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# Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

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## ABSTRACT

**Objectives:** Our aim was to explore the experiences engaging in a community-based exercise program (CBEP) from the perspective of people living with HIV (PLWH).

**Design:** We conducted a descriptive qualitative study using semi-structured interviews.

**Setting:** We recruited adults living with HIV who participated in a 16 week CBEP in Toronto, Canada.

**Participants:** Eleven participants, the majority men (64%), with a median age of 52 years, and living with a median of five concurrent health conditions in addition to HIV participated in the study.

**Outcome Measures:** We asked participants about their overall experiences; strengths, limitations and perceived benefits of the CBEP; factors influencing participation; and current level of exercise after completion of the CBEP. We administered a self-reported demographic questionnaire followed by the Rapid Assessment of Physical Activity (RAPA) questionnaire. We analyzed interview data using thematic analysis.

**Results:** We developed a Framework that describes the experiences before, during and after the CBEP; and the perceived impact of the CBEP on health, which influenced the intent to, engagement in, and sustainability of exercise among PLWH. Participants described the positive impact of the CBEP on their physical, mental, and social health. Interviews were completed a median of six months after the CBEP, when nine participants reported ongoing engagement in exercise, but to a lesser extent than during the CBEP. Intrinsic and extrinsic factors facilitated or hindered engagement in exercise throughout all phases of the CBEP. The episodic nature of HIV and multi-morbidity influenced engagement in exercise and posed challenges to re-engagement after periods of inactivity.

**Conclusion:** Community-based exercise programs provide an opportunity to enhance physical activity, perceived health outcomes and knowledge about exercise for PLWH. Community-based exercise is a strategy that may be used by health providers to promote engagement in sustained physical activity for PLWH.

### 34 **Strengths and limitations of this study**

- 35 • To our knowledge, this was the first qualitative study to explore the experiences of  
36 participating in a community-based exercise program (CBEP) from the perspectives of  
37 adults living with HIV.
- 38 • Using a qualitative approach involving semi-structured interviews enabled participants to  
39 describe their in-depth experiences following participation in a CBEP, their perceptions  
40 about the facilitators and barriers to engaging in a CBEP; perceived benefits on health  
41 and disability outcomes; and their long-term engagement in exercise over time.
- 42 • Our team-based approach including concurrent data collection and analysis which guided  
43 ongoing revision of the interview guide, and independent coding of each transcript by at  
44 least two authors enhanced the procedural and analytical rigor of the study.
- 45 • The majority of participants completed the CBEP and thus may have represented a  
46 ‘healthy’ community-dwelling sample of PLWH. Participants were primarily men living  
47 in an urban centre who completed the CBEP and agreed to participate in an interview.  
48 Hence, the transferability of these findings to women, people living with HIV in rural  
49 settings and for those who withdrew or were lost to follow-up are less clear.

50

## 51 INTRODUCTION

52 With increased access to combination anti-retroviral therapy, people living with HIV (PLWH)  
53 are living longer with the complex and multi-dimensional health-related challenges attributed to  
54 HIV, aging and multi-morbidity, a concept known as disability [1-3]. Disability can be  
55 experienced as multi-dimensional and episodic in nature comprised of any physical, cognitive,  
56 mental and emotional symptoms and impairments, difficulties carrying out day-to-day activities,  
57 challenges to social inclusion, and uncertainty and worrying about future health [4,5]. Hence  
58 there is a need to address the prevalence and impact of disability for PLWH [6].

59  
60 Exercise is a self-management strategy that can address disability and improve strength, body  
61 composition and psychological outcomes for PLWH [7-10]. Despite the benefits, few PLWH  
62 regularly engage in exercise compared to the general population [11]. Stigma, lower socio-  
63 economic status, lack of awareness and education regarding the benefits of exercise, and  
64 transportation issues can pose barriers for older adults and individuals with stroke, and may  
65 similarly pose barriers to exercise participation for PLWH [12-14]. It is critical to consider novel  
66 ways to promote engagement in physical activity for PLWH.

67  
68 Community-Based Exercise Programs (CBEPs) offer a safe and effective strategy to reduce  
69 disability for PLWH. A CBEP includes a structured set of exercises designed for individuals  
70 with specific exercise needs; they commonly involve a group of persons with similar conditions  
71 exercising under the supervision of a physiotherapist or fitness instructor, with the goal of  
72 promoting and continuing regular exercise in the community [15-18]. CBEPs are widely used  
73 among people with chronic and episodic conditions demonstrating improvements in endurance  
74 and balance, and measures of depression for people with multiple sclerosis, cancer and stroke  
75 [19,20]. Given the increasing chronicity and multi-morbidity associated with HIV, CBEPs may  
76 offer an effective and sustainable self-management strategy to improve health outcomes for  
77 PLWH [21].

78  
79 Researchers piloted the implementation of a 16 week fitness instructor led CBEP and assessed  
80 the impact on health and disability before and after the program [22]. However, the experiences  
81 participating in a CBEP from the perspective of PLWH and the extent to which a CBEP may

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2  
3 82 influence ongoing long-term engagement in exercise are unknown. Our aim was to explore the  
4  
5 83 experiences engaging in a CBEP from the perspective of PLWH. Specific objectives were to  
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7 84 describe: 1) the nature and extent of exercise; 2) facilitators and barriers of engaging in a CBEP;  
8  
9 85 3) perceived benefits of participating in a CBEP on health and disability outcomes; and 4) the  
10  
11 86 impact of a CBEP on the long-term engagement in exercise over time.  
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## 14 88 **METHODS**

15 89 We conducted a descriptive qualitative study in collaboration with the Central Toronto YMCA  
16 90 and Toronto People with AIDS (PWA) Foundation in Toronto, Canada [23, 24]. This study was  
17 91 approved by the University of Toronto HIV/AIDS Research Ethics Board.  
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19 92

20  
21 93 Our study builds on a pilot study that explored the implementation of a CBEP with the aim to  
22 94 reduce disability and improve health for PLWH [22]. The CBEP included a combination of  
23 95 aerobic, resistance, flexibility and balance training for 90 minutes, three times per week for 16  
24 96 weeks at the YMCA in Toronto, Canada [22]. Exercise sessions were supervised and progressed  
25 97 weekly by a fitness instructor. Participants were asked to attend monthly educational self-  
26 98 management sessions focused on topics including exercise, healthy eating, role of occupational  
27 99 therapy, and complementary and alternative therapies for PLWH [22]. Participants received a 16  
28 100 week YMCA membership for the duration of the study.  
29  
30 101

31 102 We recruited adults (18 years of age or older) living with HIV who participated (but did not need  
32 103 to complete) the CBEP [22]. We contacted participants from the pilot study by email or  
33 104 telephone who agreed to be contacted about future phases of research. Members of the research  
34 105 team identified themselves to potential participants as students in the Department of Physical  
35 106 Therapy at the University of Toronto (CAM, KJH, SRK, TBK and CFMY) who were advised by  
36 107 a faculty advisor throughout the research (KKO). Face-to-face interviews were conducted at a  
37 108 community-based organization (Toronto PWA Foundation), the YMCA, or the University of  
38 109 Toronto based on the preference of participants. Five members of the team (CAM, KJH, SRK,  
39 110 TBK and CFMY) conducted the interviews using a semi-structured interview guide (Additional  
40 111 file 1) [25]. Specifically, we asked participants about the strengths and limitations of the  
41 112 program, if and how personal and environmental factors influenced their participation in the  
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3 113 CBEP, perceived benefits (if any), and how the CBEP influenced their ongoing engagement in  
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5 114 exercise after the program. One team member interviewed and the other took field notes.  
6  
7 115 Interviews were audio recorded and transcribed verbatim.  
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9 116

10  
11 117 We administered a self-reported demographic questionnaire followed by the Rapid Assessment  
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13 118 of Physical Activity (RAPA) scale, a nine-item questionnaire that describes the frequency and  
14  
15 119 intensity a participant spends in vigorous or moderate aerobic activity within a week (RAPA 1)  
16  
17 120 and the frequency a participant engages in strength and flexibility activities within a week  
18  
19 121 (RAPA 2) [26].  
20  
21 122

### 22 123 **Data analysis**

23 124 We conducted a thematic analysis examining transcripts line-by-line to create codes we  
24  
25 125 interpreted as key concepts related to experiences with the CBEP program [27,28]. Three  
26  
27 126 transcripts were independently coded by all members of the team who subsequently met to  
28  
29 127 collectively review codes and establish a preliminary coding scheme. Pairs of researchers  
30  
31 128 independently coded the remaining transcripts, met to discuss their coding interpretations, and  
32  
33 129 created analytic memos for each transcript. We clustered the codes into broader categories;  
34  
35 130 defined each category, discussed relationships between categories and grouped categories into  
36  
37 131 broader themes [27]. We used NVivo qualitative software to ease data management [29]. We  
38  
39 132 organized the themes and categories into a framework to describe the experiences participating  
40  
41 133 in the CBEP from the perspective of PLWH.  
42  
43 134

44 135 For the demographic questionnaire, we calculated median and interquartile ranges (IQR) for  
45  
46 136 continuous variables and frequencies and percent for categorical variables. We calculated median  
47  
48 137 (IQR) for RAPA 1 scores ranging from 1 (least active) to 7 (most active) and median (IQR)  
49  
50 138 RAPA 2 scores ranging from 0 (not engaging in strength and flexibility) to 3 (doing both  
51  
52 139 strength and flexibility activities) [26]. Higher RAPA scores indicated greater frequency,  
53  
54 140 intensity, and duration of activity [26].  
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144 **RESULTS**

145 Eleven adults living with HIV participated in a 30-90 minute interview between February and  
 146 June 2016. The majority were men (64%), median age of 52 years, with a median of five self-  
 147 reported concurrent health conditions in addition to HIV (Table 1). Nine participants (82%)  
 148 completed the CBEP.

149 **Table 1:** Characteristics of participants (n=11)

Characteristic	Number of participants (%*)
Gender	
Man	7 (64%)
Woman	1 (9%)
Other	3 (27%)
Age (years), median (IQR)	52 years (48, 60)
Year of HIV diagnosis, median (IQR)	2004 (1990, 2008)
Currently taking antiretroviral therapy	11 (100%)
Viral load Undetectable	5 (45%)
Partnership Status	
Married or common law	4 (36%)
Widowed	2 (18%)
Single	4 (36%)
Separated or divorced	1 (9%)
Lived Alone	8 (73%)
Current Employment Status	
Working, volunteering or student	7 (64%)
Retired	1 (9%)
Not working	3 (27%)
Household Income per year (Canadian dollars)	
<\$39,999	5 (45%)
\$40,000-69,99	2 (18%)
\$70,000-99,9999	2 (18%)
\$100,000-150,000	2 (18%)
Median number of Concurrent Health Conditions in addition to HIV (IQR)	5 (4,6)



Most commonly self-reported concurrent health conditions. Number of participants living with...	
Mental health condition	6 (55%)
Bone and joint disorder	5 (45%)
High cholesterol	4 (36%)
Neurocognitive decline	4 (36%)
Addiction	3 (27%)
Human Papillomavirus	3 (27%)
Peripheral neuropathy	3 (27%)

\* Percentages may not add up to 100% due to rounding to nearest %

CBEP: Community-Based Exercise Program

Interviews occurred a median of six months after the CBEP. At the time of the interviews, 10 (91%) participants were still exercising, nine (90%) of which were exercising to a lesser extent than during the CBEP (Table 2).

**Table 2:** Exercise characteristics of participants related to the CBEP (n=11)

Characteristic	Number of participants (%*)
Time since Community Based Exercise Program Participation, median (IQR)	6 months (4,8)
Self-Reported Level of Exercise Prior to the CBEP	
Not engaging in exercise	4 (36%)
Exercising < 2 times per week	5 (45%)
Exercising ≥ 2 times per week	2 (18%)
Self-Reported Level of Exercise Immediately after Completing the CBEP	
Exercised regularly ≥ 2 times per week	3 (27%)
Exercised not regularly < 2 times per week	5 (45%)
Did not exercise	
Self-Reported Level of Exercise at Time of Interview as Compared to participant exercise level during the CBEP	
Exercising less	9 (82%)
Exercising more	1 (9%)
Exercising similarly to CBEP	1 (9%)

\* Percentages may not add up to 100% due to rounding to nearest %

CBEP: Community-Based Exercise Program

157 At the time of the interview, four participants (36%) reported actively engaging in aerobic and  
 158 anaerobic (both strength and flexibility) (Table 3).

159

160 **Table 3:** Self-Reported Level of Physical Activity as measured by the RAPA Questionnaire

RAPA Classification RAPA Interpretation	Number of participants (%*)
<b>Aerobic Activity</b>	
Under-active regular-light activities Performs some light physical activity every week	2 (18%)
Under-active regular activities Performs moderate physical activities every week but < 30 minutes a day or 5 days a week <b>OR</b> Performs vigorous physical activities every week, but < 20 minutes a day or 3 days a week	5 (45%)
Active Performs 30 minutes or more a day of moderate physical activities, 5 or more days a week <b>OR</b> Performs 20 minutes or more a day of vigorous physical activities, 3 or more days a week	4 (36%)
<b>Anaerobic Activity (measured as done more than once per week)</b>	
Strength training only Performs activities to increase muscle strength, such as lifting weights or calisthenics, once a week or more	1 (9%)
Flexibility only Performs activities to improve flexibility, such as stretching or yoga, once a week or more	2 (18%)
Both Strength and Flexibility	4 (36%)
Neither Strength or Flexibility	4 (36%)

\* Percentages may not add up to 100% due to rounding to nearest %

RAPA: Rapid Assessment of Physical Activity

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## 165 **Framework of Experiences of People Living with HIV Participating in a Community-** 166 **Based Exercise Program**

167 The Framework describes participants' experiences across three time phases (before, during, and  
168 after the CBEP) (Figure 1). The perceived impact of the CBEP influenced the intention to,  
169 engagement in, and sustainability of exercise among participants. Intrinsic and extrinsic  
170 contextual factors could facilitate or hinder participants' participation in exercise throughout all  
171 phases of the CBEP. The episodic nature of HIV and multi-morbidity further influenced  
172 engagement and re-engagement in exercise throughout the continuum.

