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Turning Disability into Ability: Barriers and Facilitators to Initiating and Maintaining Exercise Among Older Men Living with HIV

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Abstract

Physical activity reduces the risk for comorbidities, but little is known about barriers to exercise among older adults living with HIV. Three focus groups were conducted among 19 adults living with HIV, aged 50 years, who were enrolled in or recently completed a supervised exercise intervention. Sessions were recorded, transcribed, and coded first using inductive methods. All participants were male, and the majority were white, non-Hispanic; 53% were receiving disability benefits. All had suppressed HIV infection on antiretroviral therapy, with almost 20 years since HIV diagnosis. Participants noted a lack of self-efficacy, motivation, and physical limitations that contributed to a sense of “disability” as barriers to exercise prior to the intervention. Through social support and improvements in self-efficacy, participants were motivated to start and continue exercising. Perceived sense of disability may impede (or interfere with) exercise initiation and maintenance; self-efficacy and social support may facilitate exercise maintenance in older adults living with HIV.

Keywords

research, qualitative; self-efficacy; comorbidities; HIV; aging; exercise; physical activity

INTRODUCTION

Almost half of people living with HIV (PWLH) in the U.S. are now aged 50 and over and experiencing an increasing burden of comorbidities (Deeks, Lewin, & Havlir, 2013; Simonik et al., 2016). Regular physical activity is an effective intervention to prevent or slow the progression of many comorbidities (Hand, Lyerly, Jagers, & Dudgeon, 2009; Lindegaard et al., 2008; Monroe et al., 2017; Souza, Jacob-Filho, Santarem, Zomignan, & Burattini, 2011),

however, rates of routine physical activity are low (Schuelter-Trevisol et al., 2012; Vancampfort, Mugisha, Richards, De Hert, Probst, et al., 2017). Barriers to exercise among younger PLWH are similar to those among uninfected populations (Clingerman, 2003; Rehm & Konkle-Parker, 2016; Simonik et al., 2016). Little is known, however, about how barriers change when sedentary older adults with HIV *initiate* an exercise regimen. Perceptions about exercise initiation are likely to influence individual exercise maintenance and can inform public health interventions to sustain physical activity efforts in older adults with HIV. This study examined the barriers and facilitators to exercise among older PLWH initiating an exercise regimen.

METHODS

PLWH were recruited from a randomized controlled trial (clinicaltrials.gov: NCT02404792) of exercise in older adults with and without HIV; PLWH enrolled for 4 weeks were invited to join the focus groups. All participants provided written, informed consent. The study was reviewed and approved by the Colorado Multi-Institutional Review Board.

Participants in the parent study were sedentary, age 50 to 75 years, on antiretroviral therapy with HIV-1 RNA < 200 copies/mL for 2 years, without contraindications for exercise. Few women joined the parent study and therefore were included in this analysis. A semi-structured guide of open-ended questions was used to facilitate discussion. Focus groups were audio-recorded and transcribed verbatim.

Analysis

An inductive and deductive analytic toolkit for applied behavioral analysis was used (Jones, Nowels, Kutner, Matlock, 2014). The transcripts were individually coded by two team members involved in the interview process and one who was not. Inductive methods were first employed, seeking broad themes related to our research question. An *a priori* list of key domains from previous qualitative research in exercise barriers was used (Baert, Gorus, Mets, & Bautmans, 2015; Bethancourt, Rosenberg, Beatty, & Arterburn, 2014; Lee, Avis, & Arthur, 2007; Rehm & Konkle-Parker, 2016; Roos, Myezwa, & van Aswegen, 2015; Shin, Hur, Pender, Jang, & Kim, 2006), and new *in vivo* codes were added. Codes were compared and contrasted within and across the transcripts and discrepancies resolved through consensus discussions. Consensus approach to theme naming and inclusion were used to arrive at the final product. Quotes were utilized to provide insight into themes. No new themes were identified when coding the third transcript. A community advisory board reviewed and confirmed the findings.

RESULTS

Nineteen men participated in three focus groups (n=7, 7, and 5). The majority of participants had been diagnosed with HIV for nearly 20 years and were effectively treated with ART. Focus groups participants were similar to those enrolled in the larger parent exercise study (n=32), Table 1.

