories prior to enrollment varied from little to no recent exercise to regular exercise (e.g., running, swimming). Consequently, participants expressed a range of exercise-related interests during the screening interviews (e.g., lose weight, improve strength, increase flexibility).

Distributed

As an online exercise study, the intervention involved participants who were geographically distributed across the Greater Toronto Area. Since initial implementation took place under public health restrictions during the COVID-19 pandemic, the intervention team all worked from their homes. Intervention delivery was administered via two separate institutions (the Central Toronto YMCA and the University of Toronto).

Dynamic

Health-related consequences of HIV are referred to as *episodic disability* and include physical, cognitive, and emotional symptoms as well as difficulties participating in social situations and performing daily activities of living (23). Consequently, we expected the health of some participants might fluctuate during the period between enrollment and baseline testing. One participant had surgery during this period. Other dynamic situations involved frequent technology software updates (re. WPAMs, Zoom, and personal devices) as well as shifts in participant work schedules, in pandemic restrictions, in COVID-19 viral mutations, and in seasonal conditions.

Potentially high hazards

With physical activity comes the risk of injury (mitigated by safeguards in keeping with YMCA policy). However, risks were not only physical. Mental health and other concurrent health conditions such as depression were raised by potential participants during screening for eligibility, and during subsequent baseline assessments.

Many coupled subsystems

Technically linked subsystems included device/internet interoperability (including synched WPAM accounts with YMCA accounts, and compatible hardware/software combinations to enable Zoom meetings). To enable communication amongst the implementation team, file sharing and encrypted servers were required. Other interacting subsystems involved procuring and assembling exercise equipment (requiring YMCA power tools); and managing and scheduling equipment distribution (involving either travel/transit for in-person pick-ups or home delivery work-arounds for those participants not travelling during the pandemic).

Automated

Several technology systems associated with the intervention functioned automatically (e.g., internet connectivity, app software updates, university server back-ups, and password management software).

Uncertain data

This characteristic was not a significant source of complexity during initial implementation. (Note: Data such as WPAM reports of "active zone minutes", which count the duration of elevated heart rate activities, may be associated with uncertain data, but fell outside the initial phase of this sub-study.)

Mediated interaction

With the entire intervention administered online, every activity was mediated via computers, tablets, or smartphones, including communications over email and Zoom, WPAM orientation, baseline testing, data collection, project planning and administration, etc. Aspects of the intervention, such as the intentions and schedules of individuals, were not directly observable.

Subject to Disturbances

Disturbances came from a variety of sources between enrollment and intervention initiation, including episodic health disturbances (as outlined above), unexpected software updates, hardware problems, internet connectivity issues, videoconferencing glitches, and shifting pandemic-related risks and restrictions. There was a potential that widespread supply chain disruptions might delay equipment deliveries (of wood plyo boxes), and while there was a delay, it was not due to a supply chain problem (the driver could not find the drop-off location, requiring a re-order).

Schematic of a complex online CBE system (objective 1b)

The schematic (**Figure 3**) depicts components of the system according to the five layers of sociotechnical complexity introduced previously. Primary components (in black) are internal to the system under study and include participants and their physical, social, and digital settings, and staff at the two managing institutions (YMCA and University of Toronto). Secondary components (in grey) are external to the system and fall outside the scope of analysis. They include stakeholders such as the full research team, community-based organizations, healthcare clinics, and funders as well as technology suppliers (e.g WPAM outlets). Entities that flow between primary components are illustrated by coloured lines (i.e., money, personal data, TEx Study information, and exercise equipment). Entities flowing between primary and secondary components were omitted for clarity.

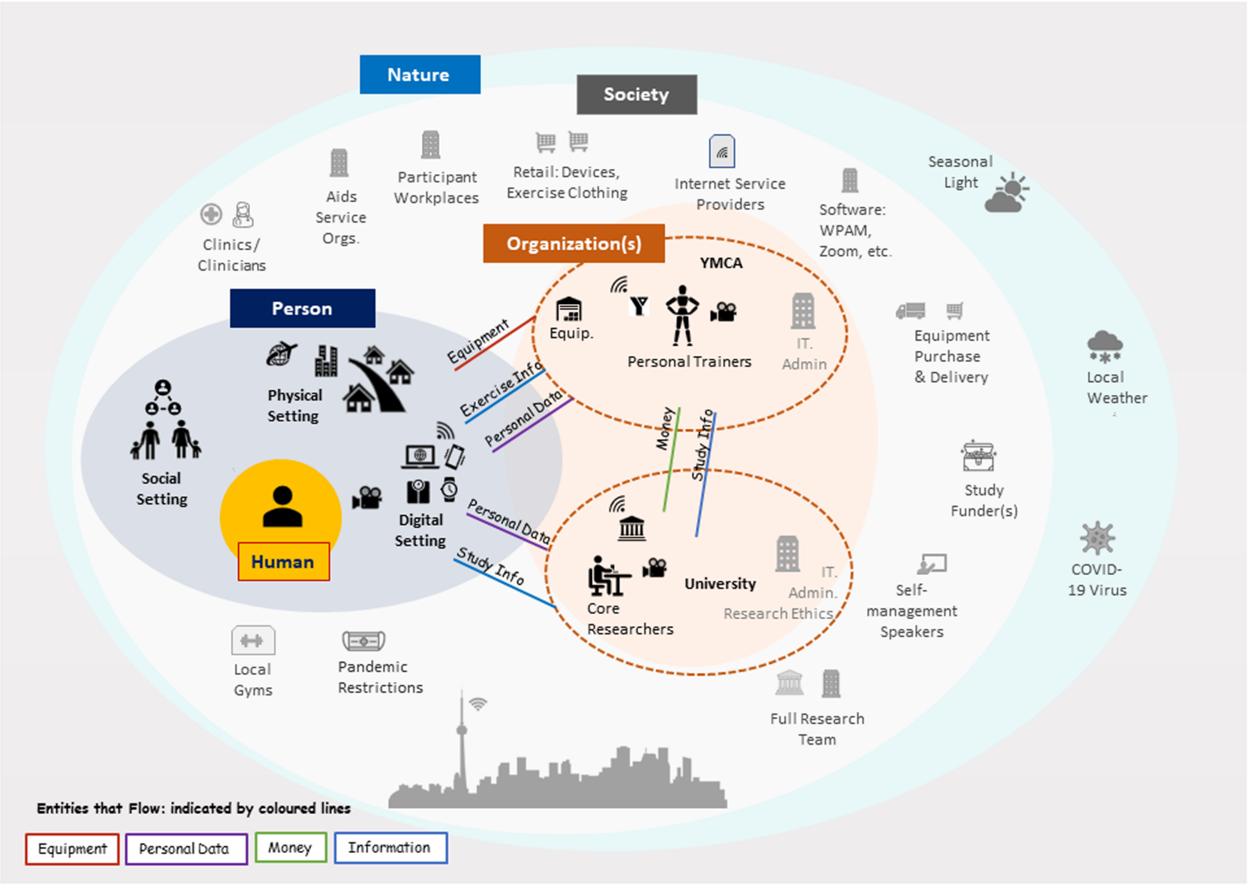

FIGURE 3
Schematic for the online exercise system. Components in black are primary to the system. (Toronto skyline by Bob Comix is licensed under CC BY 4.0).

Regarding the characteristics of sociotechnical complexity (Objective 1a), they were illustrated in this schematic where possible. For example, many components are depicted, not only of the intervention, but also of the broader system at play (i.e., *large problem space*). For simplicity, the highly *social* nature of this intervention (43 individuals) is implied, though what is clear is the *distributed* nature of the intervention, with participants and team members at home (in their personal environments), two primary organizations (YMCA, University of Toronto) located in the city centre, other secondary organizations (e.g., health clinics) located throughout the city, and technology providers (e.g., WPAM manufacturer) in unknown locations. Interconnections between components span layers and were omitted for clarity. These include *automated* technical connections between devices (e.g., between a wearable WPAM and a phone app), social connections (e.g., between participants and team members), and societal connections (e.g., between public health restrictions and local gym closures).

Initial implementation factors (objective 2)

We identified 55 factors influencing initial implementation (**Figure 4**), spanning five CWA layers, Natural, Societal, Organizational, Personal, and Human. The *Organizational* layer pertained to members of the implementation team only. All other layers pertain to both team members and potential participants. We describe the layers below.

Natural layer

Five factors arose in the natural layer during initial implementation. The presence of COVID-19 influenced virtually every facet of society, including personal layer fears of contracting COVID-19. Other factors raised by participants concerned worries of diminished activity levels in winter weather and seasonal affective disorder in low light conditions.

