



A Qualitative Study of Fitness Coaches' Experiences in Community Based Exercise with People Living with HIV

Journal of the International Association of Providers of AIDS Care
Volume 20: 1-8
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DOI: 10.1177/23259582211046762
journals.sagepub.com/home/jia



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Abstract

Fitness coaches need to understand the needs of people living with HIV engaged in community-based exercise (CBE) to be competent in developing exercises programs with this population. Our aim was to understand coaches' experiences engaging in a CBE intervention with PLWH in an urban center in Canada. As part of a broader study, coaches supervised weekly hour-long individualized exercise sessions with PLWH over a six-month period. Using qualitative longitudinal methods, we interviewed coaches up to three times over six months. Transcribed interviews were analyzed cross-sectionally and longitudinally. Seven coaches participated in 15 interviews. Developing confidence, improving health and experiencing a sense of community were viewed as key benefits to PLWH by the coaches. Challenges included accommodating the episodic nature of HIV and ensuring they felt prepared to work with PLWH. Understanding the experiences of coaches engaged in CBE can assist in tailoring exercise programs to meet the needs of PLWH.

Keywords

Community-based exercise, exercise, HIV, qualitative research

Date received: 4 May 2021; revised: 24 August 2021; accepted: 29 August 2021.

What Do We Already Know about the Topic?

While exercise is safe and effective for people living with HIV, they are less physically active than those with other chronic illnesses.

How Does Your Research Contribute to the Field?

Fitness coaches in community settings experienced challenges related to the episodic nature of HIV when working with people living with HIV.

What are Your Research's Implications Towards Theory, Practice and Policy?

Findings highlight the importance of preparing fitness coaches to recognize episodes of illness and to adapt exercise programs to meet the needs and abilities of people living with HIV.

Introduction

As HIV transitions into a chronic illness for those who have access and adhere to antiretroviral medication, it is important for people living with HIV to engage in self-management strategies to

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maintain health and promote quality of life.¹ Exercise is one self-management strategy that is safe and effective for people living with HIV.²⁻⁴ Exercise is particularly important as people living with HIV have been shown to be less active than others with chronic illness.⁵ They are also less likely to meet weekly activity level recommendations than those living with other chronic illness.⁶

Community-based exercise (CBE) is a promising approach to improve the health of people living with HIV. CBE involves individuals exercising with the assistance of a fitness coach with the goal of promoting regular exercise in the community.⁷⁻⁹ CBE can provide support and encouragement to exercise, and promote emotional, cognitive and behavioural self-management strategies to help independently manage chronic health challenges.^{10,11} In people living with HIV, supervision of exercise is also predictive of lower drop out rates highlighting the importance of professional support in maintaining exercise regimes in this population.¹²

People living with HIV may experience health challenges which require fitness personnel to adapt or tailor their CBE programs. As they age, people living with HIV experience increased incidence of a number of co-morbid conditions including bone and joint disorders, cardiovascular disease, metabolic syndrome, earlier onset of frailty and increased risk of neurocognitive decline.¹³ Additionally, people living with HIV have unique needs related to the episodic nature of their illness in which they may experience fluctuating periods of illness and wellness.^{14,15} People living with HIV are also disproportionately from vulnerable populations and often experience multilayered stigma related to age, gender, sexual orientation, ethnicity and their HIV positive status.¹⁶ A qualitative study of people living with HIV who participated in CBE over a six month period found they valued the motivation provided by fitness coaches and increased their confidence over time; however concerns about the gym environment, stigma and episodic health challenges affected their overall experiences, further highlighting the importance of adapting exercise programs to meet their multifaceted needs.¹⁷

Fitness personnel should be sensitive to the unique psychosocial context of living with HIV and require background knowledge to best tailor exercise programs to the needs and abilities of people living with HIV. It is important to understand the experiences of fitness coaches when engaging with CBE so that educational programs can be designed to familiarize the coaches with the needs of people living with HIV and to ensure they are knowledgeable and confident in their interactions with a novel population. To our knowledge, there has been no qualitative inquiry of the fitness personnel (coaches) involved in delivering CBE to adults living with HIV. The purpose of this study was to understand fitness coaches' experiences of engaging in a CBE intervention with people living with HIV. Specifically, we examined the coaches' perceived challenges and benefits of their experiences.

