Experiences of People Living With HIV in Community Based Exercise: A Qualitative Longitudinal Study

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Abstract

This qualitative longitudinal study examined the experiences of people living with HIV who engaged in a structured community-based exercise (CBE) program under the supervision of a fitness coach. Twenty people living with HIV were invited to participate in 3 semi-structured interviews over time. Participants engaged in exercise 3 times per week for 6 months with one weekly session supervised by a coach. Interviews were audio-recorded, transcribed verbatim and underwent longitudinal thematic analyses. Eleven participants were included representing a total of 30 interviews. Participants valued their experiences with the CBE program, particularly the motivation provided by the coach. Concerns about the environment, stigma and episodic health challenges affected their overall experience. To foster independence and promote self-management, health providers should consider these findings when encouraging CBE with people living with HIV. It is important to understand their goals and offer a variety of exercise options to meet their needs.

Keywords

community-based exercise, exercise, HIV, qualitative research

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Introduction

The life expectancy of people living with HIV, who have access and are adherent to anti-retroviral therapy, is approaching that of individuals without HIV. Consequently, HIV has been transformed into a chronic illness in which many may experience disability related to the side effects of medication, effects of the virus and natural consequences of aging.^{2,3} Rehabilitation can play an important role in helping people living with HIV manage their disability and increase their quality of life. 4 As with many chronic illnesses, self-management strategies can be important to the overall management of HIV- related disability.⁵

Exercise is a self-management intervention that can address disability among people living with HIV. 6 In people living with HIV, formal exercise and physical activity have been associated with enhancements to physiologic and metabolic outcomes, 7-10 cognitive health, 11 social support, and quality of life. 12 Regular exercise is safe and can lead to improvements in cardiopulmonary fitness, strength, body composition, and mental health in people living with HIV. 13-15

In spite of the documented benefits, engagement in physical activity and exercise is challenging for people living with HIV. A recent systematic review reported people living with HIV were less active than others with chronic illness and recommended that physical activity counselling be a key component of their

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What Do We Already Know about This Topic?

In spite of the documented benefits, engagement in physical activity and exercise is difficult for people living with HIV due to unique physical, mental health and psychosocial challenges.

How Does Your Research Contribute to the Field?

While people living with HIV who engaged in community based exercise were able to increase their confidence over time, concerns about the environment, stigma and episodic health challenges affected their overall experience.

What Are Your Research's Implications Toward Theory, Practice or Policy?

To foster independence and promote self-management, health providers should consider several factors when encouraging community-based exercise with people living with HIV.

rehabilitation. ¹⁶ They are also less likely to meet recommended weekly activity levels than others with chronic illness. ¹⁷

Community based exercise (CBE) is a promising approach to improve the health of people living with HIV within a self-management framework. CBE involves a group of individuals exercising with the assistance of an instructor with the goal of promoting regular exercise in the community. ¹⁸⁻²⁰ CBE can foster social interaction, provide support and encouragement to exercise, and can promote emotional, cognitive and behavioural self-management strategies to help independently manage chronic health challenges. ^{21,22}

People living with HIV have unique health challenges or disability, defined as physical, cognitive, mental and emotional symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty or worrying about future health.²³ Disability experiences can impact the ability of people living with HIV to engage in CBE, including those related to physical health (e.g., fatigue),²⁴ mental health (e.g., depression), ²⁵ and psychosocial (e.g., stigma, poverty)²⁶ well-being. Additionally, disability associated with HIV is recognized as having a temporal component as it may be episodic in nature. 23,27 The fluctuations over time and associated uncertainty that result from episodic disability may complicate both engagement in and measurement of effectiveness of CBE interventions. Understanding how episodic disability affects the CBE experiences of people living with HIV will be incomplete using only cross-sectional research designs. Quantitative study designs do not provide an in-depth understanding of the lived experiences of people living with HIV engaging in CBE. Qualitative longitudinal study designs can complement quantitative designs and provide nuanced insights for developing treatment strategies to decrease disability.²⁸ This methodology can promote increased understanding of health challenges and strategies that individuals use to make sense of the past and plan for the future.²⁹

The overall purpose of the study was to examine the experiences of adults living with HIV who participated in a structured 6-month exercise intervention in a community setting over time.

Methods

We used qualitative longitudinal methods to examine the experiences of adults living with HIV who engaged in a CBE intervention. The primary aim of qualitative longitudinal research is to understand changes that occur over time and the processes associated with these changes. ^{30,31} It seeks to explore how and why change occurs. ³¹

This study was part of a larger 3-phase community-based exercise study which examined changes in fitness among 108 adults living with HIV.²² Adults living with HIV who considered themselves safe and medically able to engage in exercise were recruited from community-based organizations in Toronto, Canada.