173  
174 [Insert Figure 1]  
175

### 176 **Phase 1: Prior to the Community-Based Exercise Program**

#### 177 ***Intention to Join***

178 Participants expressed different motivators for joining the CBEP. Program attributes that  
179 influenced the intention to join the CBEP included its reputability associated with a research  
180 study and specificity of the program for PLWH: "*The real plus about [the] research ... was that*  
181 *it structured it for [PLWH]*" (INT-10). The accessibility of the YMCA location, fitness  
182 instructors and having membership fees waived for participating in the research were additional  
183 motivators for joining the program. Furthermore, the CBEP provided participants the chance to  
184 initiate exercise routines, and healthy life choices: "*[...] when I first learned of the study, I was*  
185 *really excited because I saw it as an opportunity to really, get serious about physical exercise*  
186 *and diet*" (INT-9).

#### 187 188 ***Goals***

189 Prior to participating in the CBEP, participants individually set goals with their fitness instructor  
190 to define their desired outcomes of the program. Examples of goals participants articulated in the  
191 interviews included: gaining strength and muscle mass, managing weight, reducing pain, and  
192 improving energy. Some goals were to address disability and represented motivators to facilitate  
193 participation in the CBEP: "*I wanted to build up muscle, I knew I had a knee problem, so I*  
194 *wanted to ease the pain in my knee*" (INT-4).

195  
196

## 197 **Phase 2: During the Community-Based Exercise Program**

### 198 *Nature and Extent of Exercise*

199 Participants engaged in individualized exercise regimes ranging from 45 minutes to two hours  
200 per session, two to five times per week, for 16 weeks. Exercises varied from weight lifting,  
201 endurance, flexibility and balance training. Participants met with their fitness instructors once  
202 weekly for supervision and progression of their programs, and continuing their exercise  
203 programs independently for the remainder of the week. One participant described his experience  
204 engaging with the CBEP:

205  
206 *I met someone every week and I could go over what was working and what wasn't*  
207 *working and my routine or regimen was changed a few times, plus I got things to do*  
208 *while I was traveling. Or else I wouldn't have done anything because you're on the road*  
209 *[...] (INT-11).*

### 210 211 **Accountability**

212 Several participants described a sense of accountability towards the CBEP, specifically a  
213 responsibility to the research, their fitness instructors, and to themselves. This feeling of  
214 obligation motivated participants to continue their participation with the CBEP:

215  
216 *I promised I would go every week, and I promised I would work two times on my own,*  
217 *and I managed for the most part I think to do all those things. So the fact that we made*  
218 *all those kinds of promises to the research, I think helped (INT-10).*

219  
220 Another participant described the accountability he felt towards himself and to other PLWH:

221  
222 *I'm the only one alive. Everyone else died. And I think it's part of my pledge or promise*  
223 *to those that have already died from HIV is to look after myself for as long as I can,*  
224 *because [...] by living as good a life as I can, I'm paying homage to the fact that they*  
225 *weren't able to. I'm not wasting the years, or at least I'm trying not to (INT-3).*

226  
227

## 228 ***Positive Experience***

229 Positive features of the CBEP included the environment and fitness instructors which acted as  
230 motivators to continue exercising throughout the CBEP.

### 231 *1) Environment and Atmosphere*

232 Participants described the YMCA atmosphere as non-judgmental, accessible, and a place of  
233 familiarity:

234  
235 *It's also encouraging [...] that there are all sorts of ages, shapes, and sizes and*  
236 *limitations at the Y and there is no judgment. It's just a place where people go to try*  
237 *and optimize their health benefit (INT-3).*

238  
239 However, several participants disliked the noise at the facility: *"I loved the facility; I just don't*  
240 *like it when there's all the screaming kids"* (INT-9).

241

### 242 *2) Fitness Instruction*

243 A key component to participants' positive experiences was the fitness instructors' openness to  
244 learn about HIV, and their ability to modify activities based on individual needs. Participants  
245 described a fondness of the fitness instructors' flexibility during fluctuating periods of illness and  
246 wellness: *"The fitness trainer was just wonderful, both in terms of the instruction, but also her*  
247 *understanding, her sensitivity [...] to my life situation"* (INT- 9). Fitness instructors provided  
248 ongoing support and motivation throughout the CBEP.

249

## 250 **Impact of the Community-Based Exercise Program**

### 251 ***Perceived Changes to Physical, Mental and Social Health***

252 The majority of participants described improvements in their physical, mental and social health  
253 which encouraged them to remain engaged during and after the CBEP: *"I did appreciate the*  
254 *benefits of it. That's what motivated me to continue"* (INT-8). See Table 4 for a detailed  
255 overview of perceived changes in health outcomes.

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260

258 **Table 4:** Participants perceived changes in physical, mental and social health with the  
 259 Community-Based Exercise Program

Area of Health	Perceived Change in Health with the CBEP	Examples of Supporting Quotations
<b>Physical</b> (related to the body)	<ul style="list-style-type: none"> <li>• weight loss</li> <li>• increased muscle mass</li> <li>• improved endurance</li> <li>• improved energy</li> <li>• improved function / ability to perform activities of daily living</li> <li>• decreased pain</li> <li>• decreased fatigue</li> <li>• improved sleep</li> </ul>	<p><i>"I slept better, I ate better, I felt better, had more energy" (INT-1).</i></p> <p><i>"I lost all my joint pain" (INT-3).</i></p> <p><i>"It's like, this is, it's like a life saver! So, I feel that if I hadn't... been participating in this I think I would, instead of losing weight and gaining muscle and losing fat, that I would probably be the same as I was before or even gaining more weight" (INT-4).</i></p>
<b>Mental</b> (related to the mind)	<ul style="list-style-type: none"> <li>• improved confidence</li> <li>• improved self- esteem and body image</li> <li>• decreased stress and anxiety</li> <li>• improved mood</li> <li>• sense of accomplishment, feeling proud</li> </ul>	<p><i>"Certainly the increased energy level. Sense of well-being. Sense of accomplishment" (INT-3).</i></p> <p><i>"I looked good in front of my father, he didn't see a son that was sick and who would be dying soon. He saw a healthy son" (INT-2).</i></p> <p><i>"Probably the anxiety was related to underlying depression or those feelings of fear and failure, and on the positive side, I found it really helped to make me feel better after the exercise" (INT 7).</i></p>
<b>Social</b> (related to external relationships)	<ul style="list-style-type: none"> <li>• improved relationships with family members, partners or friends</li> </ul>	<p><i>"It helped with building family bonds [...] going to the gym gets me physically active and gives me the abilities that when I leave the gym, I can go running in the park with the kids" (INT-2).</i></p> <p><i>"I met some people there that were also exercising and I think this was another motivator, that I would see them at the gym. So I was more motivated because I was looking [forward] to see them at the class or um at the treadmills or somewhere" (INT-7).</i></p>

260 CBEP: Community-Based Exercise Program

### 261 *Acquiring Knowledge*

262 Participants' experiences were enhanced by their increased knowledge about exercise. They  
263 learned how to safely use exercise equipment and about the physical and mental benefits of  
264 exercise from the educational sessions, and fitness instructors. However, a large impact of the  
265 CBEP on knowledge acquisition appeared to emerge from their actual perceived benefits  
266 experienced with exercise:

267  
268 *I think you can tell people that exercise is good for you until you are blue in the face, but*  
269 *until you experience that exercise is good for you [...] it's just not going to be real (INT-*  
270 *11).*

271  
272 This knowledge had a sustained impact following completion of the program: *"Well the most*  
273 *important thing that I learned is that any type of physical activity is useful so I [have] definitely*  
274 *been walking more since I participated in the program"* (INT-5).

### 276 *Shifting Perceptions of Exercise*

277 Initially, participants felt fear and apprehension regarding exercise, but after participating in the  
278 CBEP, they reported gaining confidence and knowledge, which instilled a sense of comfort,  
279 empowerment, and achievement with exercise:

280  
281 *I think I had a lot of fears before, not knowing what I was doing [...] I went in really*  
282 *hating exercise [...] I don't think I missed [an exercise] session, I really enjoyed it (INT-*  
283 *8).*

284  
285 This shifting perception of exercise persisted after the CBEP:

286  
287 *You know it's basically like a life saver ... I do it because I feel that I have been fit in*  
288 *terms of how I feel but also in terms of how I manage my health over time, and you*  
289 *know looking after myself. So I see it as a necessity (INT-4).*

290

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3 291 Lastly, after completion of the CBEP, participants viewed exercise as a necessary self-  
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5 292 management strategy:  
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9 294 *If it could become part of the suite of therapies available to people living with HIV that*  
10 295 *would be great. I think it should be essential of living strategies for living with HIV (INT-*  
11 296 *9).*  
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14 297  
15  
16 298 ***Adopting Structure and Routine***

17 299 Several participants described leading busy lives with multiple work and family responsibilities  
18 300 and appreciated the consistency and structure provided by the CBEP: “[...] with such a chaotic  
19 301 life with so many volunteer obligations, it was nice three times a week to just have a morning  
20 302 that was just on me” (INT-11). The structure and routine was further described as a motivator to  
21 303 maintain participation in the CBEP: “What helped me? Probably how I structured my day, some  
22 304 days I went in early in the morning to do it and sometimes it was once I finished working” (INT-  
23 305 10). After participants completed the CBEP, they described experiencing a lack of structure and  
24 306 routine which contributed to their inability to continue at the same level of activity: “I know  
25 307 myself well enough to know that if I don’t participate in a structured class that probably I will  
26 308 fall out of the pattern” (INT-3).  
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37 310 **Phase 3: After the Community-Based Exercise Program**

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39 311 ***Current Level of Exercise***

40 312 Interviews in this study occurred a median of six months after the CBEP. Six of the eleven  
41 313 participants (55%) continued their YMCA membership after the CBEP. Types of activity  
42 314 participants engaged in at the time of the interview included, but were not limited to: increased  
43 315 amounts of walking for transportation, increased use of stairs, and riding bicycles. Ten  
44 316 participants (91%) reported continuing to engage in exercise, nine of which (90%) reported  
45 317 exercising to a lesser extent since the CBEP. Three participants (27%) reported not continuing  
46 318 with exercise long-term due to injury, substance abuse, or no given reason.  
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### 322 ***Future Intention to Exercise***

323 Participants viewed exercise as an ongoing self-management strategy to maintain and promote  
324 healthy living and all expressed a desire to incorporate exercise in their future. One participant  
325 stated: “*I can see myself doing this for the rest of my life*” (INT-4). Furthermore, participants  
326 described using exercise as a self-management strategy aging with HIV:

327  
328 *[I’m] mindful of the fact that as [...] anybody gets older, if we don’t maintain a degree of*  
329 *physical activity...It’s a slippery slope – and the less you do the less you are able to do*  
330 *(INT-3).*

### 331 **Intrinsic Factor**

#### 332 ***Age***

333  
334 Participants described how age influenced their experiences across the CBEP. Of the nine  
335 participants that reported their age, five were (56%) older than 50 years from a range of 38 to 61  
336 years. Participants described how their age influenced their goal setting and motivation for  
337 joining the CBEP:

338  
339 *[...] I think exercise for me [...] is going to be about being focused on that as I age*  
340 *and keeping my body less frail, more mobile, those kinds of things are important to me*  
341 *(INT-10).*

342  
343 Within the CBEP, the majority of participants expressed that their age had little to no influence  
344 on their experiences. After the CBEP, many saw aging as a way to motivate them to remain  
345 active and decelerate aging:

346  
347 *If I’m not mindful in looking after myself, the nursing home beckons, and I really don’t*  
348 *want that. So I have to keep as active as I can so that I can stay in my own home and*  
349 *look after myself (INT-3).*

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3 353 **Extrinsic Factors**

4  
5 354 Extrinsic factors in the environment including stigma, social support, and weather and holidays  
6  
7 355 influenced participants' experiences with exercise.  
8

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10  
11 357 ***Stigma***

12 358 Prior to the CBEP, participants reported concerns regarding potential stigma related to body  
13  
14 359 image in a gym environment, however, during the CBEP participants found the YMCA gym  
15  
16 360 environment less stigmatizing than originally feared.  
17

18 361

19 362 *So I've learned to not be intimidated by going, because whether or not it's body image*  
20  
21 363 *issues that one can have or the fear [...] the idea of gym class was something that was*  
22  
23 364 *anathema to me and going back to that environment with a lot of jocks or people that*  
24  
25 365 *are more well-defined or whatever you will can be a little intimidating [...] (INT-3).*  
26

27 366

28 367 ***Social Support***

29  
30 368 Participants described having various levels of social support, assistance, and care from others  
31  
32 369 during the CBEP, but did not feel connected with other study participants, despite the group  
33  
34 370 monthly education sessions. Some participants preferred to exercise alone, while others  
35  
36 371 expressed a desire to expand their social network and seek support from other participants. One  
37  
38 372 participant used his partner as a source of continued motivation throughout the CBEP:  
39

40 373

41 374 *That sense of connection is very important so the fact that I was able to establish that*  
42  
43 375 *in the context of that program by working out with a buddy probably gave, I got more*  
44  
45 376 *out of it for having done it that way (INT-10).*  
46

47 377

48 378 Participants described various levels of support from their healthcare professionals. Some felt  
49  
50 379 that their health providers encouraged and motivated their participation, while others felt no  
51  
52 380 influence:  
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382 *One of my HIV doctors said, when he saw my MRI, oh I guess you should see a*  
383 *physiotherapist, and I said oh I'm part of this research project [...] and he said oh*  
384 *that's better than going to see a physiotherapist, do that (INT-4).*