Methods

We used qualitative descriptive longitudinal methods to examine the experiences of fitness coaches who supervised

people living with HIV or "clients" in a CBE intervention over time. The primary aim of qualitative longitudinal research is to study changes that occur over time and the processes associated with these changes.^{18,19} This study was part of a larger three-phased intervention study which examined the impact of a six-month CBE intervention on health and fitness outcomes among 108 adults living with HIV.¹¹ Adults living with HIV who considered themselves safe and medically able to engage in exercise were recruited from HIV community organizations in Toronto, Canada. Details of the protocol for the larger study are published elsewhere.¹¹

The setting was a community-based fitness center (YMCA). Phase 1 was a baseline monitoring phase (8 months). Phase 2 was the exercise intervention phase, in which clients were provided with a YMCA membership and expected to engage in aerobic, resistance, flexibility and balance exercises three times per week for 90 min each (6 months). A key feature of the intervention was one-on-one supervision by a fitness coach for 60 min in one of the weekly sessions. During this phase, clients were invited to attend monthly in-person self-management education sessions related to HIV and health. In Phase 3, clients were expected to continue with exercise independently three times per week at the YMCA (8 months).

All coaches affiliated with the CBE study were YMCA staff. Prior to beginning their engagement with clients living with HIV in the CBE intervention, coaches were asked to complete three self-directed interprofessional online learning modules related to HIV and rehabilitation. The three modules were (1) Introduction to HIV and Rehabilitation; (2) Rehabilitation Roles and Interventions; and (3) HIV and Aging. These are available on the website of Realize, a non-profit organization dedicated to fostering positive change in people living with HIV and other episodic disabilities. (<http://www.realizecanada.org/en/our-work/hiv-and-rehab/inter-professional-education/>). Coaches also participated in an orientation meeting which provided an overview of the study and procedures prior to the baseline monitoring phase. Coaches were asked to attend regular CBE study meetings throughout the study phases. As part of the study, clients completed the Goal Attainment Scale²⁰ and these goals were shared with the coaches to assist in developing tailored programs for their clients.

We invited all coaches to participate in a series of semi-structured in-person interviews. Our goal was to interview five coaches from a total of 18 on three occasions for a total of 15 interviews. We purposively recruited five coaches based on the overall number of clients they would be expected to supervise. Our goal was to conduct interviews just prior to the start of the exercise intervention (Time 1), mid-way (Time 2) and at the end of the intervention (Time 3). In the initial interview, one of three experienced interviewers asked coaches to reflect on their expectations, anticipated benefits and concerns with the upcoming CBE intervention. In subsequent interviews (Time 2 and 3), we explored experiences with the CBE intervention. Interviews were audio recorded and transcribed verbatim. Interviews were conducted from April 2017 to May 2018.

Ethics approval was received by the University of Toronto HIV Research Ethics Board (Protocol #32910). All fitness

coaches provided written informed consent prior to enrolment in the study.

Analyses

We conducted a descriptive thematic analysis using content analytical techniques.^{21,22} We used previously documented analytic processes to guide our longitudinal qualitative analyses.²³ We initially coded the first set of interviews using conventional content analysis focussing on the coaches' experiences, and perceived challenges and benefits of their experiences. Next, we developed in-depth cross-sectional summary profiles of the experiences of each coach at their initial interview from the transcript. For coaches who were interviewed on multiple occasions we conducted a longitudinal qualitative analysis, which required summaries of data both cross-sectionally at each time point and longitudinally.²³ Cross-sectional summary profiles were developed for subsequent interviews documenting coaches' experiences and emergent issues that had occurred over time on a summary form. Next, using the forms, we developed an in-depth summary profile of each coach over time. We used the initial profile for those who were interviewed on one occasion. In the final step, we compared the longitudinal summary profiles of each coach to document similarities and differences in the challenges and benefits of their experiences over time. This comparison resulted in the identification of themes reflecting the coaches' experiences. All interview summary sheets were developed by the first author (PS), and then independently reviewed and supplemented by another author (SCC, AMD, RA or KKO).