Participants engaged in aerobic, resistance, flexibility and balance exercises. Phase 1 was a baseline monitoring phase (8 months). Phase 2 was the exercise intervention phase in which participants were provided with a Young Men's Christian Association (YMCA) membership and expected to exercise 3 times per week for 90 minutes each (6 months). A key feature was the supervision by a certified personal coach for 60 minutes for one of the sessions each week. The qualitative study occurred primarily in Phase 2. During this phase, participants also were invited to attend monthly in-person self-management education sessions related to HIV and health. Self-management educational sessions took place each month of the intervention phase (6 sessions in total), focused on topics related to self-management and healthy lifestyle living with HIV. Participants had the option to attend 6 of 7 possible sessions, of which topics included: HIV and exercise, nutrition and healthy weight, mindfulness and stress reduction, sleep health and hygiene, HIV and neurocognitive health, complementary and alternative therapies in HIV, and role for rehabilitation in the context of HIV. In Phase 3, participants were expected to continue with exercise independently 3 times per week at the YMCA (6 months). Participants underwent physical fitness and questionnaire assessments at 2-month intervals as part of the study evaluation.

We invited 20 participants from the larger study to participate in a series of 3 semi-structured interviews. We used purposive sampling in which we sought variation in gender, age, ethno-cultural background, time since HIV diagnosis and experience with exercise. There is little literature to guide sample size calculations in qualitative longitudinal research. For single interview studies, a sample size between 20 and 30 is considered a conservative guideline.³² Qualitative longitudinal research elicits a large amount of data, thus we recruited 15 adults living with HIV (potentially 45 interviews). As some participants withdrew after the first interview, we recruited

5 additional participants. Qualitative interviews occurred just prior to the start of the exercise intervention (Time 1), mid-way (Time 2) and at the end of the intervention (Time 3). As we were interested in the experiences of those who completed the intervention, we included only those who participated in at least 2 interviews including the final interview.

Three experienced interviewers were involved in data collection over the course of the study. In the initial interview, interviewers explored past experience with exercise, limitations to functional activities and their motivation and goals for participating. Participants were asked to reflect on their expectations, anticipated benefits and concerns with the upcoming CBE intervention. In the subsequent interviews (Time 2 and 3), we explored experiences with the CBE intervention. Interviewers shared the participant's responses allowing them to reflect and build upon past interviews, a form of transactional validity in which member checking is part of the data collection process.³³ We further explored issues that were identified at Time 1, probing the participants to consider if any and what changes had occurred. Emergent themes were documented and discussed with participants at Time 2 and/or Time 3. Interviews were audio recorded and transcribed verbatim.

Analyses

Longitudinal qualitative analyses are complex, requiring summaries of data both cross-sectionally and longitudinally. A previously documented analytic process guided our qualitative analyses.²⁸ We developed in-depth summary profiles for each participant at their initial interview from the verbatim transcript. Cross-sectional summary profiles were then developed for subsequent interviews, documenting perceived changes in health and disability 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 participant's experiences with the CBE intervention over time. In the final step, we compared the longitudinal summary profiles of each participant to document similarities and differences in the experiences over time. This comparison resulted in the identification of preliminary themes reflecting the participants' experiences over time. Final themes resulted from team consensus following discussion and modification of the preliminary themes. All interview summary sheets were developed by the first author, and then independently reviewed, verified and supplemented by at least one other co-author.

Ethical Approval and Informed Consent

Ethics approval was received by University of Toronto (HIV Ethics Board; Approval #32910). All participants provided written informed consent prior to enrolment in the study.

Results

Thirty interviews from 11 participants were included in the analyses; 8 participants completed 3 interviews and 3

Table 1. Demographic Characteristics of Participants (n = 11).