Barriers to Exercise

Intrapersonal reasons were reported as common barriers to exercise (Table 2), including a lack of motivation: *“It takes a lot to motivate. Especially when you have a disability like I do and stuff... You need something to commit to”* and *“being on disability, without a regular schedule or something like that, you know you’re left to your own free will”*. Others felt that the disabling impact of the loss of family, friends, or social networks contributed to low motivation: *“...and then I lost my mom and dad. I lost them and I didn’t care about nothing...”*. Some noted that exercise was boring, or noted a shortage of time or other conflicting responsibilities.

A lack of exercise familiarity, poor self-confidence, or insecurity in exercise ability, particularly prior gym experiences, were considered barriers: *“And there was literally no one in the weight room except for the guys who were obviously not eating the same food I was eating...it really wasn’t that kind of environment where I could feel comfortable.”* Participants were also worried that HIV status might be disclosed, if relevant to the type or extent of exercise: *“[Be]cause in my life, no one knows my HIV status. My family doesn’t. My friends don’t. When I was told to come here [to exercise], I said, ‘Oh my god, I’ll probably meet somebody I know’”*.

An overarching theme linking exercise barriers to benefits was that of a transition from disability to ability. “Disability” was not identified as a barrier or motivator prior to initiating exercise, but instead other barriers were validated through the presence of disability (*“It takes a lot to motivate. Especially when you have a disability like I do...”* and *“...being on disability, without a regular schedule...”* and *“I’m on disability- I couldn’t afford a gym membership”*). Once engaged in exercise, physical and psychological limitations were no longer identified as barriers.

Motivators/Facilitators to Exercise

Participants spoke of what motivated them to exercise in the past, and motivating factors to join the study (Table 2). Most motivators to exercise were social and environmental: healthcare provider recommendations and “having a workout buddy” motivated participants to start and continue exercising: *“Cause I’ve always...I mean I started gaining weight, so I was like, Oh god. They are going to laugh at me...And they were all in the same boat [referring to living with HIV], you know? We are all...so we are all doing this because we want to. And I started liking it. Because I don’t like to walk. I don’t like to run. I don’t like doing any of that. But when I’m here, it is great.”* Short-range motivators were often intrapersonal: a recent weight gain, “feeling flabby”, or wanting to look better. Lastly, convenient and fun activity encouraged participants to continue exercising.

Benefits to Exercise

As a result of the exercise intervention, participants described many physical improvements: *“I had the opportunity to sing at a funeral recently. And that is when I noticed what the exercise has been doing for me. I’d never been able to hold a 3 measure note before...And I hadn’t sung for 2 years...”* Participants experienced rapid improvements in their health and well-being: *“And the thing about exercise is as soon as you start doing it, you start feeling*

good” and “*In a very short period of time you can go from being a couch potato, from being a blob, to feeling good...your mood changes and you start to feel like, my god, I’m happier than I was.*” Antihypertensive agents, antidepressants, and insomnia medications were discontinued; health improvements were attributed to accomplishments achieved through exercise (Table 2). Participants across all focus groups noted elements of increased self-efficacy as a benefit from exercise and a motivator to continue: “*pain was controlling me from exercising and I couldn’t deal with it. And then when I started exercising and I learned to...use the exercise to help build inner core to bring the pain down to a minimum*”. Lastly, social interactions and confidence were strengthened by the intervention: “*I feel empowered when I’m here. I think it pulled me out of always wanting to be alone.*” Relationships improved as depression decreased and self-confidence improved: “*I mean I’ve noticed my partner - my husband - will say, ‘you are looking better. You are looking slimmer’. He is noticing muscles on me.*”

DISCUSSION

In the context of initiating a supervised exercise intervention, we described many barriers and benefits similar to prior studies of older adults without HIV while HIV-related stigma and disability created unique barriers. Although no participants had major physical disabilities per parent study eligibility, over 50% received disability benefits. These benefits provide essential support to many PLWH, however, the label of disability may have unintended impact on self-perceived ability (Chalk, 2016) and act as an “incentive to remain ill” (Brew & Gleason, 2014). We found “being in the same boat” as a support to continued exercise and possible HIV disclosure as a barrier to group exercise: prior studies have also reported that social support influences physical activity and creates a safe environment for exercise (Clingerman, 2003; Simonik et al., 2016). Overall, the physical, cognitive, and psychological exercise benefits experienced by our participants suggests that many of the perceived exercise barriers can be overcome in the context of a supportive, safe, and stigma-free exercise environment.