### 386 ***Weather and Holidays***

387 Participants described how weather and seasonal holidays influenced their motivation and  
388 engagement in exercise. The CBEP occurred in the spring and summer months; hence  
389 participants perceived warm weather, as a facilitator that increased their activity levels. After the  
390 CBEP, participants reported the colder weather was a barrier to exercise. In some instances,  
391 participants perceived exercise as additional work, and viewed holidays and vacations, as a time  
392 to pause from their exercise programs:

393  
394 *[...] I was pretty active up until like November, umm when it started getting really cold,*  
395 *then I took a break over December and Christmas and then I started again in January*  
396 *and then it got really cold and I just had to stop (INT-4).*

### 398 **Episodic nature of HIV and multi-morbidity**

399 Some participants experienced fluctuating periods of wellness and illness which resulted in  
400 periods of inactivity due to poor health. These varying episodes affected experiences across all  
401 three phases, and influenced their ability to exercise and re-engage in exercise after a period of  
402 inactivity. One participant described living with the episodic nature of HIV:

403  
404 *I got sicker and sicker. Same way I got better and better, I just started you lose your*  
405 *mobility and your ability to stretch and your motivation as time goes on. And the less you*  
406 *do, the less you wanted to do" (INT-2).*

407  
408 We defined multi-morbidity, as the presence of one or more health conditions, in addition to  
409 living with HIV. Mental health conditions and bone and joint disorders were the most prominent  
410 (Table 1). Before the CBEP, one participant described how mental health was a motivator for  
411 exercise, helping shape her goals and experiences:

1  
2  
3 413 *Lot of [my goals] had to do with mental and emotional health, so one of the things I*  
4  
5 414 *talked about was my anxiety and how it played out in different areas of my body so we*  
6  
7 415 *worked on some exercises that would just help me relax (INT-5).*  
8

9 416  
10 417 Multi-morbidity was dually experienced as a barrier to exercise. Two participants (18%)  
11  
12 418 withdrew from the CBEP due to concurrent health conditions, one of whom described his  
13  
14 419 experience with addiction disrupting his ability to engage in exercise:  
15

16 420  
17 421 *[The CBEP] was complete stop. It was an immediate plunge back into abuse. I mean,*  
18  
19 422 *maybe it was a relapse for, for the first few days but then it just became [...] again it*  
20  
21 423 *became my choice. I chose [...] to go ever deeper into, my substance abuse (INT- 9).*  
22

23 424  
24 425 The flexibility offered by the program and the fitness instructor was helpful for participants to  
25  
26 426 deal with and overcome the unpredictable and episodic nature of multi-morbidity and HIV  
27  
28 427 during the CBEP:  
29

30 428  
31 429 *And one of the things I most appreciated was the flexibility, you know it wasn't, you*  
32  
33 430 *know I was concerned that [fitness instructors] would dictate what the routine is but*  
34  
35 431 *no, there was complete flexibility (INT-9).*  
36

37 432  
38 433 Several participants described experiencing an improvement with their multi-morbidity after  
39  
40 434 their engagement in the CBEP, ultimately leading to the desire to incorporate exercise as a  
41  
42 435 lifestyle strategy in their future. However, as time progressed, some participants struggled with  
43  
44 436 complications of HIV and multi-morbidity, and expressed difficulty sustaining and returning to  
45  
46 437 their exercise regimes.  
47

48 438  
49 439 Finally, the majority of participants described the need for return-to-exercise strategies. One  
50  
51 440 participant stated: *"I guess the one goal I had was continuing to exercise after the program. And*  
52  
53 441 *I did. But, I got sick [...], once you lose the rhythm, you really lose the rhythm" (INT-11).*  
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3 444 **DISCUSSION**  
4

5 445 To our knowledge, this is the first qualitative study to explore the experiences of participating in  
6  
7 446 a CBEP from the perspectives of PLWH. Perceived benefits of the CBEP were influential in  
8  
9 447 promoting adherence to exercise and adoption of exercise as a long-term self-management  
10  
11 448 strategy. Engagement in exercise across the phases in our Framework may be considered  
12  
13 449 analogous to the precontemplation, contemplation, preparation (before CBEP), action (during  
14  
15 450 CBEP), and maintenance (after CBEP) stages of behaviour change in the Transtheoretical Model  
16  
17 451 (TTM) [30-32]. Earlier stages of the TTM, specifically readiness to engage in exercise, has been  
18  
19 452 explored from the perspectives of PLWH highlighting the contemplation phase when living with  
20  
21 453 HIV and complex multi-morbidity [33]. Our Framework depicts how PLWH transition through  
22  
23 454 stages of exercise behaviour change (contemplation and preparation) and further considers the  
24  
25 455 phases during (action) and after (maintenance) of a formalized CBEP, exploring the potential to  
26  
27 456 adopt exercise as a self-management strategy living with HIV. Strengthening the impact of a  
28  
29 457 CBEP to yield positive experiences during a CBEP can subsequently promote maintenance of  
30  
31 458 exercise for PLWH post-CBEP.

32 459  
33 460 Participants described how perceived benefits experienced during the CBEP promoted adherence  
34  
35 461 to, and ongoing maintenance with, exercise. Improvements in physical, mental, and social health  
36  
37 462 were similarly reported in systematic review evidence on the effects of exercise for PLWH  
38  
39 463 [7,9,10,34,35]. However, acquiring knowledge that mitigated uncertainty with exercise and  
40  
41 464 incorporating exercise as a structure and routine were additional benefits articulated by  
42  
43 465 participants' that positively influencing their engagement with exercise. These additional  
44  
45 466 benefits may be attributed to the YMCA environment, weekly supervision from a fitness  
46  
47 467 instructor, and the monthly education sessions [36]. Similar positive features of CBEPs were  
48  
49 468 documented when individuals with pulmonary disease, multiple sclerosis, and stroke engaged in  
50  
51 469 CBEPs [37-39]. Future programs should consider the importance of education about the safety  
52  
53 470 and effectiveness of exercise, discussing pre-existing perceptions of exercise, and offering  
54  
55 471 support for adopting exercise as part of a regular routine. Future research may explore the extent  
56  
57 472 to which these features of a CBEP may influence long-term sustainability engaging in exercise  
58  
59 473 and the potential benefits of a combined CBEP program with PLWH and other chronic illnesses.  
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2  
3 475 The episodic nature of HIV and multi-morbidity was an underlying factor that influenced  
4  
5 476 engagement in and re-engagement in exercise after a period of inactivity for PLWH. Mental  
6  
7 477 health and addiction issues were examples of concurrent health conditions that influenced  
8  
9 478 ongoing participation in exercise. Knowledge among fitness instructors about the episodic nature  
10  
11 479 of HIV, their supportive approach to adapting the CBEP to accommodate changes in health of  
12  
13 480 participants' along with the inclusive and accommodating nature of the YMCA facilitated  
14  
15 481 engagement in the CBEP. PLWH who are medically stable can safely exercise two to four times  
16  
17 482 weekly, at 40-60% heart-rate-reserve, for 30-120 minutes per session, utilizing a variety of types  
18  
19 483 of exercise activity [40,41]. Knowledge among health providers about the safety and  
20  
21 484 effectiveness of exercise can help to ensure they adequately promote participation in exercise in  
22  
23 485 a manner that recognizes, supports, and accommodates the needs of PLWH while offering  
24  
25 486 variable ways to maximize engagement despite fluctuations in health.  
26

27 487  
28 488 Of the 11 participants, 10 remained physically active after the program ended, nine of which  
29  
30 489 were less active than during the CBEP. Nevertheless, ongoing engagement in physical activity  
31  
32 490 among almost all participants may be considered a success of the intervention. Some participants  
33  
34 491 expressed challenges returning to exercise after episodes of illness or multi-morbidity. Fitness  
35  
36 492 instructors adjusted the programs according to the health of participants. Future programs should  
37  
38 493 consider strategies to help PLWH return to exercise or maintain exercise despite the potentially  
39  
40 494 episodic nature of HIV and multi-morbidity.  
41

42 495  
43 496 Our study builds on a pilot study that examined the process and implementation of a CBEP for  
44  
45 497 PLWH [22]. Using a qualitative approach, we were able to describe the experiences, influencing  
46  
47 498 factors, and perceived impact of community-based exercise while illustrating the complex  
48  
49 499 interactions between the components and underlying influence of the episodic nature of HIV and  
50  
51 500 multi-morbidity. This Framework can be used by clinicians, representatives from the fitness  
52  
53 501 community, and PLWH to inform the understanding of experiences engaging in exercise, and the  
54  
55 502 features to consider when designing and implementing future exercise programs for PLWH.  
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57 503  
58 504 Our study possesses some limitations. The majority of participants completed the CBEP and thus  
59  
60 505 may have represented a 'healthy' community-dwelling sample of PLWH. Nevertheless, many

1  
2  
3 506 described having to cancel appointments or scale back on exercise due to periods of illness.  
4  
5 507 Participants in this study were primarily men living in downtown Toronto who completed the  
6  
7 508 CBEP and agreed to participate in an interview. Hence, the transferability of these findings to  
8  
9 509 women, PLWH living in rural settings and for those who withdrew or were lost to follow-up are  
10  
11 510 less clear.

## 13 511 **CONCLUSIONS**

15 512 Results describe experiences before, during and after engaging in a CBEP from the perspective  
16  
17 513 of adults living with HIV. The positive impacts of the CBEP and the episodic nature of HIV and  
18  
19 514 multi-morbidity influenced engagement in and sustainability of exercise among PLWH. Future  
20  
21 515 CBEPs should include strategies to accommodate potential fluctuations in health and promote  
22  
23 516 return-to-exercise strategies to assist with re-engagement in exercise after an episode of illness.  
24  
25 517 This Framework may be utilized by healthcare professionals when recommending and discussing  
26  
27 518 exercise with PLWH, and can inform the design of future CBEPs in order to promote imitation  
28  
29 519 and sustained engagement in physical activity among PLWH.

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46 528 development of our protocol.

## 50 530 **AUTHORS' CONTRIBUTIONS**

52 531 KKO (PhD) designed the study and provided guidance throughout the research process. KKO  
53  
54 532 possesses expertise in qualitative methodology and HIV and exercise research. KKO supervised  
55  
56 533 CAM, KJH, SRK, TBK and CFMY who developed the protocol, collected and analysed the data,  
57  
58 534 and drafted the manuscript in partial fulfillment of requirements for an MScPT degree at the

1  
2  
3 535 University of Toronto. CAM, KJH, SRK, TBK and CFMY (MScPT students) developed skills in  
4  
5 536 qualitative research methodology including attending lectures; completing readings on  
6  
7 537 qualitative research study design; understanding steps of recruitment, data collection and  
8  
9 538 analysis; completing a literature review; developing the research protocol; interview guide and  
10  
11 539 demographic questionnaire; and considering the ethical issues associated with this research. All  
12  
13 540 steps were closely reviewed and guided by KKO (advisor). All authors read and approved the  
14  
15 541 final manuscript.

16 542

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24 547

### 27 548 **COMPETING INTERESTS**

28  
29 549 The authors have no competing interests to declare.

30 550

### 32 551 **ETHICS APPROVAL**

33  
34 552 University of Toronto HIV/AIDS Research Ethics Board

### 37 553 **DATA SHARING STATEMENT**

38  
39  
40 554 The data collected and analyzed during the study are not publicly available in accordance with  
41  
42 555 our study protocol that was approved by the University of Toronto HIV/AIDS Research Ethics  
43  
44 556 Board. Data may be available on reasonable request by contacting the corresponding author.

45 557

### 47 558 **FIGURE LEGENDS**

#### 49 559 **Figure 1: Framework of Experiences of Adults Living with HIV Participating in a** 50 560 **Community- Based Exercise Program**

51  
52  
53 561 This Framework describes participants' experiences across three time phases (before, during and  
54  
55 562 after the CBEP) and the perceived impact during and after the CBEP. Intrinsic and extrinsic  
56  
57 563 contextual factors facilitated or hindered participants' experience across all phases of the CBEP.



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3 564 The episodic nature of HIV and multi-morbidity further influenced the intention to, engagement  
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5 565 in and sustainability of exercise throughout the continuum.  
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7 566 CBEP: Community-based exercise program.  
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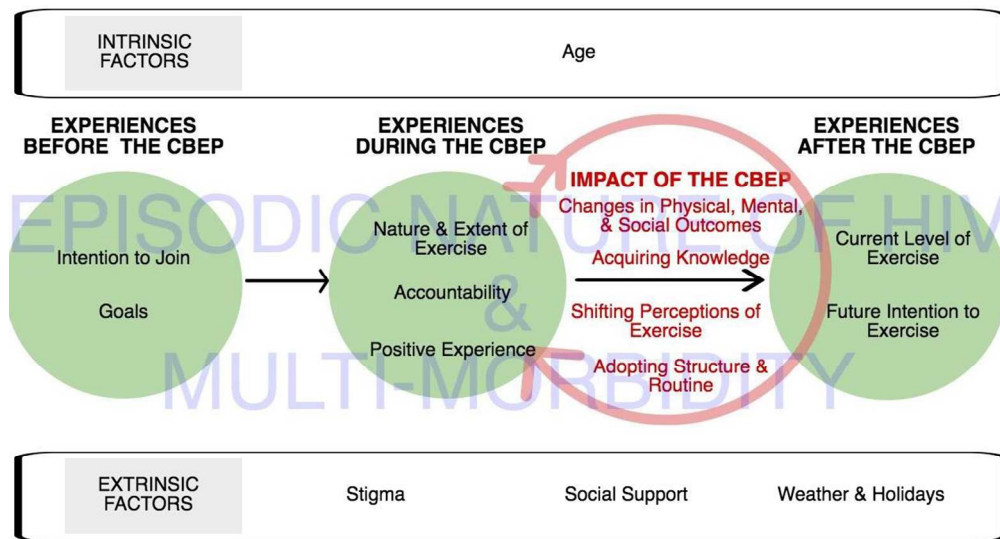


Figure 1: Framework of Experiences of Adults Living with HIV Participating in a Community- Based Exercise Program

335x181mm (96 x 96 DPI)

review only

## Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

Thank you for agreeing to participate in this study. I am meeting with you to understand your experiences participating in the 4-month community-based exercise program at the YMCA that occurred back in the spring/summer of 2015. While this study follows up on the YMCA program, we are a different team of researchers with different goals. Specifically, we are interested in learning about your current level of exercise and how participation in the YMCA program may have affected your ability to exercise over the long term. We are interested in exploring any factors you found helpful and any factors that limited your ability to participate in the community-based exercise program. We are also interested in exploring any benefits you experienced during and after participating in the program.