Societal layer

Three societal factors arose related to pandemic restrictions. Vaccine mandates at the YMCA and concerns over possible infection on public transit impacted the equipment distribution. Consequently, some participants requested home deliveries. To accommodate these requests, we applied for approval from the Research Ethics Board to obtain participant home addresses; and, to maintain privacy, one member of the team delivered the equipment throughout the city by car, rather than sharing addresses with a courier service. In addition, participants reported stress, and isolation due to the

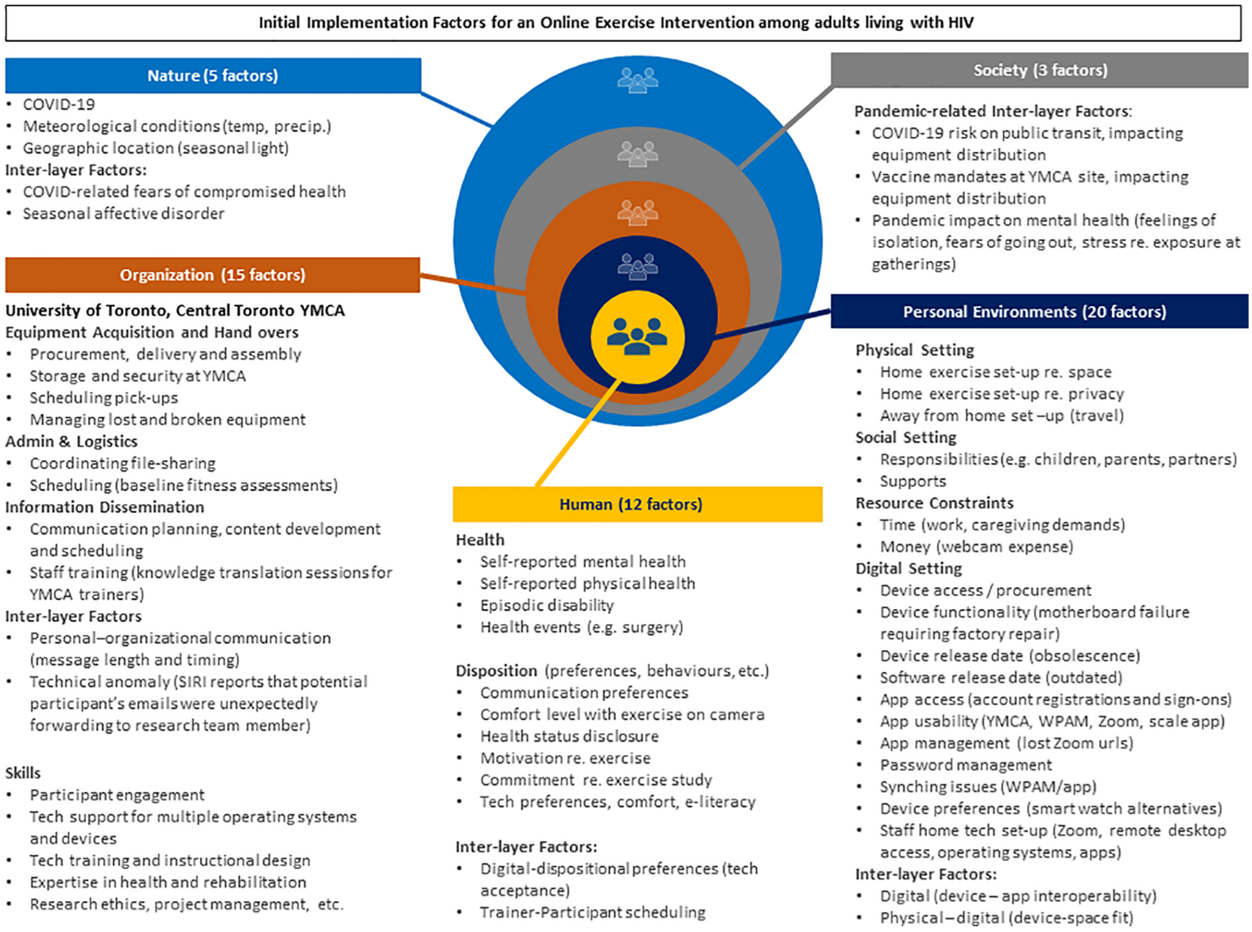

FIGURE 4
Fifty-five initial implementation factors that influence an online community-based exercise intervention with adults living with HIV.

pandemic restrictions. Staff too were affected by COVID-19 pandemic restrictions (i.e., team members were under the same lockdown mandates and also susceptible to pandemic-related anxieties).

Organizational layer

Fifteen factors arose in the organizational layer, comprising the Toronto YMCA and University of Toronto. Substantial coordination was required to schedule in-person equipment distribution at the Toronto YMCA, which, prior to hand-over, also required the exercise equipment to be procured, assembled, stored, and delivered. Scheduling Zoom videoconferences for 33 participants to complete baseline questionnaires and fitness assessments also demanded significant coordination. Moreover, additional technology training was needed for several participants, requiring fast turn-around for technology orientation e-learning modules and phone/videoconference tech support.

Personal layer

Of the 20 factors in the immediate environment, 11 concerned technology, including password management, app usability, and device obsolescence. Other technology-related issues included a lack of access to a webcam, which was required for the TEx Study. Webcam set-ups proved challenging where physical space was limited, since trainers required a full-body view of participants as they exercised. Other factors related to social settings, including responsibilities that hampered exercise plans and supports that facilitated them. Resources constraints related to time to exercise and money to purchase equipment or memberships. Staff environmental issues included home videoconferencing set-ups that would ensure participant privacy.

Human layer

Twelve factors are listed in this layer. Regarding participants, several comorbidities were reported. Concurrent health conditions, including mental health, such as depression, were raised in screening interviews and during baseline assessments. Dispositional factors concerned aspects such as motivation to exercise and commitment to exercise thrice or more weekly. Inter-layer factors primarily concerned technology, for instance, participants reported that challenges setting up the technology caused stress.

Both participants and team members had communication preferences, some preferring phone to email, for example. Some individuals, including intervention team members, were new to

Zoom videoconferencing and other technological aspects of the TEx Study, including WPAMs and online exercise platforms. This affected comfort with technology. Scheduling baseline fitness sessions also proved challenging for some at the outset, resulting in missed appointments. (Note that only the factors are reported here. Details of participant experiences will be reported in future.)

Discussion

In this article, we adopted a systems engineering perspective regarding the initial implementation of an online exercise intervention study, involving 33 adults with HIV and 10 implementation team members. After reviewing 11 characteristics of complexity (Objective 1a), we devised a system schematic depicting the primary (internal to the system) and secondary (external to the system) components of an online exercise system (Objective 1b). Subsequently, we recorded 55 factors that arose during initial implementation, divided amongst five layers: *nature*, *society, organization*, *person*, and *human* (Objective 2).

In taking a CWA perspective, the complexity of this online exercise system became clear. With 43 individuals directly involved in the intervention, including both participants in the community and team members working from home, activity in this system was *distributed*, with behavior conditioned by organizational and societal norms, and influenced by natural conditions. Furthermore, with everyone's unique hardware-software configurations, there was a risk of significant technological challenges associated with *automated* events such as software updates, and *disruptive* events such as device failures. *Multiple interacting systems* made some events difficult to predict (e.g., Apple Siri reports that a potential participant's emails were unexpectedly forwarding to a research team member). The *large problem space*, populated by multiple variables, contributed to these events (15). Some TEx Study participants expressed reluctance to leave their webcams on, uncomfortable with exercising in front of others, possibly due to issues of body image, stigma, or privacy.

Digital environments and issues of access

While digital rehabilitation interventions can be advantageous for some in terms of ease of "access", "convenience", and operating costs (26), there are disadvantages too. Technological issues, for example, dominated initial implementation of the online exercise intervention. Factors included the upfront costs of peripheral hardware, aging devices (such as smartphones), and e-literacy challenges (including managing app registrations and passwords). The difficulties stressed and frustrated some participants and required ongoing communication and tech support from the implementation team as well as rapid development of new instructional materials and e-learning modules. We learned that implementing a digital health intervention requires substantial investment of time and resources as well as a dedicated, multi-skilled team.

In the context of HIV, the technological difficulties we experienced may come as little surprise. A qualitative descriptive study exploring online exercise involving adults living with HIV described digital health as offering "geographical independence" for some, but also considerable challenges for others due to limited internet and device access (6). In low- and middle-income countries, for instance, investigators have identified outdated phones with limited memory capacities as a barrier to digital health for adults living with HIV (27). Although we implemented this intervention in a high-income country, we still found digital access to be a barrier for some (6). Consequently, we recommend that implementation specialists not only pay close attention to the minimum device requirements needed for app functionality, but also plan for technological challenges, including service outages, and software and hardware disruptions. In particular, we recommend developing training materials and, crucially, work-around procedures at the outset that anticipate technological failures.

Complexity and HIV research

Researchers in implementation science are increasingly drawing on the perspectives and methods of complexity. The 2021 updated Medical Research Council's Framework for complex interventions now suggests addressing "sources of complexity", listing entities associated with an intervention (e.g., "number of components") and dimensions associated with a context (e.g., "social, political, economic and geographical") (28). More technically, a computational approach within digital health models how "a participant's state can be represented in a multidimensional [contextual] state space" (29). The 55 system factors we uncovered, which range from the individual human layer to the natural world layer, are in keeping with these approaches, suggesting systems perspectives, like CWA, are becoming increasingly common within complex intervention and digital health research.

Likewise, in an HIV context, researchers continue to frame activities such as exercise in terms of its multiple layers. In one systematic review, the authors uncovered 55 possible "physical activity correlates", divided into personal categories (i.e., "demographic"; "biological"; "behavioral"; and "psychological, cognitive and emotional" correlates), and environmental categories (i.e., "social/cultural"; "physical environment"; and "policy" correlates) (8). Similarly, investigators exploring considerations for engaging in online exercise with adults with HIV divided findings along "personal", "structural", and "community" dimensions (6). Our findings align with these categories and dimensions, and build on them by including aspects of the natural world and by considering how layers of a system may relate (by specifying inter-layer factors and identifying entities that flow between components and layers, like information).

Where a systems view appears to have taken root in the HIV research community is in considering social determinants of health. The World Health Organization defines these determinants as "the non-medical factors that influence health outcomes… the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems" (30).

Researchers are beginning to investigate these determinants more deeply. Qualitatively, Safa et al. (2022), in their scoping review of physical activity involving people living with HIV, found gender, social support, social status and income to be among the most often studied in literature (31). While quantitatively, Hogan et al. (2021) explained how social determinants of health can be mathematically modelled with respect to HIV outcomes (32).