Gender	
Man 7 (64%)	
Woman 4 (36%)	
Age (years), median (25-75th percentile) 52 (37, 61)	
Year of HIV diagnosis, median 2006 (1995, 20	12)
(25-75th percentile)	,
Currently taking antiretroviral therapy (100%)	
Viral load undetectable ($n = 3 \text{ missing}$) 8 (73%)	
Partnership status	
Married or common law 3 (27%)	
Single 6 (55%)	
Separated or divorced 2 (18%)	
Living Arrangement—Living	
Alone 5 (45%)	
With a partner 3 (27%)	
With children I (9%)	
With sibling(s) I (9%)	
With unrelated people I (9%)	
Current employment status	
On disability 5 (46%)	
Working, volunteering or student 3 (27%)	
Retired I (9%)	
Unemployed or other 2 (18%)	
Household income per year (Canadian	
dollars) (n = 1 missing)	
<\$20 000	
\$20 000-40 000 2 (18%)	
\$70 000–999 999 I (9%)	
Most commonly self-reported concurrent	
health conditions. Number of	
participants living with:	
Joint pain (arthritis) 5 (45%)	
Mental health condition 5 (45%)	
High cholesterol 5 (45%)	
Elevated lipid level 4 (36%)	
Muscle pain 3 (27%)	
Bone and joint disorder 3 (27%)	
Elevated triglycerides 3 (27%)	

participants completed 2 interviews. The majority identified their gender as man (n = 7; 64%) with a median age of 52 years (interquartile range (IQR) 37, 61) and median 11 years since HIV diagnosis (IQR 22, 5). Additional demographic and exercise characteristics of participants are outlined in Tables 1 and 2.

The emergent themes reflected the experiences of the participants over time including development of increased confidence. They experienced worrying about their body image and exercising in a gym environment, which changed over time as some became more confident and comfortable. These experiences were affected by their complex lives with episodic illness challenging their ability to engage in CBE. They encountered motivating factors including meeting their goals as they progressed. Participants also described valuing the relationship that developed with their coaches over time. Each of the themes are described in detail below with representative quotes.

Table 2. Exercise Characteristics of Participants (n = 11).

Characteristics	Number of participants (%)
Self-reported level of exercise prior	
to the CBE	1 (0%)
Do not exercise, and do not intend to start	l (9%)
Do not exercise, but thinking of starting	4 (36%)
Currently exercise some, but not regularly	4 (36%)
Currently exercise regularly	I (9%)
Exercised regularly in the past but not	I (9%)
currently	
Number of coaches during intervention	
phase	
I coach	6 (55%)
2 coaches	3 (27%)
3 coaches	l (9%)
4 coaches	I (9%)
Number of participants who attended	6 (55%)
a minimum of I monthly educational session	` '

Increasing Confidence

Participants spoke of experiencing increased confidence in a number of areas and feeling better about themselves over time. Several who had never exercised in the past were nervous about starting the intervention and about their ability to complete an exercise program at Time 1. Others initially worried about being able to exercise regularly when having an exacerbation of symptoms and developed the ability to modify their program when having a "bad day". By the end of the program most expressed confidence in their ability to exercise safely, remember their exercise program, and knowledge of how to progress their exercises.

But when I go in this study I get the proper instruction or is it I'm doing right or wrong. (My coach) knows better. Like what is my goal, he can give some guidance. According to that I can go from that. So that next year without his help I can do my own. (P29, man, 40 years old, >5 years since HIV diagnosis)

This increased confidence affected other aspects of participants' lives. Some made other lifestyle changes, for example, watching their diet and quitting smoking. Several spoke of being able to communicate better with family members or partners. Many spoke of feeling happier and less depressed. This woman commented on how her improved mental health, resulted in better sleep and helped her to cope with uncertainty:

Now I really learn a lot from this because when I started I was emotionally and mentally not good at all because I didn't accept (my diagnosis). But since I started the exercise my mind is better and I'm sleeping much better because before I was thinking too much what will happen, what will happen, when something is going to strike me, when I'm going to die. But now I'm seeing there's light to it. So one day at a time and my life is not ending (P61, woman 55 years old, >5 years since HIV diagnosis)

This participant spoke directly to the effect of the program and how others had seen a change:

It boosts my own self confidence and my self esteem and my personal image of myself. That energy shift inside translates outwardly and people see that and people respond to that. (P56, woman, 39 years old, >5 years since HIV diagnosis)

Worrying About Body Image and the Gym Environment

Many participants experienced worries about how they would integrate into the YMCA environment initially. Most were not interested in attending group exercise classes. They did not see themselves as people who engaged in "hard core workouts" or as competent exercisers and perceived that others in the gym would be observing them. Others worried that they were "too skinny" or "too old" or about others in the environment observing the effects of lipodystrophy. One 70-year-old man spoke of how uncomfortable he felt exercising among young men who were in "great shape". Over time, some grew more comfortable exercising in an open gym environment, stating they didn't feel as "out of place."