Sometimes there is confusion about what the difference is between *exercise* and *physical activity*. For this study, we define exercise as a planned, structured, specific form of activity with the aim of improving or maintaining overall fitness, health, and well-being. On the other hand, physical activity refers to any effortful movement that occurs in your everyday life, such as walking the dog or gardening. For this study, we are interested in the impact of the community-based program on both your level of exercise and your level of physical activity. The findings from the interview will be used to better understand the experience of taking part in a community-based exercise program. Results from this study will help to inform the future development of community-based exercise programs for people living with HIV.

Would you mind if I take notes during the interview?  
Do you have any questions before we begin?

1. **Please think back to when you were involved in the community-based exercise program at the YMCA. Can you describe your experience taking part in the community-based exercise program?**
  - i. How did you come to take part in the programs?
    1. How did you find out about the programs?
    2. What motivated you to decide to take part in the program?
  - ii. What was your physical activity level like *prior* to taking part in the community-based exercise program?
  - iii. Can you describe the nature of your community-based exercise program?
    1. What types of exercise did you do? [type of activity, aerobic / resistive component, group or individual activity]
    2. How often? [frequency]
    3. How intense did you exercise? [intensity]
    4. How long did you exercise? [time]
    5. Where did you do the exercise? [location]
    6. How did you progress your exercise program? [progression]
    7. Can you describe the level of supervision or coaching that you had as part of the program?
    8. How often did you attend (or take part) in the exercise? [adherence]
    9. Did you miss any of the exercise sessions? If so, can you speak to some of the barriers that kept you from going? [e.g. episodic illness, other life stressors, vacation, etc.]
    10. We understand that you set goals before starting the program. What were your goals at the beginning of the program?



**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

**2. Thinking back to when you were involved in the community-based exercise program at the YMCA, what were some of the positive aspects of the community-based exercise program?**

- i. Nature of the facility [YMCA, location, hours of operation]
- ii. Coaching staff
- iii. Other members of the facility
- iv. Exercise equipment
- v. Getting into a routine
- vi. Monthly education sessions
- vii. Interacting with other participants in the study

**3. What were some of the challenges or drawbacks you experienced with the community-based exercise program?**

- i. Nature of the facility [YMCA, location/transportation, hours of operation]
- ii. Coaching staff
- iii. Scheduling
- iv. Exercise equipment
- v. Getting into a routine
- vi. From our research, we know that living with chronic illness is always a fluctuating challenge for people and we are interested in how these challenges affected your participation in the CBE intervention? Fluctuating periods of health (episodic nature)
- vii. Concurrent health conditions (Do you have any other health problems that may have affected your participation?)  
[note some of the above may fall into the barriers and facilitators.....]
- viii. Do you have any suggestions to change the program to make it better?
  1. Would you mind expanding on those ideas?

*The next few questions ask about things that may have influenced your experiences taking part in the community-based exercise program and may have influenced your experience with exercise. [objective2]*

**4. Thinking back to when you were involved in the community-based exercise program, what were some of the factors that influenced your ability to participate in the exercise program?**

**4a. Were they any management strategies in your day-to-day life you used that influenced your ability to participate in the exercise program? [living strategies] A management strategy is any tool that you use to keep you motivated towards your goals. (if still requiring examples can say: ride system with a friend, social interactions, positive self-talk)**

- i. What were your general attitudes or outlook towards exercise during the community-based exercise program?
- ii. Have those attitudes or outlook changed since your involvement in the community-based exercise program? If so can you describe how?
- iii. Did these strategies affect your willingness or ability to participate in the exercise program?
- iv. Examples of living strategies could be:
  1. Seeking social interactions (new personal and professional relationship)
  2. Maintaining a sense of control (this concept may influence their disability)

**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

1. To re-establish a sense of purpose, redefining base level of health
  2. Re-evaluation of lifestyle (sleep, nutrition, substance use, medication, exercise, financial security)
  3. Achieving healthy life balance
  4. Planning to anticipate the future
  5. Paying attention to numbers (CD4 count, viral load)
3. Having a positive outlook on life
  4. Comparing experiences of others living with HIV
  5. Faith and spiritual beliefs

**4b. In some cases, exercise itself could be considered a living strategy (or self-management strategy) for enhancing overall health for people for living with HIV. Do you consider exercise a living strategy for living with HIV?**

- i. If yes, can you describe? [e.g. lifestyle, re-establishing purpose in life, maintaining life balance, planning for the future]

**4c. Many people living with HIV are now living longer and aging with HIV. Can you comment on how the concept of ageing may have influenced your experience taking part in the community-based exercise program?**

- i. Can you explain or give me an example of how this happens?

**4d. We are also interested in any similarities or differences experienced by men and women in the program. Do you think that your gender identity influenced your participation in the community-based exercise program in any way?**

- i. If so, can you explain how?

**4e. Do you mind commenting on how any other health conditions played a role, if any, in influencing the experience with the community-based exercise program? (examples if needed: diabetes, osteoporosis, a heart condition, depression/mental illnesses, etc.)**

**4f. Describe how the support of others may have influenced your participation in the community-based exercise program?**

- i. How did friends or family affect your participation in the program?
- ii. How did the other participants in the study affect your participation in the program?
- iii. How did the fitness supervisors in the study affect your participation in the program?
- iv. Did your health care providers – did they know about your involvement in the community-based program and did they influence your involvement at all? If so, how?

**4g. Did you experience any stigma during your involvement in the community-based exercise program? If so can you describe?**

- i. If so, did the stigma impact your participation in the program? How?

*The aim of the CBE program at the YMCA was to enhance the overall health and reduce health-related challenges experienced by adults living with HIV. [Objective #3]*

**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

**5. Did you experience any benefits from participating in the community-based exercise program in relation to your health?**

- i. How about physical benefits (e.g. fatigue, pain, weakness)? Cognitive health benefits (e.g. ability to remember things, think clearly)? Mental health benefits (e.g. anxiety, depression)? Impact on social well-being?
- ii. Has your participation in the program affected your day-to-day activities?
  1. How so?
- iii. How has participating in this CBE impacted your experience living with HIV?
- iv. Dealing with the uncertainty or worrying about future health living with HIV?
- v. Some people may experience fluctuating periods of wellness and illness with HIV (known as episodic), is this something that you have experienced? If so, can you explain how the program affected this episodic nature of living with HIV?  
[Note: interviewer consider episodic nature of HIV]
- v. Earlier I asked about what your goals were when starting the CBE program. Do you feel as if you achieved those goals? [refer back to question 1, last prompt]

*We are interested in the extent to which exercise may become a part of a living strategy for people living with HIV. We are interested in learning about your current level of physical activity (or exercise) and whether the community-based exercise program had any influence on your current activity level in any way or the continuation of exercise of the long-term.*

**6. What type of physical activity (or exercise) have you been doing since the community-based exercise program ended?**

- i. Have you been able to sustain or keep up with your exercise program?
- ii. Describe the nature and different types of exercise that you participate in (such as swimming, biking...etc.) [if not stated]
  1. Do you still go to the YMCA in order to exercise?
  2. If not, where do you exercise?
  3. How intense do you exercise?
  4. How long do you exercise for?
  5. How often do you exercise?
- iii. Have your episodes of illness impacted your ability to maintain this level of physical activity, during or since the community-based exercise program?

**6b. Have you experienced any changes in your health status since the community-based exercise program that impacted your ability to continue with exercise?**

**6c. Has there been anything that has impacted your ability to continue with exercise since the CBE program?**

- i. Illness
- ii. Finances- inability to pay for the YMCA membership
- ii. Other factors?

**7. Based on what we discussed today, do you see yourself continuing to exercise (or starting back up with exercise if they trailed off) in the future? If so, can you explain?**

1 **Additional File 1 - Interview Guide – Experiences participating in a community-based**  
2 **exercise program from the perspective of people living with HIV: A qualitative study**  
3

4 **Concluding remarks:**

5 Do you have any final thoughts about your experiences taking part in the community-based  
6 exercise program at the YMCA? Do you have recommendations when it comes to exercise and  
7 people living with HIV?  
8

9  
10 Thank you for participating in this interview and for your time. The information you gave will help  
11 us gain a better understanding of your experiences participating in a community-based exercise  
12 program.  
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For peer review only

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

Domain 1: Research team and reflexivity			Comment
<b>Personal Characteristics</b>			
1.	Interviewer/facilitator	Which author(s) conducted the interview?	See Methods (Page 5)
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	Credentials are included in the Author's Contributions section (Page 22-23)
3.	Occupation	What was their occupation at the time of the study?	See Affiliations of the author team (Page 1)
4.	Gender	Was the researcher male or female?	See Authors Contributions (Page 22-23)
5.	Experience and training	What experience or training did the researchers have?	See Author's contributions (Page 22-23)
<b>Relationship with participants</b>			
6.	Relationship established	Was a relationship established prior to study commencement?	Relationship was not established prior to the interviews.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. personal goals, reason for doing the research</i>	Participants knew that the research team was comprised of a group of MScPT students at the University of Toronto who were advised by faculty at the Department of Physical Therapy. (see Methods – Page 5).
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g. bias, assumptions, reasons and interests in the research topic</i>	Participants knew that this research was done by students in partial fulfillment of the requirements for a MScPT degree at the UofT (see Methods Page 5 and Authors' Contributions Page 22-23).
<b>Domain 2: Study design</b>			
<b>Theoretical framework</b>			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? <i>E.g. grounded theory,</i>	We conducted a descriptive qualitative study (See the first sentence in the Methods – Page 5)

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

		<i>discourse analysis, ethnography, phenomenology, content analysis</i>	
<b>Participant selection</b>			
10.	Sampling	How were participants selected? <i>E.g. purposive, convenience, consecutive, snowball</i>	See Page 5 (Methods)
11.	Method of approach	How were participants approached? <i>E.g. face-to-face, telephone, mail, email</i>	See Page 5 (Methods)
12.	Sample size	How many participants were in the study?	11 participants. See the first sentence in the results (Page 6-7)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Of the 15 individuals who were approached and met inclusion criteria, 11 responded and agreed to participate. No participants withdrew from an interview.
<b>Setting</b>			
14.	Setting of data collection	Where was the data collected? <i>E.g. home, clinic, workplace</i>	Community-based organization in Toronto, YMCA, or the University of Toronto. See Methods (Page 5)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Two members of the research team (1 interviewer; 1 field note taker) See Methods (Page 5-6)
16.	Description of sample	What are the important characteristics of the sample? <i>E.g. demographic data, date</i>	See Table 1 (Page 7-8) and Table 2 (Page 8) and Table 3 (Page 9)
<b>Data collection</b>			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See Methods (Page 5-6) and Additional File 1 (Interview Guide)
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

19.	Audio/visual recordings	Did the research use audio or visual recording to collect the data?	Each interview was audio recorded. See Methods (Page 6)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were taken throughout the interview. See Methods (Page 5-6)
21.	Duration	What was the duration of the interviews or focus group?	Approximately 30-90 minutes. See Results (Page 6)
22.	Data saturation	Was data saturation discussed?	Yes. We ceased the interviews at 11; which was the point when no new categories emerged.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
<b>Domain 3: analysis and findings</b>			
<b>Data analysis</b>			
24.	Number of data coders	How many data coders coded the data?	See Data Analysis (Page 6)
25.	Description of coding tree	Did authors provide a description of the coding tree?	See Data Analysis (Page 6)
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data. See Data Analysis (Page 6)
27.	Software	What software, if applicable, was used to manage the data?	NVivo 10© qualitative software (Page 6)
28.	Participant checking	Did participants provide feedback on the findings?	No. We are in the process of translating the findings back to the community (presentations, etc).
<b>Reporting</b>			
29.	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	See Results (Pages 10-19)

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

		<i>E.g. participation number</i>	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes. See Results (Page 10-19) and Figure 1
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. See Results (Page 10-19) and Figure 1



# BMJ Open

## Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

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Keywords:	HIV & AIDS < INFECTIOUS DISEASES, exercise, REHABILITATION MEDICINE, community-based exercise, multi-morbidity, physical activity

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# Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

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1 \*These authors have contributed equally to the work.

Word Count (Maximum – 4000) – Currently: 4469

Keywords: HIV, exercise, community-based exercise, multi-morbidity, physical activity, rehabilitation

## ABSTRACT

**Objectives:** Our aim was to explore the experiences engaging in a community-based exercise program (CBEP) from the perspective of people living with HIV (PLWH).

**Design:** We conducted a descriptive qualitative study using semi-structured interviews.

**Setting:** We recruited adults living with HIV who participated in a 16 week CBEP in Toronto, Canada.

**Participants:** Eleven participants, the majority men (64%), with a median age of 52 years, and living with a median of five concurrent health conditions in addition to HIV participated in the study.

**Outcome Measures:** We asked participants about their overall experiences; strengths, limitations and perceived benefits of the CBEP; factors influencing participation; and current level of exercise after completion of the CBEP. We administered a self-reported demographic questionnaire followed by the Rapid Assessment of Physical Activity (RAPA) questionnaire. We analyzed interview data using thematic analysis.