Theoretical and conceptual work can inform analytical models, and this is where approaches like CWA can contribute, by way of tools that help researchers understand the structure of a system. While we adopted a CWA perspective in this article and completed preliminary work associated with its knowledge elicitation stage (see Methods), we have yet to apply CWA's formal modeling tools. Future work involves developing a system map which presents a detailed description of *what* a system is, and *how* and *why* it functions (16). This multi-level means-ends map links objects and resources at a system's most concrete level (i.e., means) with overall purposes and values at its most abstract and intentional levels (i.e., ends). By proceeding with a hierarchical mapping, analysts can first conceptualize what a system is, including the context of an intervention; and then devise holistic evaluations that can help address the key implementation science question, "What works for whom in what settings to change what behaviors, and how?" (9). Without understanding the components that comprise a system, answering this question will remain problematic.

Strengths and limitations

In this article, we adopted a systems approach to study the factors influencing initial implementation of an online exercise intervention in an HIV context. The strength of this approach is that it offers researchers a holistic perspective of a system, and conceptual tools to address complexity in a manner that respects the primacy of the environment and its impact on human behaviour (15). All rehabilitation systems may be studied in this light, which is akin to recognizing how environments, from the outset, can enable or disable.

Limitations relate to the flexibility of the CWA approach. Because a system in CWA can be parsed in many ways, no one way is considered correct. Much depends on the training and perspectives of the study team members and the purpose of the overall analysis. Regarding the system schematic, its aim is to illustrate a system pragmatically to further understanding, analysis, and stakeholder communication, so no formal rules governing the content or level of detail exist. Some depictions may benefit an analysis more than others. Other limitations relate to the 33 participants and 10 team members involved with the sub-study. A different set of individuals may have led to different results, including a different set of early implementation factors. Data sources were also subject to reporting inaccuracies, and their analyses, subject to misinterpretation. Furthermore, this sub-study was limited to initial implementation, disregarding factors that may be pertinent to other phases of the intervention. Finally, the sub-study took place in a Canadian urban centre, so how well these findings transfer to other geographical regions, particularly rural regions, is unclear.

Conclusion

We identified 55 factors influencing initial implementation of an online exercise intervention for adults living with HIV that pertain to natural, societal, organizational, personal, and human layers. These factors illustrate the complexities of online exercise with adults living with HIV. Initial implementation required a dedicated, rehabilitation-centred, multi-skilled and multi-stakeholder team to address the diverse set of factors.

CWA can help guide the study of multi-component digital rehabilitation interventions for adults living with HIV, including how to incorporate social determinants of health and other environmental factors into a systems analysis. Future work includes systematically mapping factors influencing the full implementation to visualize and inform fidelity and broader online exercise scale-up in the context of HIV.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by University of Toronto Research Ethics Board. The patients/participants provided their written informed consent to participate in this study.

Author contributions

TJ: is a Postdoctoral Fellow, who conducted screening interviews, performed the systems analysis, and wrote the manuscript. KO: co-led the conceptualization of the study objectives, and drafted the protocol, led the application for acquisition of funding, and is the lead investigator on the study. AB: is a co-investigator on the research team and reviewed the manuscript in depth. FI: is a co-investigator and core team member who designed technology training modules. MK: (PT, Research Coordinator) and BT (PT, Research Coordinator) are members of the core research team involved in recruitment of participants, implementation of the intervention, data collection and contributed to the refinement of the manuscript. OK, FI, SC, AB, and AT: are all co-investigators on the research team, and were involved in the conceptualization of the study design, development of the protocol and acquisition of funding. ML: is a co-investigator on the research team, involved in the refinement of the protocol, and facilitation of recruitment with the Maple Leaf Medical Clinic. DB: is a collaborator on the research team and was involved in the conceptualization of the study design, and development of the protocol. SC: reviewed the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

Publisher's note

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Access to physiotherapy services in South African settings: stretching a hand to under-resourced communities with students as agents of change

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Background: Physiotherapy is a healthcare profession that enhances human functioning and prevents further disability. In addition to this physiotherapy promotes health, wellbeing and the prevention of diseases. In South Africa, physiotherapy and rehabilitation services are largely accessed by those living in urban communities and those with private medical funding. Rehabilitation is an essential component of the package of care yet these services do not reach disadvantaged communities who vitally need them. Through the equitable provision of service-learning, physiotherapy students can play a vital role in improving rehabilitation access to vulnerable communities.
Aim: This paper illustrates how physiotherapy students studying at a South African university provide equitable services to disadvantaged rural and urban communities.
Discussion: The first and second years of study focus on theoretical and classroom-based learning where students gain an understanding of basic principles of inclusion, equity, diversity, and self-awareness. In later years, students provide community-based services in urban and rural communities with a focus on increasing access to rehabilitation services. The clinical objectives which students are required to fulfil are guided by principles of public health and community rehabilitation. The Covid-19 pandemic highlighted the issue of poor access to rehabilitation services and the case study we provide demonstrates the roles physiotherapy students played to fill this gap. The authors offer a reflection from their involvement in physiotherapy student training and provide an example of a moment which displayed equity, diversity, and inclusion in their career.
Conclusion: There is a huge gap to fill in the provision of equitable rehabilitation services for the South African population. Institutions responsible for the training of physiotherapists, or any rehabilitation profession, should realize their role in service delivery through a service-learning approach.

KEYWORDS
physiotherapy, access, advocacy, diversity & inclusion, equity

Background

The history of the South African health system is well documented with multiple policies dating back to pre-apartheid colonial subjugation. The vast income inequalities (1), a two-tiered health care system consisting of public and private sectors (2), and geographical sub-divisions have resulted in public health challenges where those who are rich or well-geographically positioned are favoured. A lack of human resources in the public health sector (3, 4), coupled with poor management has resulted in an inadequate response to the basic health needs of the country. People with disabilities and those who lack access to basic health services have been historically disadvantaged and left with poorer health outcomes (5), despite the well documented South African policies acknowledging their needs. These are policies that are infamously known to be poorly implemented, especially considering the diverse needs of the two-tiered system.

The private health sector caters to <20% of the South African population via medical insurance, out-of-pocket payments, and hospital plans, while the vulnerable >80% population relies on the public health sector (2, 5). Public health service users are often deprived access to rehabilitation services due to factors such as long distances to facilities, maldistribution and lack of rehabilitation health workers, lack of assistive devices to enable mobility and transportation to the facility, or simply not knowing about rehabilitation and what it offers (5–7). The need for rehabilitation services in South Africa has been highlighted with the shift from communicable to non-communicable diseases (6, 8) which has placed a huge demand on the provision of rehabilitation services.

Rehabilitation has not been a priority in the South African health sector, instead, there has been a huge focus on saving lives from communicable diseases which has proven successful (5, 9). However, rehabilitation is an essential component of the package of care to ensure universal health coverage across one's life. Rehabilitation is an ongoing process that aims to minimize disability and improve functional ability (10). The components which are central to rehabilitation include preventive care, assessment and intervention using therapeutic approaches and promoting reintegration to the community. The need for rehabilitative care is increasing due to a growing elderly population, sequelae of chronic conditions and musculoskeletal problems (11). The World Health Organization (WHO) launched a global agenda to strengthen rehabilitative care, "Rehabilitation 2030" by improving integration of rehabilitation into the health sector, strengthening multisectoral collaboration, and developing context-specific service delivery models that will ensure access to rehabilitative care (10). Although rehabilitation is an essential component of the package of care, rehabilitation services do not reach disadvantaged communities who need them and therefore strategies are required to strengthen universal health coverage (12).

While the South African government has introduced a reform to the provision of universal health coverage through the National Health Insurance strategy (13), a lot more still needs to be done to address the rehabilitation inequities of the past. The strategy falls short on rehabilitation outcomes (14). These shortfalls include a lack of focus on rehabilitation, a shortage of human resources, and a lack of outreach transportation and assistive devices to name a few.

Training health professionals to respond to the health and rehabilitation needs of marginalised South Africans is one strategy of strengthening universal health coverage. The physiotherapy training programme at the University of the Witwatersrand, South Africa, has a strong focus on empowering students to address issues related to healthcare system access such as diversity, inclusion, and equality. In this paper diversity is conceptualized as an acknowledgment of the differences in terms of race, socioeconomic status, experiences, sexual orientation, ability or disability. In terms of diversity in healthcare, it is the ability of health professionals to respect and render patient-centred care that seeks to understand the patient's needs and context regardless of their race, ethnicity or economic status (15). The concept of diversity is closely linked to inclusion and equity. Inclusion in the rehabilitation setting encompasses patient-centred care where patients or clients are treated according to their specific, individual needs and are encouraged to actively participate in the decision-making process (16). Inclusion and active participation have been identified as essential in addressing the health inequities experienced by people with disabilities (17). This paper illustrates how physiotherapy students training at a South African university practice to address health inequities in disadvantaged rural and urban communities.

Physiotherapy students as change agents: inclusion, diversity, and equity in practice

The physiotherapy programme at the University of the Witwatersrand is a four year training degree that places emphasis on patient-centred care. The training highlights the importance of understanding the patient and their community's context, professional behaviour and sensitivity to the diverse cultures as well as the importance of applying theories and concepts to address the inequities in health care. The scope of the public health and community physiotherapy curriculum within the physiotherapy training programme exposes students to under-served and under-resourced communities where they must assess the community's health needs and design interventions to address the identified needs.