It's one of those stigma things and you not lifting all the heavy weights, you not doing all the stuff that's around you and all that moaning and groaning. I always feel that people are looking at you if you're just doing very light things (P89, man, 62 years old, >5 years since HIV diagnosis)

Others engaged in different strategies to increase their comfort level. For example, this man chose to get an upgraded membership which allowed him to work in a smaller, quieter gym due to these concerns.

I just find (the small gym) not as threatening or intimidating by a bunch of younger men and in better great shape. There are some young men in great shape there but I avoid them more by being in the plus membership. (P108, man, 70 years old, >5 years since HIV diagnosis)

Over time, most participants were very positive about the staff and felt the YMCA was a welcoming and non-stigmatizing environment though there was still a preference for individual exercise sessions. Three participants were concerned about accidental HIV disclosure and stigma. They worried that they would be identified as being part of a study specific to people living with HIV, which could result in unintended disclosure. For instance, one man was concerned that others would wonder how he could afford a coach and would identify him as living with HIV participating in a study. These individuals were reluctant to interact with others stating they would be more comfortable exercising in an environment exclusively with those living with HIV. These views did not change over time.

I will see (if I will interact with others in the program). I don't know. I'm not trusting that much because I lost so much trust in people. (P26, woman, 48 years old, >5 years since HIV diagnosis)

Living Complex Lives With Episodic Challenges

Many participants described complex lives which challenged their ability to adhere to the exercise program. They experienced episodic health challenges and co-morbidities (e.g., diabetes, fibromyalgia, chronic pain) that meant there was a need for the coach to be flexible about attendance. Some recognized they had "good and bad days" and worried about motivating themselves to attend. One woman spoke of how interruptions due to episodes of ill health led to a feeling of forever "restarting" her program. This man spoke of his struggles of managing multiple episodic co-morbidities:

...it is a lot of struggle to maintain day to day routines and all. If one problem, it's still manageable. But two or three problems...it's too many problems. (P29, man 40 years old, >5 years since HIV diagnosis)

While only a few participants indicated that they suffered with mental health issues initially, over time all spoke of experiencing challenges such as depression and anxiety. Participants stated it was difficult to find motivation to attend exercise sessions when "feeling down". The episodic nature of these mental health challenges was apparent over time. For example, one woman, a non-exerciser, was socially isolated, depressed and living precariously in a shelter at Time 1. At Time 2, she was very positive, had connected with others who supported her exercise program, had lost weight and was confident in her ability to exercise. By Time 3, she had begun the follow-up phase of the study (Phase 3), and missed the motivation of her coach, her attendance had decreased and she stated that her friends were too busy to support her stating, "(I need) a friend to exercise with me to give me the motivation to come more often than staying in the house and doing nothing." (P43, woman, 31 yea.rs old, <5 years since HIV diagnosis).

Contextual factors compounding participants' physical and mental health challenges added further complexity to their lives. Managing their complex lives often meant that exercise was not a top priority. Some participants described living precarious lives with financial insecurity and relying on disability pensions, and were often socially isolated. As one man stated, "HIV is our first thing but we have all this other crap that goes with it." (P89, man, 62 years old, >5 years since HIV diagnosis).

Experiencing Motivation and Setting Goals

Participants experienced motivators which enabled them to engage and continue in the CBE intervention. The intervention served as a catalyst for those who had exercised in the past but needed an incentive to get started again, or as one participant described it, "a push." As many were living on limited income such as disability pensions, the free membership to the YMCA offered through the study also provided the initial motivation. Geographical proximity to home and easy access by public transport made attendance easier. A routine structure was

important; knowing that there was a schedule to adhere to allowed participants to plan their weeks as noted by this woman:

But this time I know that I am scheduled in something I have to do. I know someone is waiting for me. I know that someone made time for me. I have to go. (P26, woman aged 48, >5 years since HIV diagnosis)

The regular fitness assessments that were part of the study evaluation was a motivator that served as an objective indicator of improvement towards their goals. For some, the contribution to research was an important goal as they perceived that they could "give back" to others in the HIV community. Those who set specific goals were able to acknowledge their accomplishments and this motivated them to continue. Some worked to accomplish goals in each session so they had "something to work towards." Others stated long term functional goals in their initial session with their coach. Meeting their goals became evident over time. For example, one woman found it was easier to pick up her daughter and carry her to bed stating she felt like "superwoman." A man noticed his balance was improved making it easier to navigate public transit. Another man set a goal of being able to walk long distances on upcoming travel. At the end of the study he reflected:

I definitely notice that I can do more without getting winded, out of breath. So I have better stamina. I think it really helped for going on the two trips that I did because you know I didn't have any problems walking. (P108, man, 70 years old, >5 years since HIV diagnosis)