**Results:** We developed a Framework that describes the experiences before, during and after the CBEP; and the perceived impact of the CBEP on health, which influenced the intent to, engagement in, and sustainability of exercise among PLWH. Participants described the positive impact of the CBEP on their physical, mental, and social health. Interviews were completed a median of six months after the CBEP, when nine participants reported ongoing engagement in exercise, but to a lesser extent than during the CBEP. Intrinsic and extrinsic factors facilitated or hindered engagement in exercise throughout all phases of the CBEP. The episodic nature of HIV and multi-morbidity influenced engagement in exercise and posed challenges to re-engagement after periods of inactivity.

**Conclusion:** Community-based exercise programs provide an opportunity to enhance physical activity, perceived health outcomes and knowledge about exercise for PLWH. Community-based exercise is a strategy that may be used by health providers to promote engagement in sustained physical activity for PLWH.

### 34 **Strengths and limitations of this study**

- 35 • To our knowledge, this was the first qualitative study to explore the experiences of  
36 participating in a community-based exercise program (CBEP) from the perspectives of  
37 adults living with HIV.
- 38 • Using a qualitative approach involving semi-structured interviews enabled participants to  
39 describe their in-depth experiences following participation in a CBEP, their perceptions  
40 about the facilitators and barriers to engaging in a CBEP; perceived benefits on health  
41 and disability outcomes; and their long-term engagement in exercise over time.
- 42 • Our team-based approach including concurrent data collection and analysis which guided  
43 ongoing revision of the interview guide, and independent coding of each transcript by at  
44 least two authors enhanced the procedural and analytical rigor of the study.
- 45 • The majority of participants completed the CBEP and thus may have represented a  
46 ‘healthy’ community-dwelling sample of PLWH. Participants were primarily men living  
47 in an urban centre who completed the CBEP and agreed to participate in an interview.  
48 Hence, the transferability of these findings to women, people living with HIV in rural  
49 settings and for those who withdrew or were lost to follow-up are less clear.

50

## 51 INTRODUCTION

52 With increased access to combination anti-retroviral therapy, people living with HIV (PLWH)  
53 are living longer with the complex and multi-dimensional health-related challenges attributed to  
54 HIV, aging and multi-morbidity, a concept known as disability [1-3]. Disability can be  
55 experienced as multi-dimensional and episodic in nature. Disability can include health  
56 challenges such as physical (e.g. joint pain, weakness, headaches), cognitive (e.g. difficulty  
57 remembering; focusing attention), and mental and emotional (e.g. feeling anxious) symptoms  
58 and impairments; difficulties carrying out day-to-day activities (e.g. mobility, self-care);  
59 challenges to social inclusion (e.g. engaging in personal relationships, work and leisure  
60 activities); and uncertainty and worrying about future health (e.g. worrying about when an  
61 episode of illness might occur) [4,5]. Hence, there is a need to address the prevalence and  
62 impact of disability for PLWH [6].

63  
64 Exercise is a self-management strategy that can address disability and improve strength, body  
65 composition and psychological outcomes for PLWH [7-10]. Despite the benefits, few PLWH  
66 regularly engage in exercise compared to the general population [11]. Stigma, lower socio-  
67 economic status, lack of awareness and education regarding the benefits of exercise, and  
68 transportation issues can pose barriers for older adults and individuals with stroke, and may  
69 similarly pose barriers to exercise participation for PLWH [12-14]. It is critical to consider novel  
70 ways to promote engagement in physical activity for PLWH.

71  
72 Community-Based Exercise Programs (CBEPs) offer a safe and effective strategy to reduce  
73 disability for PLWH. A CBEP includes a structured set of exercises designed for individuals  
74 with specific exercise needs; they commonly involve a group of persons with similar conditions  
75 exercising under the supervision of a physiotherapist or fitness instructor, with the goal of  
76 promoting and continuing regular exercise in the community [15-18]. CBEPs are widely used  
77 among people with chronic and episodic conditions demonstrating improvements in endurance  
78 and balance, and measures of depression for people with multiple sclerosis, cancer and stroke  
79 [19,20]. Given the increasing chronicity and multi-morbidity associated with HIV, CBEPs may  
80 offer an effective and sustainable self-management strategy to improve health outcomes for  
81 PLWH [21].

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3 82 Researchers piloted the implementation of a 16 week fitness instructor led CBEP and assessed  
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5 83 the impact on health and disability before and after the program [22]. However, the experiences  
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7 84 participating in a CBEP from the perspective of PLWH and the extent to which a CBEP may  
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9 85 influence ongoing long-term engagement in exercise are unknown. Our aim was to explore the  
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11 86 experiences engaging in a CBEP from the perspective of PLWH. Specific objectives were to  
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13 87 describe: 1) the nature and extent of exercise; 2) facilitators and barriers of engaging in a CBEP;  
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15 88 3) perceived benefits of participating in a CBEP on health and disability outcomes; and 4) the  
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17 89 impact of a CBEP on the long-term engagement in exercise over time.  
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## 19 91 **METHODS**

20  
21 92 We conducted a descriptive qualitative study in collaboration with the Central Toronto YMCA  
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23 93 and Toronto People with AIDS (PWA) Foundation in Toronto, Canada [23, 24]. This study was  
24  
25 94 approved by the University of Toronto HIV/AIDS Research Ethics Board.  
26  
27 95

28 96 Our study builds on a pilot study that explored the implementation of a CBEP with the aim to  
29  
30 97 reduce disability and improve health for PLWH [22]. The CBEP included a combination of  
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32 98 aerobic, resistance, flexibility and balance training for 90 minutes, three times per week for 16  
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34 99 weeks at the YMCA in Toronto, Canada [22]. The intervention was specifically tailored to each  
35  
36 100 participant depending on their individual goals, abilities, and interests. Hence the intensity, type  
37  
38 101 and time of each form of exercise varied among participants. Exercise sessions were supervised  
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40 102 and progressed weekly by a fitness instructor. Participants were asked to attend monthly  
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42 103 educational self-management sessions focused on topics including exercise, healthy eating, role  
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44 104 of occupational therapy, and complementary and alternative therapies for PLWH [22].  
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46 105 Participants received a 16 week YMCA membership for the duration of the study.  
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49 107 We recruited adults (18 years of age or older) living with HIV who participated (but did not need  
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51 108 to complete) the CBEP [22]. We contacted participants from the pilot study by email or  
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53 109 telephone who agreed to be contacted about future phases of research. Members of the research  
54  
55 110 team identified themselves to potential participants as students in the Department of Physical  
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57 111 Therapy at the University of Toronto (CAM, KJH, SRK, TBK and CFMY) who were advised by  
58  
59 112 a faculty advisor throughout the research (KKO). Face-to-face interviews were conducted at a  
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3 113 community-based organization (Toronto PWA Foundation), the YMCA, or the University of  
4  
5 114 Toronto based on the preference of participants. Five members of the team (CAM, KJH, SRK,  
6  
7 115 TBK and CFMY) conducted the interviews using a semi-structured interview guide (Additional  
8  
9 116 file 1) [25]. Specifically, we asked participants about the strengths and limitations of the  
10  
11 117 program, if and how personal and environmental factors influenced their participation in the  
12  
13 118 CBEP, perceived benefits (if any), and how the CBEP influenced their ongoing engagement in  
14  
15 119 exercise after the program. One team member interviewed and the other took field notes.  
16  
17 120 Interviews were audio recorded and transcribed verbatim.  
18  
19 121

20  
21 122 We administered a self-reported demographic questionnaire followed by the Rapid Assessment  
22  
23 123 of Physical Activity (RAPA) scale, a nine-item questionnaire that describes the frequency and  
24  
25 124 intensity a participant spends in vigorous or moderate aerobic activity within a week (RAPA 1)  
26  
27 125 and the frequency a participant engages in strength and flexibility activities within a week  
28  
29 126 (RAPA 2) [26].  
30  
31 127

### 30 128 **Data analysis**

31  
32 129 We conducted a thematic analysis examining transcripts line-by-line to create codes we  
33  
34 130 interpreted as key concepts related to experiences with the CBEP program [27,28]. Three  
35  
36 131 transcripts were independently coded by all members of the team who subsequently met to  
37  
38 132 collectively review codes and establish a preliminary coding scheme. Pairs of researchers  
39  
40 133 independently coded the remaining transcripts, met to discuss their coding interpretations, and  
41  
42 134 created analytic memos for each transcript. We clustered the codes into broader categories;  
43  
44 135 defined each category, discussed relationships between categories and grouped categories into  
45  
46 136 broader themes [27]. We used NVivo qualitative software to ease data management [29]. We  
47  
48 137 organized the themes and categories into a framework to describe the experiences participating  
49  
50 138 in the CBEP from the perspective of PLWH.  
51  
52 139

53  
54 140 For the demographic questionnaire, we calculated median and interquartile ranges (IQR) for  
55  
56 141 continuous variables and frequencies and percent for categorical variables. We calculated median  
57  
58 142 (IQR) for RAPA 1 scores ranging from 1 (least active) to 7 (most active) and median (IQR)  
59  
60 143 RAPA 2 scores ranging from 0 (not engaging in strength and flexibility) to 3 (doing both

144 strength and flexibility activities) [26]. Higher RAPA scores indicated greater frequency,  
145 intensity, and duration of activity [26].

146

## 147 RESULTS

148 Of the 15 individuals who were approached and met inclusion criteria, 11 responded and agreed  
149 to participate. Eleven adults living with HIV participated in a 30-90 minute interview between  
150 February and June 2016. The majority were men (64%), median age of 52 years, with a median  
151 of five self-reported concurrent health conditions in addition to HIV (Table 1). Nine participants  
152 (82%) completed the CBEP.

153 **Table 1:** Characteristics of participants (n=11)

Characteristic	Number of participants (%*)
Gender	
Man	7 (64%)
Woman	1 (9%)
Other^	3 (27%)
Age (years), median (IQR)	52 years (48, 60)
Year of HIV diagnosis, median (IQR)	2004 (1990, 2008)
Currently taking antiretroviral therapy	11 (100%)
Viral load Undetectable	5 (45%)
Partnership Status	
Married or common law	4 (36%)
Widowed	2 (18%)
Single	4 (36%)
Separated or divorced	1 (9%)
Lived Alone	8 (73%)
Current Employment Status	
Working, volunteering or student	7 (64%)
Retired	1 (9%)
Not working	3 (27%)
Household Income per year (Canadian dollars)	
<\$39,999	5 (45%)
\$40,000-69,99	2 (18%)
\$70,000-99,9999	2 (18%)
\$100,000-150,000	2 (18%)



Median number of Concurrent Health Conditions in addition to HIV (IQR)	5 (4,6)
Most commonly self-reported concurrent health conditions. Number of participants living with...	
Mental health condition	6 (55%)
Bone and joint disorder	5 (45%)
High cholesterol	4 (36%)
Neurocognitive decline	4 (36%)
Addiction	3 (27%)
Human Papillomavirus	3 (27%)
Peripheral neuropathy	3 (27%)

\* Percentages may not add up to 100% due to rounding to nearest %

^ Included gender fluid; two-spirited; masculine

CBEP: Community-Based Exercise Program

Interviews occurred a median of six months after the CBEP. At the time of the interviews, 10 (91%) participants were still exercising, nine (90%) of which were exercising to a lesser extent than during the CBEP (Table 2).

**Table 2:** Exercise characteristics of participants related to the CBEP (n=11)

Characteristic	Number of participants (%*)
Time since Community Based Exercise Program Participation, median (IQR)	6 months (4,8)
Self-Reported Level of Exercise Prior to the CBEP	
Not engaging in exercise	4 (36%)
Exercising < 2 times per week	5 (45%)
Exercising ≥ 2 times per week	2 (18%)
Self-Reported Level of Exercise Immediately after Completing the CBEP	
Exercised regularly ≥ 2 times per week	3 (27%)
Exercised not regularly < 2 times per week	5 (45%)
Did not exercise	
Self-Reported Level of Exercise at Time of Interview as Compared to participant exercise level during the CBEP	
Exercising less	9 (82%)
Exercising more	1 (9%)
Exercising similarly to CBEP	1 (9%)

\* Percentages may not add up to 100% due to rounding to nearest %

CBEP: Community-Based Exercise Program

162 At the time of the interview, four participants (36%) reported actively engaging in aerobic and  
 163 anaerobic (both strength and flexibility) (Table 3).

164  
 165 **Table 3:** Self-Reported Level of Physical Activity as measured by the RAPA Questionnaire

RAPA Classification RAPA Interpretation	Number of participants (%*)
<b>Aerobic Activity</b>	
Under-active regular-light activities Performs some light physical activity every week	2 (18%)
Under-active regular activities Performs moderate physical activities every week but < 30 minutes a day or 5 days a week <b>OR</b> Performs vigorous physical activities every week, but < 20 minutes a day or 3 days a week	5 (45%)
Active Performs 30 minutes or more a day of moderate physical activities, 5 or more days a week <b>OR</b> Performs 20 minutes or more a day of vigorous physical activities, 3 or more days a week	4 (36%)
<b>Anaerobic Activity (measured as done more than once per week)</b>	
Strength training only Performs activities to increase muscle strength, such as lifting weights or calisthenics, once a week or more	1 (9%)
Flexibility only Performs activities to improve flexibility, such as stretching or yoga, once a week or more	2 (18%)
Both Strength and Flexibility	4 (36%)
Neither Strength or Flexibility	4 (36%)

\* Percentages may not add up to 100% due to rounding to nearest %  
 RAPA: Rapid Assessment of Physical Activity

166

167

## 168 **Framework of Experiences of People Living with HIV Participating in a Community-** 169 **Based Exercise Program**

170 The Framework describes participants' experiences across three time phases (before, during, and  
171 after the CBEP) (Figure 1). The perceived impact of the CBEP influenced the intention to,  
172 engagement in, and sustainability of exercise among participants. Intrinsic and extrinsic  
173 contextual factors could facilitate or hinder participants' participation in exercise throughout all  
174 phases of the CBEP. The episodic nature of HIV and multi-morbidity further influenced  
175 engagement and re-engagement in exercise throughout the continuum.