The structure of the curriculum focuses on aspects of inclusivity, diversity, and equity as outlined in **Table 1** and described thereafter. Through this curriculum, it is envisaged that students will go into communities of different contexts and provide physiotherapy and rehabilitation services that addresses the health inequities created partly by apartheid segregation. The curriculum empowers students to be change agents who can make a difference in the diverse context of South Africa. **Table 1** outlines the undergraduate curriculum with topics that foster inclusion, diversity and equity.

Laying the foundation: first year of study

Students in the physiotherapy programme come from diverse backgrounds of gender, culture, ethnicity, socioeconomic status, and geographical region. The diversity in the student body enables the facilitation of the conversation on the history of physiotherapy which has historically been a white female dominated profession (18). The first year of study is predominantly theoretical learning with case presentations and classroom discussions. The students are

TABLE 1 Topics covered in the physiotherapy degree programme fostering inclusion, diversity, and equity over a four-year period.

1st year	2nd year	3rd year	4th year
❑ Introduction to diversity and disability ❑ History of physiotherapy ❑ Introduction to public health ❑ Principles of adult learning and health education ❑ Group rehabilitation and group dynamics ❑ Interdisciplinary care ❑ Communication skills ❑ Cultural differences affecting communication ❑ Transformative approach to disability awareness ❑ Cultural, ethnic, religious & educational diversity and their impact on subjective examination ❑ Self-health assessment ❑ Adolescence ❑ Professional behaviour and wellness ❑ International classification of disability, function, and health (ICF) ❑ Bioethics	❑ Health and society ❑ Determinants of health ❑ Understanding health in urban and rural contexts ❑ Health and aging (gerontology) ❑ Rehabilitation process ❑ HIV and rehabilitation ❑ Social exclusion as a determinant of health	❑ Family centred practice ❑ Participation ❑ Childhood disability in the South African context ❑ Integrative medicine ❑ Mental health and awareness ❑ Social security and social grants ❑ Health promotion ❑ Primary health care ❑ Community development ❑ Community based rehabilitation ❑ Home based rehabilitation ❑ Community assessment ❑ Community participation ❑ Ethics in physiotherapy and health care	❑ Health challenges for children in South Africa ❑ Public health laws ❑ Planning and managing physiotherapy services in a district health system ❑ Health screening in a community setting ❑ Occupational health and safety ❑ Self-efficacy and management

taught communication skills as these are central to building a therapeutic relationship with patients and can enhance patient-centred care. The adult learning theory emphasises the need to respect adult learners and to ensure learning is practical and relevant to the needs of adults. This principle is important because when students are in the community they need to render services respectfully and according to the patient or community's needs. Professional behaviour topics include professionalism, reflective practices and wellbeing. Through these topics students come to understand professional behaviour, the importance of reflective practice and personal wellbeing. The students are also introduced to the South African public health system and the contextual challenges that influence health outcomes. These topics become a foundation to developing professional identity, self-awareness and respecting others.

Persons with disability are often marginalised from accessing rehabilitation services, which increases their risk of living in poverty, being unemployed, and having less access to healthcare compared to the general population (19). The first-year students in the physiotherapy programme are introduced to the concept of disability through a transformative approach to disability awareness (20). The topic on disability aims to raise awareness on issues of equity in rehabilitation. The students are given a group activity where they explore challenges facing people with disabilities. This project allows students to better understand the type of everyday issues faced by a person living with a disability. During this project, advocacy is strongly enforced, and the students must discuss how they would advocate for the social inclusion of a person with a disability.

Second year of study

Students in the second year of study are introduced to the international classification of function, disability and health (ICF) framework (**Figure 1**) (21). The framework emphasizes a biopsychosocial approach to rehabilitation. It highlights the person's health condition and emphasizes the interactions between the person's participatory restrictions, activity limitations, and body impairments with the contextual factors (environmental and personal). The ICF underpins the interventions provided by physiotherapists and other

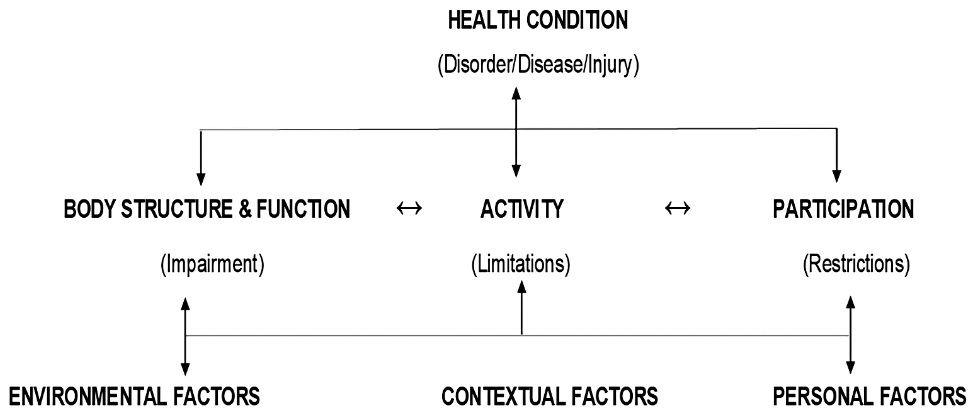

FIGURE 1
ICF framework (adapted from world health organization)^6.

CASE STUDY 1: COVID 19 PANDEMIC SERVICES RENDERED BY PHYSIOTHERAPY STUDENTS.

Students conducted community projects ranging from health education, health promotion, health screening, home-based rehabilitation, and occupational health. The rehabilitative role was highlighted during house-to-house visits to patients who could not access health facilities due to personal disability limitations, inability to afford transport to the point of care, over-crowding in community clinics and various COVID-19 protocols such as social distancing. Outreach services were conducted with community health promotors to expand access and inclusion to nongovernment organizations for the elderly and people with disabilities. The students provided in-service training on mental health, COVID-19 screening, health and wellbeing of nurses, health promotors, and community health workers. Students advocated and raised funds for resources such as cloth face masks and hand sanitizers for different community organizations.

Students compiled learning portfolios and kept a reflective diary on their experiences during clinical blocks. From the student diary reflections, it was evident that students felt proud to have made a difference and be active agents of change. Students expressed feelings of anxiety, stress, frustration, and fear during the service-learning process. However, the process developed resilience in the students.

rehabilitation professionals such as audiologists, speech and language therapists, and occupational therapists.

Advocacy and inclusion of the marginalized population remains a focus of the curriculum. Additional concepts that are taught in the second year are the determinants of health (22). Students are taught the multi-level framework of applying the determinants of health, using the self-health assessment students are expected to assess their own health status at individual and household level. Understanding health and society is central to the second-year curriculum as this further prepares students for clinical and community placement at the third-year level.

To apply diversity, students are required to identify an under-resourced and marginalized community from an urban and a rural community of South Africa. They then must discuss possible health issues focusing on inclusion and access to rehabilitation services for the identified community. This learning allows students to identify their rehabilitative role as physiotherapy students and apply learned concepts to a real-life community setting.

The students are also put in a simulation situation where they get to understand social exclusion. They are split into two groups, where one group assumes the role of a physically disabled person and the other group assumes the role of a health worker or government official in charge of policy implementation. The disabled student must navigate the university premises in a wheelchair, crutches, or blindfolded. The role of the health worker is to conduct a subjective assessment of the disabled person to get an understanding of their daily challenges. The government official communicates with the health worker to discuss strategies to implement structural and social policies that enable inclusion. This highlights the need for persons with disabilities to be included in the discussions of policies that affect them, further highlighting the concept of “for the people, by the people”.

Theory to practice: third and fourth year of study

In the third and fourth years of study, students are placed in urban and rural community health centres, community health clinics or rural district hospitals to fulfil a set of clinical objectives. The students are required to engage with relevant stakeholders to develop needs-based community projects which address the issues of diversity, inclusion, and equity as listed in Table 1.

To understand the rehabilitation needs and ensure sustainability of programmes, students are expected to keep and update a community file. The file contains all information on community projects performed by previous students and includes recommendations for project sustainability. Students engage with rehabilitation health workers, clinic staff such as nurses, community leaders, community structures such as schools, and they also perform a transect walk of the community to identify the determinants of health and issues of accessibility within the community.

To bridge the gap of accessibility to the health facility, physiotherapy students perform a home visit (home-based rehabilitation) to an identified community member with a disability or physical limitation. The aim of this home-based rehabilitation is to assess and intervene an individual’s functional capacity in their own home when that person would otherwise not be able to access the local health facility. Community reintegration and caregiver strain relief forms part of the focus for home-based rehabilitation.

Patients who are identified as experiencing common disabling impairments receive group rehabilitation and social support groups are created for patients and caregivers of people with disabilities. The physiotherapy students are expected to identify a community structure such as a school, disability centre, or a community social club and assess the rehabilitative needs of this structure. Interventions such as health education and health promotion are applied based on the identified need. Students also get to engage with local community members which further deepens their understanding of the determinants of health in the community. Students are then able to provide rehabilitation services to those who are marginalised, and further involve other health workers and external stakeholders. To inform the community about rehabilitation services, students provide education at health facilities waiting areas. Students also promote physiotherapy at schools within the community to encourage learners from rural backgrounds to pursue a career in physiotherapy.

Access to rehabilitation services was further worsened by the COVID 19 pandemic (23) when national lockdown was implemented (24). Due to the country's movement restriction, fourth-year students were placed at urban primary health care facilities for their public health and community physiotherapy block. An example of a project that was conducted during the COVID 19 pandemic is illustrated below:

As a core function of public health, health promotion allows for the awareness of health issues by supporting individuals to cope with and address various health challenges. Students in the third and fourth year of study conduct health education sessions to promote health knowledge and self-management of at-risk populations. During these sessions, students must account for various factors such as language barriers, level of literacy of the audience and provide specific, evidence-based community-centred information all whilst demonstrating respect, professionalism, adaptability to the setting that they are in.