Over time participants discussed perceived impacts of their program including having more energy, feel stronger and improved body image. Several participants described an improved sense of well being and accomplishment that motivated them to continue their exercise sessions. Participants spoke of exercise as one way to cope with personal struggles especially those related to mental health. As this woman stated:

Exercising is my coping strategy for my depression. So when I feel down and I go (to the gym) I get distracted. I see people. I do something I enjoy. (P26, woman, 48 years old, >5 years since HIV diagnosis)

Even with these motivators, some participants had concerns about being able to continue with exercise after the intervention solely through self-motivation. Reinforcing the importance of having an external motivator, this woman remarked at the end of the intervention, "I need company to do exercises or else I'll quit faster than you can say." (P43, woman, 31 years old woman, <5 years since HIV diagnosis).

Valuing the Coach Relationship

Most participants spoke highly of their relationship with their coaches and expressed sadness about "losing them" following

the 6-month intervention. Participants expressed that the coaches helped them to learn and progress exercises in ways not possible in a group situation. Over time, the coaches supported the participants in many ways by providing motivation and encouragement, adapting exercises, providing feedback, and ensuring that participants "didn't cheat" as reflected by this participant:

Every time I meet the coach it's a new week. I always feel energized and ready to go, great interaction with her. I know she sees me, hears me, accommodates on my program because she's trying to get the optimum that I can do for this (P79; man, 64 years, >5 years since HIV diagnosis)

Many coaches were flexible to changing appointments to accommodate participants' schedules and fluctuations in health. Three participants spoke of how their coach went "above and beyond" by connecting with other health providers, such as concurrent physiotherapy, to ensure that the exercise program was complementing other interventions. Some developed positive relationships with their coaches over time which provided motivation to attend regularly:

It was her [the coach's] involvement with me that I felt I was her only person and I know I wasn't but that's how I felt when I was dealing with her, which is great (P89, man, 62 years old, >5 years since HIV diagnosis).

Some participants expressed mixed feelings about their coach over time. Two indicated in the interviews that they asked for a change of coach for better compatibility. A few had multiple coaches during the intervention due to staffing changes and felt consistency was key. Some participants felt that the coaches should provide additional services such as counselling and psychosocial support with one person stating, "it would be way cooler if the personal trainer was a therapist too." In spite of these concerns and expectations, by Time 3 the participants endorsed the coach as important motivation for completing their exercise intervention. The coaches promoted a sense of accountability as one participant stated, "But I'm not going to cancel on her because I made a commitment to meet with her." (P115, 57 years old, >5 years since HIV diagnosis).

Discussion

Our findings suggest that participants living with HIV valued their experiences with a 6-month CBE intervention over time, particularly the motivation and weekly support provided by the coach. While they were able to increase their confidence over time, concerns about the environment, stigma and episodic health challenges affected their overall experience.

In a cross-sectional focus group study, Neff et al also identified personal (e.g., lack of motivation and confidence), environmental (e.g., comfort in gym) and physical (e.g., pain) factors to initiating and maintaining exercise in older men

living with HIV.³⁴ However, our longitudinal design revealed unique challenges related to the episodic nature of HIV and provided insights into the changes in confidence over time. Participants also identified factors which encouraged them to continue with the program, such as location of the gym and tailoring the program to individual needs that were similar to those found in other chronic illnesses.^{35,36} Following participants over time revealed the motivation provided by meeting their goals and through the relationship they developed with their coaches.

There were concerns related to body image and exercising in an open gym environment. Some long-term survivors may have concerns related to lipodystrophy while others may be concerned with their overall body appearance in a setting where many individuals engage in weightlifting activities. These environmental concerns underline the importance of identifying who is best suited to exercising in an open gym environment. For some, especially those in which distance to the gym presented motivational challenges, home-based exercise may be an option. Recent advances in telehealth delivery promoted by the COVID 19 pandemic may extend the possibilities of remote coaching. As coaching contributed to motivation and was perceived positively by the participants, it will be important to assess the effectiveness of at-home coaching delivered online.

People living with HIV can also have challenges related to stigma, with many long-term survivors still experiencing residual trauma from the early days of the HIV epidemic. ³⁹ Although societal attitudes have changed since the early years of the epidemic, stigma remains and can add stress, particularly to those recently diagnosed, as was evident with our participants. The fear of experiencing stigma and accidental disclosure did not change over time in several of the participants suggesting that some may be more comfortable in an exercise environment which is solely targeted to those living with HIV.