176  
177 [Insert Figure 1]  
178

### 179 **Phase 1: Prior to the Community-Based Exercise Program**

#### 180 ***Intention to Join***

181 Participants expressed different motivators for joining the CBEP. Program attributes that  
182 influenced the intention to join the CBEP included its reputability associated with a research  
183 study and specificity of the program for PLWH: "*The real plus about [the] research ... was that*  
184 *it structured it for [PLWH]*" (INT-10). The accessibility of the YMCA location, fitness  
185 instructors and having membership fees waived for participating in the research were additional  
186 motivators for joining the program. Furthermore, the CBEP provided participants the chance to  
187 initiate exercise routines, and healthy life choices: "*[...] when I first learned of the study, I was*  
188 *really excited because I saw it as an opportunity to really, get serious about physical exercise*  
189 *and diet*" (INT-9).

#### 190 191 ***Goals***

192 Prior to participating in the CBEP, participants individually set goals with their fitness instructor  
193 to define their desired outcomes of the program. Examples of goals participants articulated in the  
194 interviews included: gaining strength and muscle mass, managing weight, reducing pain, and  
195 improving energy. Some goals were to address disability and represented motivators to facilitate  
196 participation in the CBEP: "*I wanted to build up muscle, I knew I had a knee problem, so I*  
197 *wanted to ease the pain in my knee*" (INT-4).

198  
199

## 200 **Phase 2: During the Community-Based Exercise Program**

### 201 *Nature and Extent of Exercise*

202 Participants engaged in individualized exercise regimes ranging from 45 minutes to two hours  
203 per session, two to five times per week, for 16 weeks. Exercises varied from weight lifting,  
204 endurance, flexibility and balance training. Participants met with their fitness instructors once  
205 weekly for supervision and progression of their programs, and continuing their exercise  
206 programs independently for the remainder of the week. One participant described his experience  
207 engaging with the CBEP:

208  
209 *I met someone every week and I could go over what was working and what wasn't*  
210 *working and my routine or regimen was changed a few times, plus I got things to do*  
211 *while I was traveling. Or else I wouldn't have done anything because you're on the road*  
212 *[...] (INT-11).*

### 214 **Accountability**

215 Several participants described a sense of accountability towards the CBEP, specifically a  
216 responsibility to the research, their fitness instructors, and to themselves. This feeling of  
217 obligation motivated participants to continue their participation with the CBEP:

218  
219 *I promised I would go every week, and I promised I would work two times on my own,*  
220 *and I managed for the most part I think to do all those things. So the fact that we made*  
221 *all those kinds of promises to the research, I think helped (INT-10).*

222  
223 Another participant described the accountability he felt towards himself and to other PLWH:

224  
225 *I'm the only one alive. Everyone else died. And I think it's part of my pledge or promise*  
226 *to those that have already died from HIV is to look after myself for as long as I can,*  
227 *because [...] by living as good a life as I can, I'm paying homage to the fact that they*  
228 *weren't able to. I'm not wasting the years, or at least I'm trying not to (INT-3).*

229  
230

## 231 ***Positive Experience***

232 Positive features of the CBEP included the environment and fitness instructors which acted as  
233 motivators to continue exercising throughout the CBEP.

### 234 *1) Environment and Atmosphere*

235 Participants described the YMCA atmosphere as non-judgmental, accessible, and a place of  
236 familiarity:

237  
238 *It's also encouraging [...] that there are all sorts of ages, shapes, and sizes and*  
239 *limitations at the Y and there is no judgment. It's just a place where people go to try*  
240 *and optimize their health benefit (INT-3).*

241  
242 However, several participants disliked the noise at the facility: *"I loved the facility; I just don't*  
243 *like it when there's all the screaming kids"* (INT-9).

### 244 245 *2) Fitness Instruction*

246 A key component to participants' positive experiences was the fitness instructors' openness to  
247 learn about HIV, and their ability to modify activities based on individual needs. Participants  
248 described a fondness of the fitness instructors' flexibility during fluctuating periods of illness and  
249 wellness: *"The fitness trainer was just wonderful, both in terms of the instruction, but also her*  
250 *understanding, her sensitivity [...] to my life situation"* (INT- 9). Fitness instructors provided  
251 ongoing support and motivation throughout the CBEP.

## 253 **Impact of the Community-Based Exercise Program**

### 254 ***Perceived Changes to Physical, Mental and Social Health***

255 The majority of participants described improvements in their physical, mental and social health  
256 which encouraged them to remain engaged during and after the CBEP: *"I did appreciate the*  
257 *benefits of it. That's what motivated me to continue"* (INT-8). See Table 4 for a detailed  
258 overview of perceived changes in health outcomes.

259  
260

261 **Table 4:** Participants perceived changes in physical, mental and social health with the  
 262 Community-Based Exercise Program

Area of Health	Perceived Change in Health with the CBEP	Examples of Supporting Quotations
<b>Physical</b> (related to the body)	<ul style="list-style-type: none"> <li>• weight loss</li> <li>• increased muscle mass</li> <li>• improved endurance</li> <li>• improved energy</li> <li>• improved function / ability to perform activities of daily living</li> <li>• decreased pain</li> <li>• decreased fatigue</li> <li>• improved sleep</li> </ul>	<p><i>"I slept better, I ate better, I felt better, had more energy" (INT-1).</i></p> <p><i>"I lost all my joint pain" (INT-3).</i></p> <p><i>"It's like, this is, it's like a life saver! So, I feel that if I hadn't... been participating in this I think I would, instead of losing weight and gaining muscle and losing fat, that I would probably be the same as I was before or even gaining more weight" (INT-4).</i></p>
<b>Mental</b> (related to the mind)	<ul style="list-style-type: none"> <li>• improved confidence</li> <li>• improved self-esteem and body image</li> <li>• decreased stress and anxiety</li> <li>• improved mood</li> <li>• sense of accomplishment, feeling proud</li> </ul>	<p><i>"Certainly the increased energy level. Sense of well-being. Sense of accomplishment" (INT-3).</i></p> <p><i>"I looked good in front of my father, he didn't see a son that was sick and who would be dying soon. He saw a healthy son" (INT-2).</i></p> <p><i>"Probably the anxiety was related to underlying depression or those feelings of fear and failure, and on the positive side, I found it really helped to make me feel better after the exercise" (INT 7).</i></p>
<b>Social</b> (related to external relationships)	<ul style="list-style-type: none"> <li>• improved relationships with family members, partners or friends</li> </ul>	<p><i>"It helped with building family bonds [...] going to the gym gets me physically active and gives me the abilities that when I leave the gym, I can go running in the park with the kids" (INT-2).</i></p> <p><i>"I met some people there that were also exercising and I think this was another motivator, that I would see them at the gym. So I was more motivated because I was looking [forward] to see them at the class or um at the treadmills or somewhere" (INT-7).</i></p>

263 CBEP: Community-Based Exercise Program

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3 2644  
5 265 ***Acquiring Knowledge***

6  
7 266 Participants' experiences were enhanced by their increased knowledge about exercise. They  
8  
9 267 learned how to safely use exercise equipment and about the physical and mental benefits of  
10  
11 268 exercise from the educational sessions, and fitness instructors. However, a large impact of the  
12  
13 269 CBEP on knowledge acquisition appeared to emerge from their actual perceived benefits  
14  
15 270 experienced with exercise:

16 271

17 272 *I think you can tell people that exercise is good for you until you are blue in the face, but*  
18  
19 273 *until you experience that exercise is good for you [...] it's just not going to be real (INT-*  
20  
21 274 *11).*

22 275

23  
24 276 This knowledge had a sustained impact following completion of the program: *"Well the most*  
25  
26 277 *important thing that I learned is that any type of physical activity is useful so I [have] definitely*  
27  
28 278 *been walking more since I participated in the program"* (INT-5).

29 279

30 280 ***Shifting Perceptions of Exercise***

31  
32 281 Initially, participants felt fear and apprehension regarding exercise, but after participating in the  
33  
34 282 CBEP, they reported gaining confidence and knowledge, which instilled a sense of comfort,  
35  
36 283 empowerment, and achievement with exercise:

37 284

38  
39 285 *I think I had a lot of fears before, not knowing what I was doing [...] I went in really*  
40  
41 286 *hating exercise [...] I don't think I missed [an exercise] session, I really enjoyed it (INT-*  
42  
43 287 *8).*

44 288

45  
46 289 This shifting perception of exercise persisted after the CBEP:

47 290

48  
49 291 *You know it's basically like a life saver ... I do it because I feel that I have been fit in*  
50  
51 292 *terms of how I feel but also in terms of how I manage my health over time, and you*  
52  
53 293 *know looking after myself. So I see it as a necessity (INT-4).*

54 294

55

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3 295 Lastly, after completion of the CBEP, participants viewed exercise as a necessary self-  
4  
5 296 management strategy:  
6

7 297  
8  
9 298 *If it could become part of the suite of therapies available to people living with HIV that*  
10 299 *would be great. I think it should be essential of living strategies for living with HIV (INT-*  
11 300 *9).*  
12  
13

14 301  
15  
16 302 ***Adopting Structure and Routine***

17 303 Several participants described leading busy lives with multiple work and family responsibilities  
18 304 and appreciated the consistency and structure provided by the CBEP: “[...] with such a chaotic  
19 305 life with so many volunteer obligations, it was nice three times a week to just have a morning  
20 306 that was just on me” (INT-11). The structure and routine was further described as a motivator to  
21 307 maintain participation in the CBEP: “What helped me? Probably how I structured my day, some  
22 308 days I went in early in the morning to do it and sometimes it was once I finished working” (INT-  
23 309 10). After participants completed the CBEP, they described experiencing a lack of structure and  
24 310 routine which contributed to their inability to continue at the same level of activity: “I know  
25 311 myself well enough to know that if I don’t participate in a structured class that probably I will  
26 312 fall out of the pattern” (INT-3).  
27  
28  
29

30 313  
31  
32  
33  
34 314 **Phase 3: After the Community-Based Exercise Program**

35 315 ***Current Level of Exercise***

36  
37 316 Interviews in this study occurred a median of six months after the CBEP. Six of the eleven  
38 317 participants (55%) continued their YMCA membership after the CBEP. Types of activity  
39 318 participants engaged in at the time of the interview included, but were not limited to: increased  
40 319 amounts of walking for transportation, increased use of stairs, and riding bicycles. Ten  
41 320 participants (91%) reported continuing to engage in exercise, nine of which (90%) reported  
42 321 exercising to a lesser extent since the CBEP. Three participants (27%) reported not continuing  
43 322 with exercise long-term due to injury, substance abuse, or no given reason.  
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### 326 ***Future Intention to Exercise***

327 Participants viewed exercise as an ongoing self-management strategy to maintain and promote  
328 healthy living and all expressed a desire to incorporate exercise in their future. One participant  
329 stated: “*I can see myself doing this for the rest of my life*” (INT-4). Furthermore, participants  
330 described using exercise as a self-management strategy aging with HIV:

331  
332 *[I’m] mindful of the fact that as [...] anybody gets older, if we don’t maintain a degree of*  
333 *physical activity...It’s a slippery slope – and the less you do the less you are able to do*  
334 *(INT-3).*

### 335 **Intrinsic Factor**

#### 336 ***Age***

337  
338 Participants described how age influenced their experiences across the CBEP. Of the nine  
339 participants that reported their age, five were (56%) older than 50 years from a range of 38 to 61  
340 years. Participants described how their age influenced their goal setting and motivation for  
341 joining the CBEP:

342  
343 *[...] I think exercise for me [...] is going to be about being focused on that as I age*  
344 *and keeping my body less frail, more mobile, those kinds of things are important to me*  
345 *(INT-10).*

346  
347 Within the CBEP, the majority of participants expressed that their age had little to no influence  
348 on their experiences. After the CBEP, many saw aging as a way to motivate them to remain  
349 active and decelerate aging:

350  
351 *If I’m not mindful in looking after myself, the nursing home beckons, and I really don’t*  
352 *want that. So I have to keep as active as I can so that I can stay in my own home and*  
353 *look after myself (INT-3).*

1  
2  
3 357 **Extrinsic Factors**

4  
5 358 Extrinsic factors in the environment including stigma, social support, and weather and holidays  
6  
7 359 influenced participants' experiences with exercise.

8  
9 360

10  
11 361 ***Stigma***

12 362 Prior to the CBEP, participants reported concerns regarding potential stigma related to body  
13  
14 363 image in a gym environment, however, during the CBEP participants found the YMCA gym  
15  
16 364 environment less stigmatizing than originally feared.