Results

Of the five coaches recruited, two left the YMCA and thus two more coaches were recruited. Thus, not all coaches were interviewed at all timepoints. Two coaches were interviewed on 1 occasion, 2 coaches were interviewed on 2 occasions and 3 coaches were interviewed on 3 occasions. This resulted in a total of 15 interviews. Two coaches identified as men and five identified as women. Of the 7 coaches, 5 were fitness coaches involved with the weekly coaching directly with clients (2 full time and 3 part-time) and 2 were involved in oversight and management of the program. Three coaches initiated the online training modules and 1 completed all 3 modules. Coaches supervised multiple clients with numbers ranging from 8 to 20. On average, interviews were 44 min in length.

Themes and subthemes are described below along with representative quotes identifying the coach (eg, C1 for Coach #1) and the timing of the interview (eg, T1 for Time 1).

Perceived Benefits

Coaches reported perceived benefits of engaging in CBE in three thematic areas: 1) clients living with HIV, 2) the coaches and 3) the YMCA organization.

1) Benefits to Clients Living with HIV

Developing confidence and improving health through coaching. Coaches perceived the primary benefit for their clients as regular access to a trained coach who provided motivation and encouraged accountability. The regular fitness assessments helped to "inspire" the clients by providing objective feedback which one coach stated made the clients feel "proud of themselves". Several coaches acknowledged that some clients had difficulties with the transition to working out "on their own" when embarking on independent exercise. Thus, developing the client's confidence in their ability to exercise was initially viewed as a key goal for the coaches:

(A benefit is) having a personal trainer, someone with a background of how to prescribe exercise and how to technically coach them throughout. So it prevents injuries. Say they were randomly given a program and they were asked to go to a gym and complete it, for most individuals it's lack of confidence and they have no idea what they're doing. (C3; T1)

Overtime coaches reinforced the importance of educating clients on how to exercise safely, monitor their status and ensure "their form" was correct. This coach spoke of his strategies for safe exercise at the third interview:

I did a lot of education in terms of safety with exercising. So I kept on reminding them so that when they exercise on their own they can know what to do, what to look for, etc (C5, T3)

Coaches perceived there were benefits to the health of their clients beyond improved fitness such as weight loss, decreasing pain and improving body shape. Overtime, some coaches experienced that their role impacted more broadly on life style and found that they provided advice on nutrition or referred clients to other services at the YMCA.

Clients might have learned something more than just the exercises. I taught them about overall how to manage their well-being through exercise and how that can play a part in their life and their lifestyle. (C3: T3)

At the third interview this coach declared that benefits to the clients' mental and emotional health were viewed as key to developing confidence and being motivated to exercise:

Another part that you can see is mental health. So you can tell that they're happy and they're okay. They're happy with what they're doing, they're happy with themselves. They're proud of themselves. (C4; T3)

Experiencing a sense of community. The "safe space" provided by the YMCA was seen as an appealing component of the intervention for clients living with HIV. The YMCA environment was perceived as being "non-specific" as related to illness or disability, which helped those clients fearful of disease disclosure to feel more comfortable. Coaches also felt that the

YMCA offered a flexible program to accommodate episodes of illness and tailoring of the program to co-morbidities.

All coaches felt that the sense of community and social connectedness was unique to the YMCA environment and was an important benefit. One coach described the YMCA as “like a family”. Most spoke of the unique mandate and mission of the YMCA which demonstrates a commitment to the community. Coaches described how seeing oneself as a member of a community, either the YMCA community or a community of people living with HIV, helped to motivate clients. Coaches spoke with pride about how the YMCA’s commitment to community values resulted in an ideal environment for clients living with HIV. While alluded to at the initial interview, this commitment to community became evident as the clients’ exercise programs progressed with this coach stating at time 2:

You could go anywhere and you can do a workout there and achieve the same results. A treadmill is a treadmill. What makes our treadmill different is the fact that there’s an element of caring, there’s an element of support ... (C2; T2)

Coaches also spoke of the holistic approach to health that was the mission of the YMCA and how it helped to promote a sense of community:

I think feeling that you belong to something ... it’s a very important piece of the overall body, spirit and mind and kind of together. (C6, T2)

2) Personal Benefits to Coaches. Coaches enthusiastically endorsed the benefits that they had personally received through their participation in the CBE intervention. There was reciprocal learning between the clients and the coaches. The coaches learned about HIV, how to decrease stigma and adapting exercise programs to accommodate co-morbidities. Initially, this coach spoke of the pleasure received through engagement in the CBE study:

Each client I see is a new learning opportunity for me and for me that’s huge. That’s why I really enjoy being a part of this study because it just opens new doors and also knowledge as well. (C3; T1)

Over time, the coaches described other skills learned through engaging in the CBE intervention. Having multiple clients living with HIV meant that coaches needed to learn time and organizational management strategies that went beyond coaching and fitness knowledge to deal with an increased caseload and scheduling.