Through the fourth-year curriculum, public health laws are taught to help students understand the "bigger picture", whereby political marginalization, discrimination and inequitable access to health services are experienced by persons with disabilities resulting in poorer health outcomes (25). Students are therefore aware of policies guiding health and rehabilitation and can advocate and mediate on behalf of their patients and/or the community they are placed in.

Conclusion

Physiotherapy training should not only include clinical skills but must incorporate fostering the students' ability to promote health and address issues of access, equity, diversity, and inclusion. In the context of challenges faced by people with disabilities as well as those at risk of developing disabilities, students can be agents of change and drivers of universal health coverage as they reach marginalized communities through outreach activities related to rehabilitation. We conclude by offering a reflection of our experience in teaching students to provide equitable access to physiotherapy services for marginalized communities.

Author 1

Getting into physiotherapy as a career was never part of the plan. It became a destiny and a personal agenda when I got exposed to public health and community physiotherapy. Since my involvement in training physiotherapy students and working with vulnerable communities, I have grown to feel like a useful member of society. I have learnt that people living in low-resource communities are very knowledgeable about health topics and have a desire to learn more, but the system does not always provide the opportunity. People are always looking to make use of the system built for them to either promote, prevent, or rehabilitate themselves but this is constantly denied due to the inaccessibility of the system. A moment in my public health and physiotherapy training career that I will forever remember was when I conducted a home visit with third year students to a client who survived a stroke, was bed-bound, and also blind. She had not been outside her bedroom for eight years since the diagnosis of stroke due to fear and lacked the motivation and reassurance of getting into a wheelchair and going outside. When the students confidently transferred her to the wheelchair and persuasively got her out of her front door into the sun she cried for minutes and repeatedly said to the students it is the best healing she has ever received as a stroke survivor.

Author 2

My experience as a clinical educator has allowed me to observe students from various backgrounds entering communities which contrast their own. During health education talks, students often provide advice on nutrition and exercise to patients in the waiting area of the Community Health Centre. Students were often aware of the setting and tailored their education to suit the diverse needs of the community. For example, students may explain healthy foods to eat during pregnancy in terms of what is available, accessible and cost-effective within the community. Elements of inclusion, equity and diversity are often noted when health education is specific and relatable to the community. However, some students often fail to adapt this to the community and do not consider the diversity of the audience to whom they were speaking. This is noted when they mention physical activities such as swimming, accessing a gym or using exercise equipment which many individuals in the community would not have access to.

Students are encouraged to include elements of diversity, equity and inclusion in every step of their clinical practice, patient engagement and professional lives. However, while these elements may be included well in theoretical training I have observed that some students experience a "culture shock" when placed in an environment which contrasts significantly to their personal lives. Acknowledgement that some students adapt to the circumstances and incorporate the elements is not enough to institute change. We need to garner an understanding of the reasons why some students can understand the importance of equity, inclusion and diversity and include it in their clinical practice and why some cannot. This will assist in tailoring curricular to produce healthcare professionals who note these elements as core principles in patients care.

Author 3

In my experience as a clinical educator, I have engaged with students from many walks of life. I have always believed healthcare professionals have a "calling", that no matter how hard you try to run away from it, the profession always chooses you. My training as an undergraduate student will always be a reminder that healthcare is complex and multifaceted, a season that will require you to plant yourself in unfamiliar territory so you can anchor yourself where growth potentially exists. Thereafter as a qualified healthcare professional, it is up to you to water yourself in other seasons of your career for continued growth. I will always encourage the students that cross my path to submerse themselves in the unknown, to get familiar with practicing reflection of self, but more than that to treat all patients with dignity and respect regardless of their socioeconomic status or cultural background, to approach every patient with empathy and compassion as if it were their own family member. A moment that stood out so vividly for me and pushed my passion for students' training was a home visit whereby students displayed attitude and disinterest towards the patient all because he had not bath yet and his home was untidy. I was disheartened and appalled by their attitude and body language, and quickly had to remind them that just because someone looks or smells different does not make them less of a human. That regardless of their home environment they still need our services, and we have to treat each patient with respect and dignity.

Author 4

I have taught public health and community physiotherapy as well as supervised physiotherapy students for ten years. I believe in holistic person-centred care where patients and community members are central to healthcare. Over the years I have observed that exposing students to urban and rural settings helps the students appreciate the diverse social context health care is delivered in. Some settings where students conduct their activities highlight the inequalities our country faces such as differences in household income, personal safety experiences, access to adequate housing, sanitation and clean water. Such experiences help students gain a better understanding of the challenges patients face and the need for social justice and efforts to address inequity. Two experiences stand out for me: I went with 3rd year students to location × for a health intervention for people with strokes. The hall was full of immigrants, young and old who needed health information on how to manage their stroke. The students conducted a health talk in English but needed to adapt and make the message accessible to the French speaking audience. My second experience is based on a home visit conducted by 4th year students in a rural setting where the students assessed a teenage girl with a spinal cord injury and her house environment. The house where the patient lived was not accessible and the father had to carry her outside the house. The students partnered with the local business community and the local businesses donated material to build a ramp. Such interventions highlight responsive care that ensures access to health care services and addressing inequity.

Data availability statement

The original contributions presented in the study are included in the article, further inquiries can be directed to the corresponding author.

Author contributions

All authors contributed to the writing of the manuscript. The first author provided the conceptualisation of the manuscript and drove the writing process. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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HIV in MOTION: a community of practice on physical rehabilitation for and by people living with HIV and their allies

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Background: This paper describes the design, implementation, and evaluation of a community of practice (CoP), HIV in MOTION (HIM), to advance physical activity rehabilitation interventions with adults living with HIV, clinicians, researchers, and representatives from community-based organizations. We attracted a diverse audience of geographically dispersed people living with HIV, clinicians, exercise personnel, and trainees to eight HIM community of practice events that featured the clinical, research, and lived experience of people living with HIV. HIV in MOTION had (a) a domain related to physical rehabilitation, exercise, and social participation for people living with HIV; (b) a community of diverse individuals; and (c) a practice, that is, a series of sustained interactions online and offline, synchronous, and asynchronous. Our team included six diverse people living with HIV, two coordinators, and three academic researchers who planned, prepared, implemented, and evaluated each online session. To evaluate the HIV in MOTION CoP, we employed an evaluation framework composed of five criteria: Goals and Scope, Context and Structure, Process and Activities, Outcomes, and Impact. We collected quantitative and qualitative evaluative data using online evaluation, audiovisual archiving, and participant observations during the debriefing with all members of our team.

Results: We widened the Goals and Scope of the HIV in MOTION CoP to include the HIV narrative of lived experiences, including autopathography, and participant storytelling. In matters of Context and Structure, we received explicit satisfaction with our governance and leadership. Also, being flexible to fit online formats was a productive strategy that made the HIV in MOTION CoP sessions agile and amenable to audiovisual archiving. Our indicators of success in Process, Activities, and Outcomes included participant retention online, elicited verbal interventions and comments in the chat room, and a rate of three repeat visits online. The indicators of success of Impact were the presence of voluntary and unscripted autopathography, the patient storytelling and how it reportedly caused changes in the participants, and the "legitimate peripheral participation" of emerging research and clinical students. In conclusion, we recommend our form of CoP for mixing the knowledge of diverse persons in this area. However, we recommend considering budget and burnout as serious challenges to sustainability.

KEYWORDS

disability, rehabilitation, HIV inclusion, community of practice, evaluation, exercise, physical rehabilitation

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Introduction

> *Thinking together about real-life problems that people genuinely care about gives life to Community of Practices (CoPs)* (1).

Succinctly described, a community of practice (CoP) is a group of people who "share a concern or a passion for something they do and learn how to do it better as they interact regularly" (2). The concept was first proposed by cognitive anthropologist Jean Lave and educational theorist Etienne Wenger in their germinal 1991 book, "Situated Learning," and applied and expanded since then (3, 4).

Working on the proven premise that CoPs mobilize research evidence (5), we set out to mobilize evidence of the role and impact of exercise and physical activity among adults living with HIV. We wanted to create opportunities for partnerships, collaboration, and information sharing. The main purpose of our CoP was to contribute to bridging gaps between research evidence and practice in physical rehabilitation and social participation for people living with HIV.

In this paper, we describe the design, implementation, and evaluation of a sustainable community of practice called HIV in MOTION (HIM) to advance physical activity rehabilitation interventions with adults living with HIV, clinicians, researchers, and representatives from community-based organizations (https://rise.articulate.com/share/HgA3hWAtWNqoIR8iKkfzdsAU0cLknrmY#/). HIV in MOTION was part of a community-based research study (2019–2023) to develop and assess the utility of a short-form HIV-specific disability patient-reported outcome (PRO) questionnaire, a tool to identify the presence, severity, and episodic nature of disability experienced among adults living with HIV for use in community-based settings, which include AIDS Service Organizations (ASOs), community health centers, and clinics.