Social support has long been considered an active ingredient in chronic disease self-management programs and has been rated as the most helpful self-management strategy in people living with HIV. 40 Following the participants over time allowed for insight into the value of the relationship with the coach for motivation, education and social support. While we also provided opportunities for educational group sessions, few participants regularly engaged in these sessions, suggesting that they did not consider their peers to be an important source of social support. This is in contrast to a previous study in which people living with HIV preferred exercising in groups, although participants in this study were not followed over time. 41 Participants' reluctance to take part in group-based exercise classes offered at the YMCA or educational group sessions may in part be due to the varied schedule of the participants, as participants were not organized to exercise in groups or partners. However, independent exercise in a traditional gym may not be the best alternative for those in which ongoing social support is an important goal.

The benefits of exercise for people living with HIV are well established. 13,14 It is evident, however, that CBE programs cannot meet the diverse needs of all people living with HIV. Given the complexities of lives of many people living with HIV, the episodic nature of the disease and the mental and physical health challenges, it will be important to have a variety of exercise programming and delivery options to meet their needs and to determine who best benefits from a CBE program. Weekly access to a coach over a 24-week period was highly valued by our participants. Yet there were some who had anticipated that the coach would provide mental health and counselling supports, a service which is outside their scope of practice. It is worth highlighting that in 3 participants, the coaches made efforts to collaborate with other health providers to ensure that the exercise program complemented other exercise initiatives and was adapted to their health challenges and disabilities. CBE programs which provide comprehensive interprofessional support may be warranted for some. Indeed, Goulding et al found that in people living with HIV experiencing depression and/or mental health issues, exercise alone was insufficient to sustain improvements in quality of life and concluded that other supporting interventions are required. 42 Some people living with HIV may benefit from a more structured group approach which provides opportunities for peer interaction and support. 43 Peer-based models of physical activity, in which people living with HIV offer mutual support and motivation to exercise, may also be more financially sustainable than formal coaching models.

The longitudinal study design was a strength of this study which allowed us greater insights into the participants' experiences over time. Additionally, our recruitment strategy ensured we had variation in gender, age, ethno-cultural background, time since diagnosis and experience with exercise. There is a possibility that those who completed the interviews were those most positive about the program and the most successful. However, there were a range of experiences with some participants critical of the program and stating that they were not likely to continue to exercise following the intervention. There were insufficient numbers of women to perform separate gender analyses. ⁴⁴ Future work should examine gender-specific exercise experiences. ⁴⁵

In conclusion, while participants in the study valued their experiences in CBE, they experienced challenges unique to living with HIV that need to be considered in program development. Given the diversity of needs of people living with HIV, it is unlikely that one program will meet the needs of this population. A menu of options and a coordinated care plan may be necessary in those with complex needs or who are experiencing an episode of ill health. Further research with people living with HIV, including quantitative studies to examine long term adherence to exercise, feasibility of sustained programs, and to identify who would most benefit from a CBE program is warranted.

Declaration of Conflicting Interests

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References

- Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet*. 2013;382(9903):1525–1533. doi: 10.1016/S0140-6736(13)61809-7
- Guaraldi G, Prakash M, Moecklinghoff C, Stellbrink HJ. Morbidity in older HIV-infected patients: impact of long-term antiretroviral use. AIDS Rev. 2014;16(2):75–89.
- Kendall CE, Wong J, Taljaard M, et al. A cross-sectional, population-based study measuring comorbidity among people living with HIV in Ontario. *BMC Public Health*. 2014;14:161. doi: 10.1186/1471-2458-14-161
- Worthington C, Myers T, O'Brien K, Nixon S, Cockerill R. Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. *AIDS Patient Care STDS*. 2005;19(4):258–271. doi:10.1089/apc.2005.19.258
- Swendeman D, Ingram BL, Rotheram-Borus MJ. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*. 2009;21(10):1321–1334.
- Botros D, Somarriba G, Neri D, Miller TL. Interventions to address chronic disease and HIV: strategies to promote exercise and nutrition among HIV-infected individuals. *Curr HIV/AIDS Rep.* 2012;9(4):351–363. doi:10.1007/s11904-012-0135-7
- Gomes-Neto M, Conceição CS, Carvalho VO, Brites C. A systematic review of the effects of different types of therapeutic exercise on physiologic and functional measurements in patients with HIV/AIDS. *Clinics (Sao Paulo)*. 2013;68(8):1157–1167. doi:10.6061/clinics/2013(08)16
- Trevisol F, Alencastro P, Ribeiro P, et al. Association of physical activity with lipodystrophy syndrome in HIV-infected patients. *J AIDS Clinic Res.* 2012;3:8. doi:10.4172/2155-6113.1000177
- Guedes DP, Gonçalves LA. Impact of the habitual physical activity on lipid profile in adults. *Arq Bras Endocrinol Metabol*. 2007;51(1):72–78. doi:10.1590/s0004-27302007000100012
- Healy GN, Dunstan DW, Salmon J, et al. Breaks in sedentary time: beneficial associations with metabolic risk. *Diabetes Care*. 2008;31(4):661–666. doi:10.2337/dc07-2046
- 11. Dufour CA, Marquine MJ, Fazeli PL, et al. Physical exercise is associated with less neurocognitive impairment among HIV-