I think this role is more than just personal training to be honest. You have to have a coordinator mindset to deal with clientele, schedule them, communicate, motivate them, be a motivator at the same time. It’s a lot to take on but it’s rewarding. (C3; T2)

Coaches talked about the rewards they experienced in “helping people” and watching them improve over time. Tracking their progress over the long term was satisfying,

allowing them to watch transitions and seeing their clients develop self-confidence. They felt pleased to participate as described by this coach at the end of the study:

So for me it was a very good experience to see how they’re living, what they’re doing and they’re like everybody else. And we just know how (HIV) can affect their lives emotionally, physically. I was very excited and happy to be part of something that can help them to improve their lives and their health. (C4; T3)

Seeing improvement in mood, motivation and mental health was particularly rewarding. Coaches described a sense of pride in seeing objective improvements in outcomes such as body fat composition and cardiorespiratory fitness (VO₂max) through the bimonthly fitness assessments over time.

... I’ve been working with (a client) probably four months now actually and (see) huge impacts on his overall health, mood, just the way he talks and behaves now, huge behaviour modification change. That translated just from the physical training itself and into a huge mental aspect of his life. (C3; T2)

3) Benefits to the YMCA. Coaches identified benefits to the YMCA as an organization. Pragmatically, the study was seen as an opportunity to increase membership of diverse groups. The study helped to bring recognition to the YMCA, providing a competitive edge and demonstrating how it was at the “fore-front of research”. Coaches also spoke passionately about the commitment that the YMCA has to the community and how this intervention exemplifies its commitment in keeping with its mandate and vision. Similarly, the study reinforced the values of acceptance and diversity which is core to its mandate.

Since we are diverse and our value is inclusion, we are finding a way to accommodate everyone that comes through our door. (C6, T2)

The CBE intervention was viewed as a model for other chronic diseases or marginalized populations, who could benefit from a focused exercise program. This coach described how the CBE model could inspire new programs:

The idea of what we’re doing here I think may be replicated in other forms or at least be the inspiration for maybe something new, a new way of reaching out into our communities and working with the individuals that are nearby accessing our services (C2; T1)

Perceived Challenges

Coaches reported challenges working with their clients related to the following three themes: 1) episodic and fluctuating nature of the health challenges experienced by clients living with HIV, 2) ensuring that coaches felt confident and prepared to work with clients living with HIV, and 3) logistical and scheduling issues.

1) *Episodic and Fluctuating Nature of HIV.* Interviewing the coaches over time allowed us to understand the challenges they experienced due to the episodic nature of their clients' illness. Most coaches encountered difficulties knowing how to help their clients when having a "bad day". One described accommodating the episodic nature of their client's illness as "the biggest challenge". They developed strategies to deal with pre-existing conditions that fluctuated over time (eg, osteoarthritis). This coach described how she tried to accommodate clients during their fitness assessments:

... I've had clients that came in and they just didn't look well or they didn't feel well. So I'll be like, are you comfortable doing this, doing the fitness assessment today. I'll give them that option of whether or not they want to kind of proceed with the fitness assessment, just because I know that if I was supposed to come in and I was not mentally and physically with the person that I'm coming in to meet, that I would want that option. (C5, T1)

Cancellations when clients were experiencing an episode of ill health were common. Episodes of illness were most commonly related to fatigue and mood. One coach understood that depression made it challenging for clients to motivate themselves and stated she had difficulty knowing whether clients had lost interest over time with the exercise intervention, or were struggling with mental health challenges:

Half of them are still suffering from depression and it's kind of hard for them to even come. (C7, T3)

Over time, some coaches developed strategies such as modifying the exercise regime that day and keeping flexible schedules to promote ease of rescheduling. At the third interview, this coach described how she learned to make concessions for clients living with HIV which she would not implement with others.