The HIV in MOTION CoP (https://hivinmotion.ca/) and the accompanying study are inscribed in a context where people who are HIV positive often experience more additional health problems and aspects of disability compared to those who do not have HIV, especially as they age. This is worsened by layers of uncertainty about the future and perceived, internalized, and/or enacted forms of stigma (e.g., for having acquired HIV through sex or use of substances) (6). The effectiveness of exercise for people living with HIV has been stated in systematic reviews including the one by O'Brien et al. (7), a Framework of the Physical Therapy Role in HIV Care in 2019 (8), and collaborative research priorities (9). In addition, research evidence tells us that rehabilitation services and programs are sorely needed by many of the estimated 62,790 people were living with HIV in Canada (People living with HIV in Canada: infographic, Accessed August 16, 2023) especially by those over 50 years who make nearly 50% of this population (10–12).

Research has found statistically significant benefits of aerobic and resistive exercise among people living with HIV. Also, various forms of movement and exercise have been found to support their cognition and increase social participation (7, 13). However, the engagement and uptake of exercise among adults living with HIV varies a great deal (14). In Canada, these foundational research findings show that there are several things we need to do. One of these important things is to teach healthcare workers, people who work in non-profits, and individuals with HIV about how exercise and movement are helpful for people with HIV. This is especially important for those who are getting older while living with HIV. This idea led to the creation of an online community called the "HIV in MOTION Community of Practice."

Communities of practice online and knowledge transfer

When we started the CoP, we wanted to attract a diverse audience of geographically dispersed people living with HIV, clinicians (occupational therapists (OTs), physical therapists (PTs), general practitioners, HIV medicine), exercise personnel, and trainees to events that featured prominently not only the clinical and research aspects but also the "lived experience" of people living with HIV.[1]

We stayed away from traditional expositive formats such as lectures that favor the academic voices and knowledge. We took advantage of the social aspects of what has been called the "Social Web" because its content can be easily generated and published by users, and "the collective intelligence of users encourages more democratic use" (16). This *democratic* aspect is key to understanding the flexible, upbeat, informative, and "low-complexity" (17) format of our CoP. We developed the HIV in MOTION CoP to support the growing interest and practice of social and physical activity among people living with HIV of all ages, no matter how challenged.

CoPs are a form of knowledge transfer (also referred to as integrated knowledge mobilization or iKMb). Specifically, integrated knowledge transfer (iKT) is an approach that applies community-based research principles and practices, such as co-ownership, collaboration, co-production of knowledge, and balancing the differing community–academic–clinical powers (e.g., perceived authority of the medical discourse about the patient) (18–22). iKT is "an alternative approach for promoting research use in which research users function as active partners to generate research from conceptualisation to implementation, rather than passive recipients of research or research products" (18, 23).

Research in this area reports that virtual CoPs are forms of active and collaborative co-learning about a shared concern, collective learning in regular interactions, identity-building, and knowledge mobilization (1, 3, 24–26). CoPs have been found to promote benefits related to patient diagnosis and treatment, clinical management, trust across sectors, supports for HIV healthcare providers initiating their practice, and updates on HIV healthcare and social services providers (27–29). The participation in a CoP

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[1] "Lived experience" is defined in this context as a philosophical stance (one's life well examined) and a phenomenological construct of the most indivisible form of experience (e.g., pain, stigma, happiness) (15).

can range from one-offs to more constant participation in a core group. Of note, it has been said that "[the involvement of] community is a facilitator of the knowledge sharing in CoPs" regardless of the frequency of their participation (30). CoPs give healthcare professionals "a stronger collective sense of their roles" (31) by creating "professional awareness regarding patient empowerment" (32).

CoPs share a basic structure of three elements: (a) a *domain* or topics that drive the community, that is, a range of matters related to physical rehabilitation, exercise, and social participation for people living with HIV; (b) a *community* of diverse individuals who recognize and value each other and the core subject matters; and (c) a *practice*, that is, a series of sustained interactions online and offline, synchronous, and asynchronous (25). In the next section, we describe how these three elements and forms of participation interplayed in the design and implementation of the CoP.

FIGURE 1
Steps to design, implement, and evaluate the HIM CoP.

Designing and implementing the HIV in MOTION CoP

Following CoP examples in the field, our design was flexible and participatory (33) and informed by our team's prior experience with online learning related to social–behavioral and physical aspects of living with HIV since 2009 (34, 35). We also tapped into an existing international collaborative center led by one of our academic authors (https://cihrrc.ca). We designed and implemented HIV in MOTION online sessions four times per year in collaboration with a group of six HIV+ "Ambassadors." The goal of each CoP session was to increase knowledge about exercise and physical activity in the context of HIV and to foster dialog, collaboration, and support in the field. The Ambassadors participated in the choice of topics, identifying potential speakers, etc., alongside the research leads and two coordinators, one Research Coordinator, and one Engagement Coordinator living with HIV. The latter's role was to support the Ambassadors and all persons living with HIV in the accompanying studies. Ambassadors were provided a yearly honorarium of 1,000 Canadian dollars (CAD) for their involvement in HIV in MOTION.

Our design emphasized the value of being informed and designed by "patients" directly. Our ambassadors have long-standing connections to AIDS service organizations and with communities impacted by HIV, and they included cis-men and women, trans persons, and HIV+ staff of regional HIV non-profits. Many of the Ambassadors had prior experience as *peer researchers* who are patients that participate in any or all the people living with HIV of a research project over time (36). We relied on a framework to support ongoing effort at engagement and opportunities to participate in panels, conference posters, and events (36).

The process of designing and implementing each HIV in MOTION online event encompassed five steps (see **Figure 1**).

Step 1—Planning: we met quarterly with the Ambassadors, coordinators, and lead researchers to choose topics, speakers, and live demonstrations.

Step 2—Preparation: speakers, panelists, and those providing 5–10 min of physical activity demonstration were briefed about their involvement in an upcoming event. We sent useful tips for speaking to the webcam, the lights, and sound. We also provided a media release form. In this step, we also prepared and launched social media promotions and pre-recorded edited videos.

Step 3—The Huddle and pre-recording: days before the public CoP online event, the team, guest speakers, and panelists huddled online for 1 h to become acquainted with each other, offer an overview of the presentation, and receive technical support (e.g., lighting, etc., for live Zoom sessions).

Also, in Step 3, we recorded short sections to be both broadcasted and integrated into our video library (https://bit.ly/HIV-in_MOTION_Audiovisual_Library). For speakers, we offered 20–30 min. We offered 10–15 min to the guests providing physical demonstration (e.g., stretching while sitting).

We sent the panelists in advance a few guiding questions and the main speaker's pre-recorded video to give everyone an opportunity to reflect on the forthcoming content presented live online.

Nonetheless, we did not confine their responses to the perspectives the speakers were addressing.

Step 4—The online event: we broadcasted always at 12–2 PM EST with the aim of capturing as wide an English-speaking audience as possible. At all steps, we considered the differing time zones of speakers/panelists as well as audience members. Our records indicate ample participation from Canada, USA, UK, New Zealand, and Australia, and a few audience members from South Africa and Israel. We capped each session at 2 h or less. We alternated between two equally strong styles of event facilitation: one facilitator worked with prepared questions and a set order of interventions for panelists; the other facilitator used a conversational style akin to a talk show. The format most often included a welcome (5 min), followed by the pre-recorded exercise or mindfulness demonstration (10–15 min), and a pre-recorded speaker's presentation. Next, we broadcasted live (synchronous) one 40–60 min panel of up to five people, always including at least two persons with lived experience, the invited speaker and the invited exercise demonstrator (e.g., a physiotherapist, an HIV+ yoga practitioner, a local YMCA coach affiliated with our studies, etc.). The facilitator would gage the interest and timing and open the panel to all in the virtual room. A facilitator's sidekick would mind the chat room questions, curate them for repetition and how they would enhance the dialog, and pass some of them onto the facilitator or resolve them in the chat room.

Step 5—Debriefing and evaluation: the Team, Ambassadors and core research team members, met within 3 weeks after each CoP session to debrief. We checked on what worked and what did not, who attended, and what we should modify in the next iteration. We completed this process eight times for each CoP session. We emailed thank you notes to the participants along with an electronic gift card as a token of appreciation to speakers, panelists, and exercise demonstrators for their involvement in the CoP session. We sent all registrants links to the audiovisual library and a link to a digital evaluation. Speakers and panelists were given a modest honorarium.

Evaluating HIV in MOTION

There is little agreement on approaches to evaluating the many aspects of CoPs (25, 37). In current scholarly work, we often measure the success of knowledge transfer activities by quantifying the number of events, participants, evaluations received, etc. (38). These standards are incommensurate with the small scale of the CoP, which produced eight events in 2 years. For an online influencer, this is peanuts. For a diverse community–academic team, this is a big effort. Literature in this regard suggests that CoPs enable micro-sociological, collaborative, and peripheral forms of participation that are not easily quantifiable (39).

To evaluate the CoP, we have employed one adapted evaluation framework composed of five criteria adapted from Alcalde-Rabanal et al. (40), McKellar (25), and Moore et al. (41). These criteria are amenable to be measured in quantitative and qualitative ways, and they include (1) *Goals and Scope*, (2) *Context* and *Structure* (e.g., types of participants and type of governance of network), (3) *Process* and *Activities* (e.g., outputs that evidence a degree of collaboration), (4) *Outcomes* (results from evaluation forms, audiovisuals produced), and (5) *Impact* (what may have changed as a result of our work in the CoP). These criteria allowed us to pay attention to motivation and participation, sprouting relationships, collective learning, and the formation or support of identities (37) as well as the nonlinearity, emergence, adaptation, uncertainty, dynamic interactions, and co-evolution of the CoP (42).

Methodology of evaluation

We included three ways of collecting quantitative and qualitative data described in this section.