17  
18 365

19 366 *So I've learned to not be intimidated by going, because whether or not it's body image*  
20  
21 367 *issues that one can have or the fear [...] the idea of gym class was something that was*  
22  
23 368 *anathema to me and going back to that environment with a lot of jocks or people that*  
24  
25 369 *are more well-defined or whatever you will can be a little intimidating [...] (INT-3).*

26  
27 370

28 371 ***Social Support***

29  
30 372 Participants described having various levels of social support, assistance, and care from others  
31  
32 373 during the CBEP, but did not feel connected with other study participants, despite the group  
33  
34 374 monthly education sessions. Some participants preferred to exercise alone, while others  
35  
36 375 expressed a desire to expand their social network and seek support from other participants. One  
37  
38 376 participant used his partner as a source of continued motivation throughout the CBEP:

39 377

40 378 *That sense of connection is very important so the fact that I was able to establish that*  
41  
42 379 *in the context of that program by working out with a buddy probably gave, I got more*  
43  
44 380 *out of it for having done it that way (INT-10).*

45  
46 381

47 382 Participants described various levels of support from their healthcare professionals. Some felt  
48  
49 383 that their health providers encouraged and motivated their participation, while others felt no  
50  
51 384 influence:

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3 386 *One of my HIV doctors said, when he saw my MRI, oh I guess you should see a*  
4  
5 387 *physiotherapist, and I said oh I'm part of this research project [...] and he said oh*  
6  
7 388 *that's better than going to see a physiotherapist, do that (INT-4).*  
8  
9 389

### 10 390 ***Weather and Holidays***

11 391 Participants described how weather and seasonal holidays influenced their motivation and  
12  
13 392 engagement in exercise. The CBEP occurred in the spring and summer months; hence  
14  
15 393 participants perceived warm weather, as a facilitator that increased their activity levels. After the  
16  
17 394 CBEP, participants reported the colder weather was a barrier to exercise. In some instances,  
18  
19 395 participants perceived exercise as additional work, and viewed holidays and vacations, as a time  
20  
21 396 to pause from their exercise programs:  
22

23 397  
24 398 *[...] I was pretty active up until like November, umm when it started getting really cold,*  
25  
26 399 *then I took a break over December and Christmas and then I started again in January*  
27  
28 400 *and then it got really cold and I just had to stop (INT-4).*  
29

### 30 401

### 31 402 **Episodic nature of HIV and multi-morbidity**

32  
33 403 Some participants experienced fluctuating periods of wellness and illness which resulted in  
34  
35 404 periods of inactivity due to poor health. These varying episodes affected experiences across all  
36  
37 405 three phases, and influenced their ability to exercise and re-engage in exercise after a period of  
38  
39 406 inactivity. One participant described living with the episodic nature of HIV:  
40

41 407  
42 408 *I got sicker and sicker. Same way I got better and better, I just started you lose your*  
43  
44 409 *mobility and your ability to stretch and your motivation as time goes on. And the less you*  
45  
46 410 *do, the less you wanted to do" (INT-2).*  
47

48 411  
49 412 We defined multi-morbidity, as the presence of one or more health conditions, in addition to  
50  
51 413 living with HIV. Mental health conditions and bone and joint disorders were the most prominent  
52  
53 414 (Table 1). Before the CBEP, one participant described how mental health was a motivator for  
54  
55 415 exercise, helping shape her goals and experiences:  
56  
57 416  
58  
59  
60

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2  
3 417 *Lot of [my goals] had to do with mental and emotional health, so one of the things I*  
4  
5 418 *talked about was my anxiety and how it played out in different areas of my body so we*  
6  
7 419 *worked on some exercises that would just help me relax (INT-5).*  
8

9 420  
10 421 Multi-morbidity was dually experienced as a barrier to exercise. Two participants (18%)  
11  
12 422 withdrew from the CBEP due to concurrent health conditions, one of whom described his  
13  
14 423 experience with addiction disrupting his ability to engage in exercise:  
15

16 424  
17 425 *[The CBEP] was complete stop. It was an immediate plunge back into abuse. I mean,*  
18  
19 426 *maybe it was a relapse for, for the first few days but then it just became [...] again it*  
20  
21 427 *became my choice. I chose [...] to go ever deeper into, my substance abuse (INT- 9).*  
22

23 428  
24 429 The flexibility offered by the program and the fitness instructor was helpful for participants to  
25  
26 430 deal with and overcome the unpredictable and episodic nature of multi-morbidity and HIV  
27  
28 431 during the CBEP:  
29

30 432  
31 433 *And one of the things I most appreciated was the flexibility, you know it wasn't, you*  
32  
33 434 *know I was concerned that [fitness instructors] would dictate what the routine is but*  
34  
35 435 *no, there was complete flexibility (INT-9).*  
36

37 436  
38 437 Several participants described experiencing an improvement with their multi-morbidity after  
39  
40 438 their engagement in the CBEP, ultimately leading to the desire to incorporate exercise as a  
41  
42 439 lifestyle strategy in their future. However, as time progressed, some participants struggled with  
43  
44 440 complications of HIV and multi-morbidity, and expressed difficulty sustaining and returning to  
45  
46 441 their exercise regimes.  
47

48 442  
49 443 Finally, the majority of participants described the need for return-to-exercise strategies. One  
50  
51 444 participant stated: *"I guess the one goal I had was continuing to exercise after the program. And*  
52  
53 445 *I did. But, I got sick [...], once you lose the rhythm, you really lose the rhythm" (INT-11).*  
54

55 446  
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57 447  
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60

1  
2  
3 448 **DISCUSSION**  
4

5 449 To our knowledge, this is the first qualitative study to explore the experiences of participating in  
6  
7 450 a CBEP from the perspectives of PLWH. Perceived benefits of the CBEP were influential in  
8  
9 451 promoting adherence to exercise and adoption of exercise as a long-term self-management  
10  
11 452 strategy. Engagement in exercise across the phases in our Framework may be considered  
12  
13 453 analogous to the precontemplation, contemplation, preparation (before CBEP), action (during  
14  
15 454 CBEP), and maintenance (after CBEP) stages of behaviour change in the Transtheoretical Model  
16  
17 455 (TTM) [30-32]. Earlier stages of the TTM, specifically readiness to engage in exercise, has been  
18  
19 456 explored from the perspectives of PLWH highlighting the contemplation phase when living with  
20  
21 457 HIV and complex multi-morbidity [33]. Our Framework depicts how PLWH transition through  
22  
23 458 stages of exercise behaviour change (contemplation and preparation) and further considers the  
24  
25 459 phases during (action) and after (maintenance) of a formalized CBEP, exploring the potential to  
26  
27 460 adopt exercise as a self-management strategy living with HIV. Strengthening the impact of a  
28  
29 461 CBEP to yield positive experiences during a CBEP can subsequently promote maintenance of  
30  
31 462 exercise for PLWH post-CBEP.  
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33 463  
34 464 Participants described how perceived benefits experienced during the CBEP promoted adherence  
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36 465 to, and ongoing maintenance with, exercise. Improvements in physical, mental, and social health  
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38 466 were similarly reported in systematic review evidence on the effects of exercise for PLWH  
39  
40 467 [7,9,10,34,35]. However, acquiring knowledge that mitigated uncertainty with exercise and  
41  
42 468 incorporating exercise as a structure and routine were additional benefits articulated by  
43  
44 469 participants' that positively influencing their engagement with exercise. These additional  
45  
46 470 benefits may be attributed to the YMCA environment, weekly supervision from a fitness  
47  
48 471 instructor, and the monthly education sessions [36]. Similar positive features of CBEPs were  
49  
50 472 documented when individuals with pulmonary disease, multiple sclerosis, and stroke engaged in  
51  
52 473 CBEPs [37-39]. Future programs should consider the importance of education about the safety  
53  
54 474 and effectiveness of exercise, discussing pre-existing perceptions of exercise, and offering  
55  
56 475 support for adopting exercise as part of a regular routine. Future research may explore the extent  
57  
58 476 to which these features of a CBEP may influence long-term sustainability engaging in exercise  
59  
60 477 and the potential benefits of a combined CBEP program with PLWH and other chronic illnesses.  
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3 479 The episodic nature of HIV and multi-morbidity was an underlying factor that influenced  
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5 480 engagement in and re-engagement in exercise after a period of inactivity for PLWH. Mental  
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7 481 health and addiction issues were examples of concurrent health conditions that influenced  
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9 482 ongoing participation in exercise. Knowledge among fitness instructors about the episodic nature  
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11 483 of HIV, their supportive approach to adapting the CBEP to accommodate changes in health of  
12  
13 484 participants' along with the inclusive and accommodating nature of the YMCA facilitated  
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15 485 engagement in the CBEP. PLWH who are medically stable can safely exercise two to four times  
16  
17 486 weekly, at 40-60% heart-rate-reserve, for 30-120 minutes per session, utilizing a variety of types  
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19 487 of exercise activity [40,41]. Knowledge among health providers about the safety and  
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21 488 effectiveness of exercise can help to ensure they adequately promote participation in exercise in  
22  
23 489 a manner that recognizes, supports, and accommodates the needs of PLWH while offering  
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25 490 variable ways to maximize engagement despite fluctuations in health.

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27 491  
28 492 Of the 11 participants, 10 remained physically active after the program ended, nine of which  
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30 493 were less active than during the CBEP. Nevertheless, ongoing engagement in physical activity  
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32 494 among almost all participants may be considered a success of the intervention. Some participants  
33  
34 495 expressed challenges returning to exercise after episodes of illness or multi-morbidity. Fitness  
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36 496 instructors adjusted the programs according to the health of participants. Future programs should  
37  
38 497 consider strategies to help PLWH return to exercise or maintain exercise despite the potentially  
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40 498 episodic nature of HIV and multi-morbidity.

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42 500 Our study builds on a pilot study that examined the process and implementation of a CBEP for  
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44 501 PLWH [22]. Using a qualitative approach, we were able to describe the experiences, influencing  
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46 502 factors, and perceived impact of community-based exercise while illustrating the complex  
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48 503 interactions between the components and underlying influence of the episodic nature of HIV and  
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50 504 multi-morbidity. This Framework can be used by clinicians, representatives from the fitness  
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52 505 community, and PLWH to inform the understanding of experiences engaging in exercise, and the  
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54 506 features to consider when designing and implementing future exercise programs for PLWH.

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56 507  
57 508 Our study possesses some limitations. The majority of participants completed the CBEP and thus  
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59 509 may have represented a 'healthy' community-dwelling sample of PLWH. Nevertheless, many  
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3 510 described having to cancel appointments or scale back on exercise due to periods of illness.  
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5 511 Participants in this study were primarily men living in downtown Toronto who completed the  
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7 512 CBEP and agreed to participate in an interview. Hence, the transferability of these findings to  
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9 513 women, PLWH living in rural settings and for those who withdrew or were lost to follow-up are  
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11 514 less clear. Finally, our aim was not to achieve saturation, but rather to obtain a rich description of  
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13 515 experiences in the CBEP. Nevertheless we ceased the interviews at 11, which we observed as the  
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15 516 point when no new categories emerged.

## 17 517 **CONCLUSIONS**

18 518 Results describe experiences before, during and after engaging in a CBEP from the perspective  
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20 519 of adults living with HIV. The positive impacts of the CBEP and the episodic nature of HIV and  
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22 520 multi-morbidity influenced engagement in and sustainability of exercise among PLWH. Future  
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24 521 CBEPs should include strategies to accommodate potential fluctuations in health and promote  
25  
26 522 return-to-exercise strategies to assist with re-engagement in exercise after an episode of illness.  
27  
28 523 This Framework may be utilized by healthcare professionals when recommending and discussing  
29  
30 524 exercise with PLWH, and can inform the design of future CBEPs in order to promote imitation  
31  
32 525 and sustained engagement in physical activity among PLWH.

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49 534 development of our protocol.

## 50 51 535 52 53 54 536 **AUTHORS' CONTRIBUTIONS**

55 537 KKO (PhD) designed the study and provided guidance throughout the research process. KKO  
56  
57 538 possesses expertise in qualitative methodology and HIV and exercise research. KKO supervised  
58  
59  
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2  
3 539 CAM, KJH, SRK, TBK and CFMY who developed the protocol, collected and analysed the data,  
4  
5 540 and drafted the manuscript in partial fulfillment of requirements for an MScPT degree at the  
6  
7 541 University of Toronto. CAM, KJH, SRK, TBK and CFMY (MScPT students) developed skills in  
8  
9 542 qualitative research methodology including attending lectures; completing readings on  
10  
11 543 qualitative research study design; understanding steps of recruitment, data collection and  
12  
13 544 analysis; completing a literature review; developing the research protocol; interview guide and  
14  
15 545 demographic questionnaire; and considering the ethical issues associated with this research. All  
16  
17 546 steps were closely reviewed and guided by KKO (advisor). All authors read and approved the  
18  
19 547 final manuscript.  
20  
21 548

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27  
28 553

## 31 554 **COMPETING INTERESTS**

32  
33 555 The authors have no competing interests to declare.  
34  
35 556

## 36 557 **ETHICS APPROVAL**

37  
38 558 University of Toronto HIV/AIDS Research Ethics Board  
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## 41 559 **DATA SHARING STATEMENT**

42  
43  
44 560 The data collected and analyzed during the study are not publicly available in accordance with  
45  
46 561 our study protocol that was approved by the University of Toronto HIV/AIDS Research Ethics  
47  
48 562 Board. Data may be available on reasonable request by contacting the corresponding author.  
49  
50 563

## 51 564 **FIGURE LEGENDS**

52  
53 565 **Figure 1: Framework of Experiences of Adults Living with HIV Participating in a**  
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55 566 **Community- Based Exercise Program**  
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3 567 This Framework describes participants' experiences across three time phases (before, during and  
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5 568 after the CBEP) and the perceived impact during and after the CBEP. Intrinsic and extrinsic  
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7 569 contextual factors facilitated or hindered participants' experience across all phases of the CBEP.  
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9 570 The episodic nature of HIV and multi-morbidity further influenced the intention to, engagement  
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11 571 in and sustainability of exercise throughout the continuum.  
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13 572 CBEP: Community-based exercise program.