So I always be cautious about their condition, health condition, so that when they're sick or when they're having difficulty doing some of the things I don't push as hard as other people who would train with me. (C7, T3)

Several coaches gave their clients their phone numbers so they could text or phone to reschedule. While coaches acknowledged that "dropouts" were common among the general membership, when a person living with HIV stopped attending it was difficult to know if this was due to episodic illness or other life priorities taking precedence.

2) *Ensuring Coaches are Prepared.* There were mixed opinions on the value of the online learning modules in preparing coaches for working with clients living with HIV. Some coaches intended to complete the modules but did not follow through; others could not recall any information that they learned. Some thought these were lengthy and suggested that there should be a focus on "need to know" information. There were suggestions that the understanding of ethical

issues, knowledge around universal precautions and common misconceptions about the disease would be sufficient. It was important to be aware of the need for confidentiality related to HIV disclosure as noted by this coach:

Confidentiality is an important piece to me overall. I mean in particular for members of the study ... I know there's concern and things like ensuring our fitness testing space has frosted glass so people can't see in, little things like that. (C2, T1)

All coaches agreed that there was a need to be aware of general knowledge about HIV transmission and the "myths" about HIV. At the end of the program this coach reflected on the importance of being prepared:

... if someone, for example, started bleeding, just being able to know and have enough knowledge to not freak out as much. I feel like that was very good (to know) because it made me feel more comfortable working with people with HIV. (C5, T3)

One coach who was new to coaching stated he was initially apprehensive about working with clients living with HIV and found the modules helpful. Another felt it was helpful to understand what the clients were "dealing with" particularly any common co-morbidities or episodic disability which could affect engagement in exercise.

I think it would be helpful to see a little bit better picture of the nature of the episodic disability and how it impacts one's for example fatigue level or energy level. (C1, T1)

By the end most coaches acknowledged that experiential learning through working with clients living with HIV was the most valued learning experience as described by this coach:

I learned more about the impact of HIV on ability to exercise or stuff like that more practically, more when I was working with (my clients) compared to when I was participating in any type of training. (C1, T3)

3) *Logistical and Scheduling Issues.* Scheduling challenges related to clients' competing priorities such as work schedules, access to transportation and childcare. The gym could become crowded during certain time periods limiting access to adequate space and equipment. This was a challenge for clients who were not comfortable exercising in an open gym environment, as noted by this coach:

Working around those peak hours, some CBE clients are a little shy. They don't want to work when there are a lot of people. They don't want to be watched and I totally understand that. (C3, T1)

Part-time coaches were more transient than full-time coaches leading to turnover of staff which meant some clients had several coaches over the course of the intervention. Coaches observed that this was unsettling for some clients. A consistent

coach helped the client to feel more confident if the coach wanted “to push” during a session. As stated by this coach:

I like to be very consistent with them because it's very important for the client to stay with the same coach. That's what I think because you get used to them. They get used to you and feel more confident ... (C4, T1)

Recognizing that the program was time limited, coaches worried about whether their clients would develop a “dependence” on them and continue their programs of exercise. In their typical role, it was unusual for coaches to have weekly sessions with clients over an extended period so they needed to develop a plan to promote independence over time. This required a deliberate approach to scheduling and progressing the client's program of exercise. One coach commented on the timing of this push to independence:

I think now they're in the connected phase. So they are good, they are confident here, they know some friends, they know our staff. So we need to find I guess some kind of tool to encourage them to go even more further (C6, T3).

Discussion

To our knowledge this is the first study to examine the experiences of fitness coaches implementing one on one weekly coaching sessions in a community based setting with clients living with HIV. Coaches became familiar with the complex nature of their clients' health issues, increased their awareness of the benefits of CBE to all stakeholders and developed strategies to assist the implementation and delivery of the exercise intervention with PLWH. Interviewing the coaches over time allowed us to confirm some of the coaches' initial expectations and note challenges and benefits that would not have been evident in a study with a cross-sectional design. For example, at time 3 coaches were able to reflect on how their role went beyond instilling confidence in exercise to include other life style recommendations and contributing to positive mental health. Similarly, the sense of reciprocal learning and satisfaction that emerged over time may not have been as apparent if the interviews were on one occasion.