- infected adults. J Neurovirol. 2013;19(5):410–417. doi:10.1007/s13365-013-0184-8
- Clingerman E. Physical activity, social support, and health-related quality of life among persons with HIV disease. *J Community Health Nurs*. 2004;21(3):179–197. doi:10.1207/s15327655jchn 2103_5
- O'Brien KK, Tynan AM, Nixon SA, Glazier RH. Effectiveness of Progressive Resistive Exercise (PRE) in the context of HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC Infect Dis.* 2017;17(1):268. doi:10.1186/s12879-017-2342-8
- O'Brien KK, Tynan AM, Nixon SA, Glazier RH. Effectiveness of aerobic exercise for adults living with HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC Infect Dis.* 2016;16(1):182. doi:10.1186/s12879-016-1478-2
- 15. Neto MG, Conceição CS, Carvalho VO, Brites C. Effects of combined aerobic and resistance exercise on exercise capacity, muscle strength and quality of life in HIV-infected patients: a systematic review and meta-analysis. *PLoS One*. 2015;10(9): e0138066. doi:10.1371/journal.pone.0138066
- 16. Vancampfort D, Mugisha J, De Hert M, et al. Global physical activity levels among people living with HIV: a systematic review and meta-analysis. *Disabil Rehabil*. 2018;40(4):388–397. doi:10.1080/09638288.2016.1260645
- 17. Martin K, Naclerio F, Karsten B, Vera JH. Physical activity and quality of life in people living with HIV. *AIDS Care*. 2019;31(5): 589–598. doi:10.1080/09540121.2019.1576848
- Winward C. Supporting community-based exercise in long-term neurological conditions: experience from the Long-term Individual Fitness Enablement (LIFE) project. *Clin Rehabil*. 2011;25(7):579–587. doi:10.1177/0269215510392075
- Salbach NM, Howe J-A, Brunton K, Salisbury K, Bodiam L. Partnering to increase access to community exercise programs for people with stroke, acquired brain injury, and multiple sclerosis. *J Phys Act Health*. 2013;11(4):838–845. doi:10.1123/jpah. 2012-0183
- Stuart M, Benvenuti F, Macko R, et al. Community-based adaptive physical activity program for chronic stroke: feasibility, safety, and efficacy of the Empoli model. *Neurorehabil Neural Repair*. 2009;23(7):726–734. doi:10.1177/1545968309332734
- 21. Lee LL, Arthur A, Avis M. Using self-efficacy theory to develop interventions that help older people overcome psychological barriers to physical activity: a discussion paper. *Int J Nurs Stud.* 2008;45(11):1690–1699. doi:10.1016/j.ijnurstu.2008.02.012
- 22. O'Brien KK, Bayoumi AM, Solomon P, et al. Evaluating a community-based exercise intervention with adults living with HIV: protocol for an interrupted time series study. *BMJ Open*. 2016;6(10):e013618. doi:10.1136/bmjopen-2016-013618
- 23. O'Brien KK, Bayoumi AM, Strike C, et al. Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health Qual Life Outcomes*. 2008;6:76. doi:10.1186/1477-7525-6-76
- 24. Pence BW, Barroso J, Harmon JL, et al. Chronicity and remission of fatigue in patients with established HIV infection. *AIDS*