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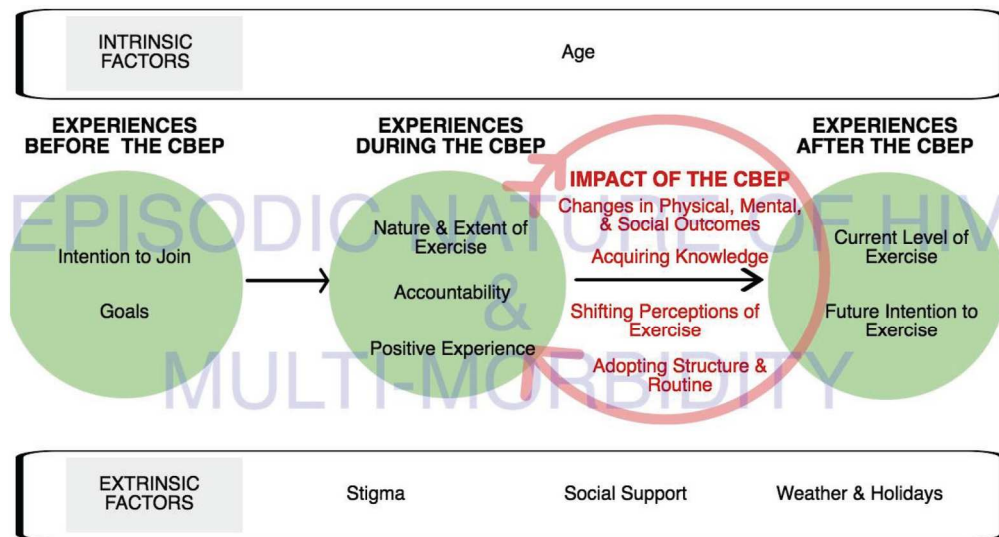


Figure 1 - Framework of Experiences of Adults Living with HIV Participating in a Community- Based Exercise Program

153x82mm (300 x 300 DPI)

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## Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

Thank you for agreeing to participate in this study. I am meeting with you to understand your experiences participating in the 4-month community-based exercise program at the YMCA that occurred back in the spring/summer of 2015. While this study follows up on the YMCA program, we are a different team of researchers with different goals. Specifically, we are interested in learning about your current level of exercise and how participation in the YMCA program may have affected your ability to exercise over the long term. We are interested in exploring any factors you found helpful and any factors that limited your ability to participate in the community-based exercise program. We are also interested in exploring any benefits you experienced during and after participating in the program.

Sometimes there is confusion about what the difference is between *exercise* and *physical activity*. For this study, we define exercise as a planned, structured, specific form of activity with the aim of improving or maintaining overall fitness, health, and well-being. On the other hand, physical activity refers to any effortful movement that occurs in your everyday life, such as walking the dog or gardening. For this study, we are interested in the impact of the community-based program on both your level of exercise and your level of physical activity. The findings from the interview will be used to better understand the experience of taking part in a community-based exercise program. Results from this study will help to inform the future development of community-based exercise programs for people living with HIV.

Would you mind if I take notes during the interview?  
Do you have any questions before we begin?

1. **Please think back to when you were involved in the community-based exercise program at the YMCA. Can you describe your experience taking part in the community-based exercise program?**
  - i. How did you come to take part in the programs?
    1. How did you find out about the programs?
    2. What motivated you to decide to take part in the program?
  - ii. What was your physical activity level like *prior* to taking part in the community-based exercise program?
  - iii. Can you describe the nature of your community-based exercise program?
    1. What types of exercise did you do? [type of activity, aerobic / resistive component, group or individual activity]
    2. How often? [frequency]
    3. How intense did you exercise? [intensity]
    4. How long did you exercise? [time]
    5. Where did you do the exercise? [location]
    6. How did you progress your exercise program? [progression]
    7. Can you describe the level of supervision or coaching that you had as part of the program?
    8. How often did you attend (or take part) in the exercise? [adherence]
    9. Did you miss any of the exercise sessions? If so, can you speak to some of the barriers that kept you from going? [e.g. episodic illness, other life stressors, vacation, etc.]
    10. We understand that you set goals before starting the program. What were your goals at the beginning of the program?



**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

**2. Thinking back to when you were involved in the community-based exercise program at the YMCA, what were some of the positive aspects of the community-based exercise program?**

- i. Nature of the facility [YMCA, location, hours of operation]
- ii. Coaching staff
- iii. Other members of the facility
- iv. Exercise equipment
- v. Getting into a routine
- vi. Monthly education sessions
- vii. Interacting with other participants in the study

**3. What were some of the challenges or drawbacks you experienced with the community-based exercise program?**

- i. Nature of the facility [YMCA, location/transportation, hours of operation]
- ii. Coaching staff
- iii. Scheduling
- iv. Exercise equipment
- v. Getting into a routine
- vi. From our research, we know that living with chronic illness is always a fluctuating challenge for people and we are interested in how these challenges affected your participation in the CBE intervention? Fluctuating periods of health (episodic nature)
- vii. Concurrent health conditions (Do you have any other health problems that may have affected your participation?)  
[note some of the above may fall into the barriers and facilitators.....]
- viii. Do you have any suggestions to change the program to make it better?
  1. Would you mind expanding on those ideas?

*The next few questions ask about things that may have influenced your experiences taking part in the community-based exercise program and may have influenced your experience with exercise. [objective2]*

**4. Thinking back to when you were involved in the community-based exercise program, what were some of the factors that influenced your ability to participate in the exercise program?**

**4a. Were they any management strategies in your day-to-day life you used that influenced your ability to participate in the exercise program? [living strategies] A management strategy is any tool that you use to keep you motivated towards your goals. (if still requiring examples can say: ride system with a friend, social interactions, positive self-talk)**

- i. What were your general attitudes or outlook towards exercise during the community-based exercise program?
- ii. Have those attitudes or outlook changed since your involvement in the community-based exercise program? If so can you describe how?
- iii. Did these strategies affect your willingness or ability to participate in the exercise program?
- iv. Examples of living strategies could be:
  1. Seeking social interactions (new personal and professional relationship)
  2. Maintaining a sense of control (this concept may influence their disability)

**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

1. To re-establish a sense of purpose, redefining base level of health
  2. Re-evaluation of lifestyle (sleep, nutrition, substance use, medication, exercise, financial security)
  3. Achieving healthy life balance
  4. Planning to anticipate the future
  5. Paying attention to numbers (CD4 count, viral load)
3. Having a positive outlook on life
  4. Comparing experiences of others living with HIV
  5. Faith and spiritual beliefs

**4b. In some cases, exercise itself could be considered a living strategy (or self-management strategy) for enhancing overall health for people for living with HIV. Do you consider exercise a living strategy for living with HIV?**

- i. If yes, can you describe? [e.g. lifestyle, re-establishing purpose in life, maintaining life balance, planning for the future]

**4c. Many people living with HIV are now living longer and aging with HIV. Can you comment on how the concept of ageing may have influenced your experience taking part in the community-based exercise program?**

- i. Can you explain or give me an example of how this happens?

**4d. We are also interested in any similarities or differences experienced by men and women in the program. Do you think that your gender identity influenced your participation in the community-based exercise program in any way?**

- i. If so, can you explain how?

**4e. Do you mind commenting on how any other health conditions played a role, if any, in influencing the experience with the community-based exercise program? (examples if needed: diabetes, osteoporosis, a heart condition, depression/mental illnesses, etc.)**

**4f. Describe how the support of others may have influenced your participation in the community-based exercise program?**

- i. How did friends or family affect your participation in the program?
- ii. How did the other participants in the study affect your participation in the program?
- iii. How did the fitness supervisors in the study affect your participation in the program?
- iv. Did your health care providers – did they know about your involvement in the community-based program and did they influence your involvement at all? If so, how?

**4g. Did you experience any stigma during your involvement in the community-based exercise program? If so can you describe?**

- i. If so, did the stigma impact your participation in the program? How?

*The aim of the CBE program at the YMCA was to enhance the overall health and reduce health-related challenges experienced by adults living with HIV. [Objective #3]*

**Additional File 1 - Interview Guide – Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study**

**5. Did you experience any benefits from participating in the community-based exercise program in relation to your health?**

- i. How about physical benefits (e.g. fatigue, pain, weakness)? Cognitive health benefits (e.g. ability to remember things, think clearly)? Mental health benefits (e.g. anxiety, depression)? Impact on social well-being?
- ii. Has your participation in the program affected your day-to-day activities?
  1. How so?
- iii. How has participating in this CBE impacted your experience living with HIV?
- iv. Dealing with the uncertainty or worrying about future health living with HIV?
- v. Some people may experience fluctuating periods of wellness and illness with HIV (known as episodic), is this something that you have experienced? If so, can you explain how the program affected this episodic nature of living with HIV?  
[Note: interviewer consider episodic nature of HIV]
- v. Earlier I asked about what your goals were when starting the CBE program. Do you feel as if you achieved those goals? [refer back to question 1, last prompt]

*We are interested in the extent to which exercise may become a part of a living strategy for people living with HIV. We are interested in learning about your current level of physical activity (or exercise) and whether the community-based exercise program had any influence on your current activity level in any way or the continuation of exercise of the long-term.*

**6. What type of physical activity (or exercise) have you been doing since the community-based exercise program ended?**

- i. Have you been able to sustain or keep up with your exercise program?
- ii. Describe the nature and different types of exercise that you participate in (such as swimming, biking...etc.) [if not stated]
  1. Do you still go to the YMCA in order to exercise?
  2. If not, where do you exercise?
  3. How intense do you exercise?
  4. How long do you exercise for?
  5. How often do you exercise?
- iii. Have your episodes of illness impacted your ability to maintain this level of physical activity, during or since the community-based exercise program?

**6b. Have you experienced any changes in your health status since the community-based exercise program that impacted your ability to continue with exercise?**

**6c. Has there been anything that has impacted your ability to continue with exercise since the CBE program?**

- i. Illness
- ii. Finances- inability to pay for the YMCA membership
- ii. Other factors?

**7. Based on what we discussed today, do you see yourself continuing to exercise (or starting back up with exercise if they trailed off) in the future? If so, can you explain?**

1 **Additional File 1 - Interview Guide – Experiences participating in a community-based**  
2 **exercise program from the perspective of people living with HIV: A qualitative study**  
3

4 **Concluding remarks:**

5 Do you have any final thoughts about your experiences taking part in the community-based  
6 exercise program at the YMCA? Do you have recommendations when it comes to exercise and  
7 people living with HIV?  
8

9  
10 Thank you for participating in this interview and for your time. The information you gave will help  
11 us gain a better understanding of your experiences participating in a community-based exercise  
12 program.  
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For peer review only

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

Domain 1: Research team and reflexivity			Comment
<b>Personal Characteristics</b>			
1.	Interviewer/facilitator	Which author(s) conducted the interview?	See Methods (Page 6)
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	Credentials are included in the Author's Contributions section (Page 22-23)
3.	Occupation	What was their occupation at the time of the study?	See Affiliations of the author team (Page 1)
4.	Gender	Was the researcher male or female?	See Authors Contributions (Page 22-23)
5.	Experience and training	What experience or training did the researchers have?	See Author's contributions (Page 22-23)
<b>Relationship with participants</b>			
6.	Relationship established	Was a relationship established prior to study commencement?	Relationship was not established prior to the interviews (see Methods - Page 5).
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. personal goals, reason for doing the research</i>	Participants knew that the research team was comprised of a group of MScPT students at the University of Toronto who were advised by faculty at the Department of Physical Therapy. (see Methods - Page 5-6).
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g. bias, assumptions, reasons and interests in the research topic</i>	Participants knew that this research was done by students in partial fulfillment of the requirements for a MScPT degree at the UofT (see Methods Page 5-6 and Authors' Contributions Page 22-23).
<b>Domain 2: Study design</b>			
<b>Theoretical framework</b>			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? <i>E.g.</i>	We conducted a descriptive qualitative study (See the first sentence in the Methods -

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

		<i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Page 5)
<b>Participant selection</b>			
10.	Sampling	How were participants selected? <i>E.g. purposive, convenience, consecutive, snowball</i>	See Page 5-6 (Methods)
11.	Method of approach	How were participants approached? <i>E.g. face-to-face, telephone, mail, email</i>	See Page 5-6 (Methods)
12.	Sample size	How many participants were in the study?	11 participants. See the first sentence in the results (Page 7)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Of the 15 individuals who were approached and met inclusion criteria, 11 responded and agreed to participate. No participants withdrew from an interview (see Results – Page 7).
<b>Setting</b>			
14.	Setting of data collection	Where was the data collected? <i>E.g. home, clinic, workplace</i>	Community-based organization in Toronto, YMCA, or the University of Toronto. See Methods (Page 5)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Two members of the research team (1 interviewer; 1 field note taker) See Methods (Page 5-6)
16.	Description of sample	What are the important characteristics of the sample? <i>E.g. demographic data, date</i>	See Table 1 (Page 7-8) and Table 2 (Page 8) and Table 3 (Page 9)
<b>Data collection</b>			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See Methods (Page 5-6) and Additional File 1 (Interview Guide)
18.	Repeat interviews	Were repeat interviews	No (Page 7)

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

		carried out? If yes, how many?	
19.	Audio/visual recordings	Did the research use audio or visual recording to collect the data?	Each interview was audio recorded. See Methods (Page 6)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were taken throughout the interview. See Methods (Page 6)
21.	Duration	What was the duration of the interviews or focus group?	Approximately 30-90 minutes. See Results (Page 7)
22.	Data saturation	Was data saturation discussed?	Yes. We ceased the interviews at 11; which was the point when no new categories emerged. See Discussion (Page 22)
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No (Page 6)
<b>Domain 3: analysis and findings</b>			
<b>Data analysis</b>			
24.	Number of data coders	How many data coders coded the data?	See Data Analysis (Page 6)
25.	Description of coding tree	Did authors provide a description of the coding tree?	See Data Analysis (Page 6)
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data. See Data Analysis (Page 6)
27.	Software	What software, if applicable, was used to manage the data?	NVivo 10© qualitative software (Page 6)
28.	Participant checking	Did participants provide feedback on the findings?	No. We are in the process of translating the findings back to the community (presentations, etc). (Page 6)
<b>Reporting</b>			
29.	Quotations presented	Were participant quotations presented to	See Results (Pages 10-19)

## COREQ Checklist

Experiences participating in a community-based exercise program from the perspective of people living with HIV: A qualitative study

		illustrate the themes/findings? Was each quotation identified? <i>E.g. participation number</i>	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes (Page 10-19)
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes. See Results (Page 10-19) and Figure 1
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. See Results (Page 10-19) and Figure 1