Coaches experienced challenges related to the episodic nature of HIV which resulted in unpredictable fluctuations in both physical and mental health. The coaches recognized these and tried to accommodate episodes of illness through flexible scheduling and adapting the exercise regime. People living with HIV participating in CBE described the complexities of living with episodic mental and physical health challenges, further reinforcing the need for coaches to adopt a client-centered approach and be sensitive to episodes of ill health.¹⁷ Our findings highlight the importance of preparing the coaches to recognize episodes of illness and develop client centred strategies to support clients through fluctuations in health. While many individuals with chronic illness experience motivation challenges when exercising, a systematic review

suggests that people living with HIV have higher dropout rates than other populations with chronic illnesses.¹² Given the high prevalence of depression among people living with HIV, coaches need to be prepared to help guide them through difficult periods.²⁴ Similarly, fatigue is also a common episodic challenge experienced by people living with HIV which requires strategies to assist with maintaining activity levels.²⁵

It was not surprising that the coaches endorsed improved health and increased confidence in exercising as benefits of personal coaching; these would be expectations for any population engaging in a supervised fitness program. The sense of community that was non-judgemental emerged as an important benefit for clients living with HIV. People living with HIV participating in CBE may also worry about unintended disclosure of their HIV positive status. The values of inclusion espoused by the YMCA, a non-profit organization, may be particularly important for those who feel marginalized or stigmatized. While not applicable to all people living with HIV, there may be a group who is better suited to a supportive and inclusive community environment.

Coaches agreed that there was a need to understand ethical issues related to confidentiality around HIV status, be aware of common myths about HIV and be familiar with universal precautions prior to commencing their coaching with clients living with HIV. While the online learning modules provided this essential information, these were not specifically developed for fitness personnel, nor for this study. This may have led to the limited uptake by the coaches. However, the coaches suggested that these provided too much detail, stating their experiences with the clients provided more relevant education. Basic information could be provided through alternate educational approaches, such as small group problem-based learning, which encourages active discussion of case scenarios, problem-solving and sharing of lived experiences, and may be more feasible in a busy gym environment.²⁶ This could promote experiential learning and provide structured time rather than the expectation that learners carve out a portion of their schedule for learning.

It was encouraging that the benefits of the CBE intervention were perceived to extend beyond people living with HIV to the coaches and the YMCA organization. Success in supervised physical activity in formal structure programs may be in part due to the therapeutic alliance developed between the coach and the client.²⁷ The coaches appeared to be highly engaged with their clients and found their experiences to be rewarding as they learned new skills and expertise. Similarly, the coaches perceived there were tangible benefits for the YMCA including recognition as a forward-thinking community organization, partnering in community-engaged research, and increasing their membership. This collaboration has also been useful in program evaluation, allowing the YMCA to demonstrate their impact to the HIV community²⁸

One-on-one coaching is perceived as a significant benefit of a CBE intervention by people living with HIV¹⁷ This was reinforced by the coaches. However, clients had access to personal coaching due to their involvement in the study. Coaching fees are often in addition to a gym membership and may not be

feasible for people living with HIV on a limited income. Remote coaching models precipitated by the novel coronavirus pandemic have the potential to provide an affordable alternative.²⁹

This study is limited as the coaches volunteered to participate in this study and thus may have more favourable attitudes to working with people living with HIV. While not all coaches were able to complete interviews at three time points, we conducted 15 interviews. Following the coaches over time allowed us to gain insights into the coaches' initial perceptions and views how these evolved over time.

In conclusion, with preparation fitness coaches can be a valued and supportive member of a team that supports people living with HIV in successful incorporation of exercise to support self-management strategies. Future research should focus on identifying who would most benefit from coaching in a community-based setting and how to best tailor education programs to meet the need of fitness coaches.

Acknowledgements

The authors would like to thank the YMCA and the fitness team for their support of this study. Ethics approval was received by the University of Toronto HIV Research Ethics Board (Protocol #32910). All fitness coaches provided written informed consent prior to enrolment in the study.


Declaration of Conflicting Interests


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This work was supported by the Canadian Institutes of Health Research (CIHR) HIV/AIDS Community-Based Research Initiative [CIHR FRN: 139685]; Kelly K. O'Brien is supported by a Tier 2 Canada Research Chair in Episodic Disability and Rehabilitation.

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