- Patient Care STDS. 2009;23(4):239–244. doi:10.1089/apc. 2008.0175
- 25. Remien RH, Stirratt MJ, Nguyen N, et al. Mental health and HIV/AIDS: the need for an integrated response. *AIDS*. 2019;33(9): 1411–1420. doi:10.1097/QAD.0000000000002227
- 26. Rueda S, Law S, Rourke SB. Psychosocial, mental health, and behavioral issues of aging with HIV. *Curr Opin HIV AIDS*. 2014; 9(4):325–331. doi:10.1097/COH.00000000000000071
- O'Brien KK, Davis AM, Strike C, Young NL, Bayoumi AM. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *J Int AIDS Soc.* 2009;12:5. doi:10.1186/1758-2652-2-5
- 28. Solomon P, Nixon S, Bond V, Cameron C, Gervais N. Two approaches to longitudinal qualitative analyses in rehabilitation and disability research. *Disabil Rehabil*. 2020; 42(24): 3566–3572. doi:10.1080/09638288.2019.1602850
- 29. Neale B, Flowerdew J. Time, texture and childhood: the contours of longitudinal qualitative research. *Int J Soc Res Methodol*. 2003; 6(3):189–199. doi:10.1080/1364557032000091798
- Farrall S. What Is Qualitative Longitudinal Research? London School of Economics and Political Science (LSE) Methodology Institute; 2006. (Papers in Social Research Methods Qualitative Series, Paper 11).
- 31. Molloy D, Woodfield K, Bacon J. *Longitudinal Qualitative Research Approaches in Evaluation Studies*. Department of Works and Pensions; 2002. (Working Paper No. 7).
- 32. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Sage Publications, Inc; 1998.
- 33. Thomas DR. Feedback from research participants: are member checks useful in qualitative research? *Qual Res Psychol*. 2017; 14(1):23–41. doi:10.1080/14780887.2016.1219435
- Neff HA, Kellar-Guenther Y, Jankowski CM, et al. Turning disability into ability: barriers and facilitators to initiating and maintaining exercise among older men living with HIV. *AIDS* Care. 2019;31(2):260–264. doi:10.1080/09540121.2018.1493186
- 35. Peek K, Sanson-Fisher R, Mackenzie L, Carey M. Interventions to aid patient adherence to physiotherapist prescribed self-management strategies: a systematic review. *Physiotherapy*. 2016;102(2):127–135. doi:10.1016/j.physio.2015.10.003
- 36. Ormel H, Van Der Schoot G, Sluiter W, et al. Predictors of adherence to exercise interventions during and after cancer treatment: a systematic review. *Psychooncology*. 2018;27(3): 713–724. doi:10.1002/pon.4612
- 37. Bonato M, Turrini F, Meloni A, et al. A mobile application for exercise intervention in people living with HIV. *Med Sci Sports Exerc*. 2020;52(2):425–433. doi:10.1249/MSS.00000000000002125
- 38. Lambert TE, Harvey LA, Avdalis C, et al. An app with remote support achieves better adherence to home exercise programs than paper handouts in people with musculoskeletal conditions: a randomised trial. *J Physiother*. 2017;63(3):161–167. doi:10.1016/j. jphys.2017.05.015
- 39. Kamen C, Vorasarun C, Canning T, et al. The impact of stigma and social support on development of post-traumatic growth

among persons living with HIV. *J Clin Psychol Med Settings*. 2016;23(2):126–134. doi:10.1007/s10880-015-9447-2

- 40. Iribarren S, Siegel K, Hirshfield S, et al. Self-management strategies for coping with adverse symptoms in persons living with HIV with HIV associated non-AIDS conditions. *AIDS Behav.* 2018;22(1):297–307. doi:10.1007/s10461-017-1786-6
- 41. Li A, McCabe T, Silverstein E, et al. Community-based exercise in the context of HIV: factors to consider when developing and implementing community-based exercise programs for people living with HIV. J Int Assoc Provid AIDS Care. 2017;16(3): 267–275.
- 42. Goulding D, Wilson MP, MaWhinney S, Jankowski CM, Erlandson KM. A supervised exercise intervention fails to improve depressive symptoms and quality of life among sedentary older adults with

- HIV infection. AIDS Care. 2020;32(6):714–721. doi:10.1080/09540121.2019.1634788
- 43. Brown D, Claffey A, Harding R. Evaluation of a physiotherapyled group rehabilitation intervention for adults living with HIV: referrals, adherence and outcomes. *AIDS Care*. 2016;28(12): 1495–1505. doi:10.1080/09540121.2016.1191611
- 44. Heidari S, Babor TF, De Castro P, Tort S, Curno M. Sex and gender equity in research: rationale for the SAGER guidelines and recommended use. *Res Integr Peer Rev.* 2016;1:2. doi:10.1186/s41073-016-0007-6
- 45. Petróczi A, Hawkins K, Jones G, Naughton DP. HIV patient characteristics that affect adherence to exercise programmes: an observational study. *Open AIDS J.* 2010;4:148–155. doi:10.2174/1874613601004010148