Online evaluation questionnaire: Among all eight sessions, 67 attendees completed the evaluation. After each CoP session, we administered an electronic self-reported evaluation questionnaire to all registrants and speakers using a link to the questionnaire.[2] The questionnaire was composed of categorical response options (e.g., "Did you have a chance to connect with someone related to the HIV in MOTION Community of Practice, before, during or after the event?") and open-ended questions to assess changes in knowledge, value, and connections made through the CoP planning, implementation, and post-CoP (see **Supplemental File 1**): "What were your overall thoughts on the HIV in Motion Community of Practice?" (Satisfaction and motivation), and "In what ways might you use the information shared at the HIV in Motion Community of Practice in your life or work?" (intent to use elements of the CoP).

The evaluation questionnaire included two retrospective pre- and post-measures of knowledge ranging from awareness to learning, for example, "Please rate on the scale from 1 (low level of knowledge) to 10 (high level of knowledge) your understanding/knowledge of [topic of the event] *before* the HIV in MOTION session of [date]," and a sister question about their knowledge *after* the event. To increase the response to the questionnaire, we raffled an e-gift card of 50 CAD to respondents, a strategy found not to influence the results (45).

Audiovisual archiving: literature in the area tells us that "audiovisual archiving" gathers outcomes and also promotes a long-term impact (46, 47). Ideally, such audiovisual materials are used by other researchers or in course instruction. More than 40 individuals have contributed to preparing the audiovisual materials of the CoP, and we hope that they have also contributed by using these materials to teach or train research teams (a long-term outcome not measured in this paper). Our audiovisual library operates, still today, as a free public asynchronous repository of our CoP efforts. To date, the library with podcasts and videos has received ≥1,500 hits over 2 years.

Recording, editing, seeking final approval from speakers, and formatting and classifying the material is a significant creative, budgetary, time, and energy effort. We paid a modicum for some of this work. The library supports the long-term goal of offering current information about physical rehabilitation, mental health benefits from exercising, and the lived experience of persons living with HIV. It has 19 short videos and podcasts (https://bit.ly/HIV-in_MOTION_Audiovisual_Library). This collection is enhanced by audiovisual work done prior to starting the CoP, also intended to highlight the research on, and the lived experience of, physical rehabilitation among people living with HIV. The collection includes presentations on sleep architecture, nutrition, and gender aspects of living with HIV. The collection also includes materials of a sister research project on conducting online exercise tele-coaching with persons living with HIV (48).

Participant observations: We relied on the participant observation of our Ambassadors and coordinators to put in

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[2] Process evaluations focus on the implementation logic while outcome evaluations focus on the results. In an evaluation, a process is "a way of talking about common action that cuts across program activities, observed interactions, and program content" (42–44).

perspective the resulting mix of formal presentations and the elicited conversation online during the event. We recorded the full session to review the presentation and comments. We told our audience that we would never make a public edited or unedited video without individual consent after each person had seen the edited clip.

Review of ethics: Considering the focus of this manuscript is centered around the delineation of the creation, execution, and assessment of a CoP, it is imperative to note that no ethical endorsement was sought for this endeavor. The CoP, in its essence, serves as a conduit for knowledge dissemination, and the individuals engaging in the CoP sessions and affiliating with its membership do not fall within the categorization of research subjects, but rather constitute integral components of a designated community of practice.

Results

In this section, we provide results in each of the measured areas: (1) Goals and Scope, (2) Context and Structure, (3) Process and Activities, (4) Outcomes, and (5) Impact. To measure each area, we identified indicators of success in each area (see **Table 1**).

Measuring the goals and scope

Our assessment is that we widened the scope of what is often included in a CoP, what is accepted as authoritative. In scholarly work in health-related areas, especially in HIV/AIDS, we often circulate somber narratives regarding the most difficult aspects of living with HIV (stigmatization of the condition by others, physical and mental health problems, etc.). These may even have subtle but iatrogenic impacts (49). We did not gloss over the challenges, facts, and emotions stirred by living with HIV, but by highlighting the lived experience of people living with HIV, we emphasized on their resilience, astute coping mechanisms, living strategies (50), and even humor (a time-honored form of resistance in AIDS activism) (51). In our deliberations and in the qualitative evaluation responses, it was made clear that we were *interrupting the HIV somber narrative of scientific research* on HIV and included other possibilities such as autopathography, that is, patient-centered storytelling (52, 53), which include contrapuntal and "polyphonic narratives" (54). These are so because people living with HIV bring to bear a number of practical (social determinants of health) and philosophical aspects in their lives and how they uniquely weave them during treatment or simply living with a condition; they can also disagree with aspects of what is being discussed. In sum, we strived to be distinctive from stagnant, long, information-heavy, and victimhood narratives of scholarly presentations about HIV (and other medical conditions) firmly installed in the late 1980s (55).

Measuring the context and structure

In this area, we boast of having retained the Ambassadors and a number of participants over the 2 years with their explicit satisfaction with the governance, leadership, and overall manner in which we carried out our activities. The CoP structure was an attempt to flatten, to some extent, the hierarchy of academic endeavors.

Flexibility of content and structure: Being flexible and making changes on the go was a productive approach. One example: when

TABLE 1 HIM CoP evaluation criteria and identified indicators of success.

Criteria	Goals/scope	Context/structure	Process/activities	Outcomes	Impact
Quantitative indicators of success	No. of affiliations of all diverse participants (e.g., clinicians, patients, etc.)	No. of agreements and disagreements with governance and structure	No. of activities	No. of liaisons reportedly started as outcome of participating in CoP	Not measured
Qualitative indicators of success	Diverse participants report understanding the goal of the events	Sense of collective ownership Ease of access	Design of the prep, online and evaluation is effective	The ease and tone of verbal or chat room participation during the online CoP sessions	What participants report they *intend* to do with the information and the experience. Trust of participants to voice their experience and expertise equally
Qualitative results	Indication provided by positive email comments from participants after a session and in-between sessions	Low complexity: each session stood alone; participants were not "lost" if they did not participate in each session. Considered differing time zones of speakers/panelists as well as audience members	16 pre- and post-event planning meetings	Eight online CoP sessions implemented on topics such as exercising through the COVID-19 lockdown, mindfulness, cognition, gender, and team exercise for social participation	Persons living with HIV participants contributed with autopathographic testimonials. Participating clinicians described how the autopathographic material puts in perspective how they practice
Quantitative results	n/a	n/a	Managing the budget to cover costs of events and post-event tasks	48 out of 67 respondents reported connecting with someone related to the HIM CoP (72%) 19 short edited audiovisual presentations (in the library) 48+ h per up to four persons in preparation and implementation of CoP event	

we noticed that the live online invited guest appearances (academic and community) were becoming long and stilted, we shortened the length of the presentation, provided the speakers with tips to "translate" scholarly material to media-friendly language and visuals, and offered to pre-record and edit 15- to 20-min sessions. This made the CoP sessions more agile and befitting of social media formats to be *consumed* synchronously and asynchronously. Thus, we followed trends in online structuration; sustained attention span, focus, concentration (56, 57); and, as importantly, we also included physical activities that would remind online participants of their bodies and avoid sedentarism and the many physical problems brought by sitting on online meetings (58). Including physical activity demonstrations online related to the theme of the event also helped reduce the anxiety of the physical demonstration presenters and afforded those online an unpressured choice to follow the exercise presented (59).

Measuring the process and activities

Although attendance is not equivalent to engagement, we can ascertain through participant observation and the results of electronic evaluations that those who came to the online events were effectively engaged. One indicator of success is having retained all the participants logged in throughout each online session, having heard their verbal interventions, or having read their comments in the chat room. Participation in the chat room must be included as an indicator of engagement (60). Chat rooms offer space for those with disabilities, learning, engagement, and differing participation styles.

Attending and engaging: A total of 451 individuals participated live online. These are not unique instances. An average of three participants came back to several CoPs online over time. Across all eight sessions from October 2020 to September 2022, attendees included 173 persons living with HIV (32%), 116 persons affiliated to non-profit organizations (21.6%), 95 academic researchers (17.7%), and 67 clinical healthcare providers (12.5%), which included physicians, OTs, and PTs.

Connecting with others in the CoP: Across all eight CoP sessions, 48 out of 67 respondents (72%) reported connecting with someone related to the CoP. Some connections were brand new, and some were firmed up among colleagues who have collaborated before. Connections included participating in the online event preparation meetings, preparing poster or oral presentations for conferences, and connecting with other participants for purposes related to living with HIV and physical rehabilitation. These forms of participation range from transactional to peripheral ("apprentices") and active (https://www.wenger-trayner.com/slide-forms-of-participation/; Accessed January 21, 2023).

Measuring outcomes

Responses to the open-ended question on overall thoughts on the HIV in Motion Community of Practice elicited responses such as "I love the fact that you got people out of their chairs and exercising. The panel members were fantastic and looked at exercise from different perspectives." Responses to the question "In what ways might you use the information shared at the HIV in Motion Community of Practice in your life or work?" elicited learnings and inspiration such as "I run a support group for folks living with HIV and I was hoping to get yoga incorporated but now I am definitely going to make sure to get this ball rolling." It also prompted testimonials of clinical applications such as "[T]he info and live chats encouraged me to start working on our residence functional fitness program. So far, we had two sessions that included both the exercise portion as well as exploration of various topics such as exercise & mind-body-spirit connection, positive habit development, excuses for not exercising, and healthy snacking."

Negative aspects to the evaluation did not outweigh the positive ones; they included technical problems (at their terminal) and wanting longer presentations and question and answer periods.

Measuring impact

Autopathography: One indicator of impact we detected in the electronic evaluations and through participant observation was the trust of attending persons living with HIV to disclose and narrate powerful stories of physical activity and social participation. Participants living with HIV shared voluntarily and unscripted, on and off webcam, many autopathographic aspects of their lives and their accompanying reflections. For example, one 50+ person living with HIV told us that they had never spoken about their exercise experience in public and expressed they did not have much to offer but for years had climbed a well-known challenging mountain with a team. It was only through this reflection that they weighed their experiences in relation to health and social participation. Other instances were public and reported in our audiovisual library, including the lived experiences of persons living with HIV who have persevered and remained adaptable to challenges (e.g., by modifying and changing activities when they had become too straining due to changing co-morbidities). One example: A 50+ woman recounted humorously her struggle of leaving a wheelchair to start walking alone or with others. Tolerance for uncertainty and adaptability remain two of several sought-after attributes of patient empowerment (61).

The autopathographic narratives did not only originate from participants living with HIV. Video interviews with the YMCA coaches associated with the HIV in MOTION study for 2 years revealed struggles with physical and mental health challenges and how becoming coaches was a life-defining choice (https://hivinmotion.ca/tele-coaching-community-based-exercise-study). This attests to the sociological mechanisms of micro-recognition and mutual recognition (62) within the CoP. The impact of caregiving burnout among healthcare providers lost its significance after the year 2000 as effective HIV treatment became the proxy for quality of life with HIV and its normalization. The impact of conducting clinical and social–behavioral research on HIV also appears to be minimal, if it is reported at all.

Based on the literature, we infer that many participants, whether HIV+ or not, want to voice their experience, and when presented with respectful and equitable conditions, they take this opportunity. Beyond medical technical information and guidelines of practice, autopathography has the potential of helping us all understand the lived experience of patients and healthcare providers (52). This often unseen *impact* is an indicator of success in this area. In the evaluation form, one practitioner wrote "[this kind of online event] can help me share the ideas relating to physical activities that can easily be performed by people regardless of their fitness level or adapted for people that are using mobility aids [and] helps me promote recreational activities that are light or moderate in intensity as lifestyle physical activities that can easily be integrated in daily living that can, consequently, help person experience numerous health benefits."

Mentorship: Including people living with HIV is a cornerstone of HIV community-based research. However, including emerging researchers and creating propitious conditions under which "patients" can truly collaborate with seasoned clinicians and established researchers is also reported in the literature as a desirable indicator of process (63, 64) Often, reported mentorship outcomes in communities of practice refer to close-knit healthcare provider settings (e.g., among early medical practitioners) and it has a teaching goal (28, 65, 66). Instead, our venture potentiated the *relational value* (67) of bringing together practitioners, patients, and academics. As in the case of working with people living with HIV, this type of mentorship required tact, care, and support. In the literature, this process of apprenticeship has been famously conceptualized by Lave and Wenger as "legitimate peripheral participation." Researchers have applied the concept to the professional formation of health professionals (26).

In our electronic evaluation survey, we gathered opinions from students in the field who attended the synchronous sessions: "I am a therapeutic recreation student and will be doing a project in the coming weeks at the [HIV medical center]. I am here to learn about how to support this community and population alongside my studies." One other student wrote, "[this type of] sessions can help practicum students understand various therapeutic approaches and research findings used across the globe; they can help my clients connect with our local recreation resources."

Discussion

HIV in MOTION was a multi-stakeholder community of practice, a form of integrated knowledge mobilization (KT) aimed to reduce the gaps between research evidence and collective. In this paper, we described the design, implementation, and evaluation of the CoP by applying a framework that included Goals and Scope, Context and Structure, Process and Activities, Outcomes, and Impact (see **Table 1**).

In terms of Context and Structure, one lesson learned is the need to have an Engagement Coordinator supporting the team as well as all those involved who are HIV+, which echoes what is being reported in the literature (68, 69). The tasks of the Engagement Coordinator are different from the academic administration of the study, often bringing in perspectives on how "patients" should receive the technical material or be explained technical language and processes and attending specifically to the concerns and ideas of people living with HIV.

In the area of Process and Activities, our outcomes reported earlier in this paper included the number of attendees, speakers, panelists, exercise demonstrators, as well as the number of times they repeatedly attended a CoP session. We spent at least 160+ h of our combined time in preparation meetings and activities, building our capacity to deliver online events and prepare the audiovisual library materials.

An important indicator of success around Process and Activities is having properly managed a modest fund to cover activities, honoraria, and costs of promotion and post-event editing. One related lesson learned from process and activities is to budget funds, researchers' time, and effort generously. The iKT process is exhilarating but it constitutes a parallel effort for academics. In an academic environment where individuals with personal experience in health conditions are often compensated for their contributions to iKT, beyond just goodwill, academics should be ready to invest a considerable amount of effort into budget-related tasks. This might involve navigating through various stages within academic institutions to facilitate payments.

Health practitioners and researchers in this area have clamored that COVID-19 has shown that public and patient involvement is now necessary more than ever (70). When measuring *impact*, our reflection on the process elicits that the HIV in MOTION CoP contributed to challenging the echo chamber of HIV research meetings which favor the discourse of specialists, researchers, or clinicians by actively including the patient, clinicians, exercise staff, and students in the area. In the evaluation, one clinician wrote: "[This is] useful for my clinical practice. I work with clients who are HIV positive." Functioning as an *anti-echo chamber* is a significant qualitative impact. The inclusion of diverse voices (gender, location, access to services, etc.) enhanced the conversation and brought in competing perspectives.

Conclusion

The indicators of success isolated in this paper give an indication of the extent we meet the adapted criteria: Goals and Scope, Context and Structure, Process and Activities, Outcomes, and Impact.

For example, by designing the CoP for dialog across roles (patient, doctor, etc.), we increased the relational and intersectional values of the venture. CoPs with an inclusive goal of connecting personal and collective intersectionalities (e.g., physicians and AIDS activists both with high social capital in the field) can enact user-friendly "micro-processes of recognition and a breaking down of conventional hierarchies" (39). A micro-process can be as simple as a candid conversation between patients and doctors in a more power balanced setting outside the traditional patient–provider and medical history formats.

We realized how much effort goes into governance, design, implementation, after-event media editing, and approvals. At the time of this writing, we are on hiatus and looking for ways to transfer this modest but powerful legacy to a sister study; passing on this legacy has emerged as our greatest challenge so far.

In terms of structure, we managed well many technical aspects but could not completely avoid a degree of burnout. Putting together an ongoing online event requires a great deal of time, focus, and funds. However, one of our greatest limitations is not having been able yet to secure the sustainability of HIV in MOTION beyond the lifetime of the accompanying research study. Our gambit for sustainability is in having produced a slew of audiovisual materials that may be used in the development of HIV research teams, mentoring emerging clinicians, and to inform and inspire persons living with HIV.

Our recommendations based on these efforts and results is to continue fostering online instances of flexible dialogs that allow the voices of "patients," clinicians, and academics to mix without apprehension that some should be more authoritative than others; it shows positive process, outcomes, and impact. There is a growing need and demand for democratic dialogical spaces for health practitioners, researchers, and patients such as the space offered by a community of practice. Also, we recommend easing our academic standards, which tend to be untenable for the lay person wanting to participate, to seek flexibility and being surprised. Communities of practice can be informal without diluting the informative, clinical, and scientific content and allowing the voice of patients to emerge but uninscribed in the authoritative business of academia.

Data availability statement

The data supporting the conclusions of this article will be made available by the authors, upon reasonable request to the corresponding authors.

Ethics statement

We consulted on the need for ethics approval with the University of Toronto Health Sciences Research Ethics Board (REB) who confirmed that given the evaluative nature of the Community of Practice, which does not involve research participants, we did not require ethics approval.

Author contributions

FIC: Lead author, literature search, outlines, drafts, and final writing. TJ: provided extensive review. KM and BT: both research coordinators contributed with literature search and feedback and coordinating draft discussion meetings. GD, CP, SI, JL, and GB: non-academic authors who provided extensive support and written feedback from the "patient" and lived experience perspectives. GD: collected all data from electronic evaluation surveys. KKO: senior author, provided extensive writing, and evaluation. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2023.1154692/full#supplementary-material

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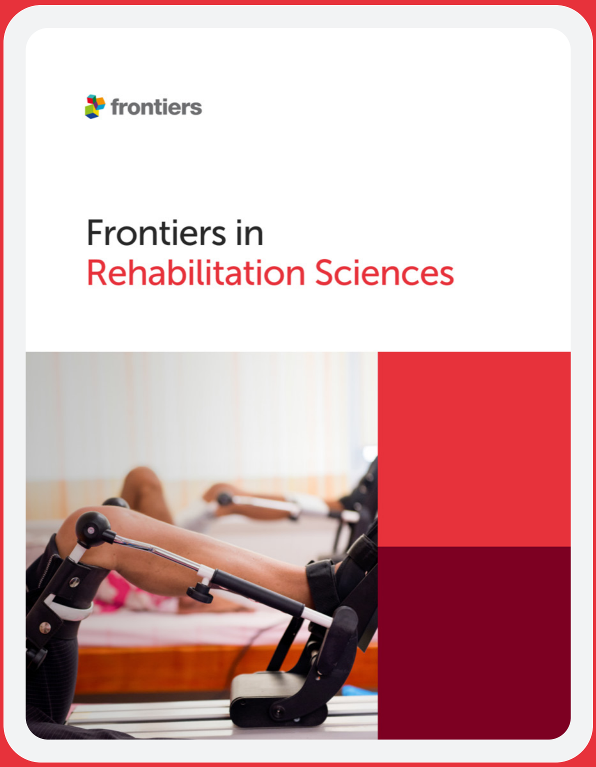

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