Our study did have several limitations: the population was restricted to males, and the number of participants and focus groups were small, although informational thematic saturation was achieved. The participants had already made the decision to start exercising and committed to the intervention, and thus may not be representative of the population of older PLWH. Lastly, because participants were in a research study that provided gym access and supervision, our findings might not take into account some social, ecological, and financial barriers.

In summary, within the context of a supervised exercise intervention, physical limitations and intrapersonal reasons were considered major barriers to exercise initiation and were most likely to improve with the exercise intervention. Motivating factors that encouraged participants to start and continue exercising were mostly social, thus highlighting the importance of creating a nonjudgmental environment where adults aging with HIV can exercise among peers and receive professional advice on safe exercise techniques. Self-identification as having a disability may serve as an initial barrier, though can be overcome through improvements in self-efficacy. While adults aging with HIV experience many of the

same barriers and motivators to exercise as their uninfected peers, unique factors associated with the exercise experience should be considered in future research interventions and health promotion programs to improve and sustain physical activity.

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Table 1.

Baseline Characteristics of Participants in the Focus Group Analysis and Participants Living with HIV from the Parent Study

Characteristic	Focus Group Participants N=19	PLWH from Parent Study N=32
Age (years)	56.9 (5.4)	56.8 (5.7)
Men	19 (100)	28 (87.5)
Race		
White	15 (79)	20 (63)
Black or African American	2 (11)	9 (28)
More than 1 Race	2 (11)	3 (9)
Hispanic or Latino Ethnicity	2 (11)	4 (13)
High School Graduate or less	6 (32)	10 (31)
Current Work Status		
Unemployed	3 (16)	7 (22)
Disability	10 (53)	12 (38)
Retired	3 (16)	5 (16)
Part/ Full Time	3 (16)	8 (25)
Current Smoker	4 (21)	5 (16)
Marijuana Use	12 (63)	19 (59)
Alcohol Use >2 drinks/day	0	0
BMI (kg/m ²)	25.9 (2.9)	27.3 (4.3)
CD4 Count (cells/ μ L)	535 (432, 664)	599 (512, 699)
Time since HIV diagnosis (years)	19.6 (15.5, 24.7)	19.0 (15.9, 22.7)
Duration of continuous antiretroviral therapy (years)	13.8 (10.3, 18.5)	11.1 (8.4, 14.6)
Three or more comorbidities	15 (79)	23 (72)

Data presented as Mean (SD), Geometric mean (95% confidence interval), or Frequency (%)

Table 2.

Identified Themes, Unique Counts, and Examples Derived from Focus Group Interviews

Main Theme	Category	Example	Count of unique times theme is mentioned
Barriers to Initiating or Maintaining Routine Exercise			
Intrapersonal	Lack of Motivation	"Once diagnosed, I kind of lost interest and I just really didn't have the motivation. The fatigue factor was huge"	15
	Routinely Boring	"Um...and you know, I always do eventually get around to it. But then, for me, it is very easy to get bored."	11
	Lack of routine	"Being on disability, without a regular schedule or something like that, you know you're left to your own free will. Well, sometimes that is not such a good thing"	10
	Lack of time/other responsibilities	Work, family, or other caregiver responsibilities	10
	General lack of confidence/self-efficacy	"What scares me is going to a gym...it is like I'm just going to wimp out and do less."	8
	Lack of familiarity with exercise	"About 5 years ago. And I went to a gym and I worked out a little bit, but I didn't know what to do. And I looked in the mirror and went I can't do this. "	6
Social/Environmental	Not feeling comfortable in gyms due to body type/age	"I go to the gym...At home I work out in my shorts and my t-shirt. I don't care what they look like. But if I go to the gym, it's like a runway show"	13
	Travel Time/Proximity	"But the traveling is definitely a minus for me."	10
	Cost	"Well, first of all, it is the cost. They have many different fee structures which they won't advertise or let you know of, until they let you walking there and get you into a high pressure sales man."	7
Physical	Physical Pain	"And I actually did run for many years. Several years ago, but I had to stop because my ankle was getting affected. And I started to hurt my ankle. I don't know what was going on structurally. But I had to stop."	11
	HIV Futility	"Well, I was underweight anyway, so why bother? So I would try ...sure, I'll drop that...It's not going to matter anyway."	7
Motivating Factors to Begin Exercise			
Intrapersonal	Wanting To Look Better	"Being single and being gay is tough. You got to be working out. I've tried the other way before and it doesn't work! So when you do exercise and you're feeling good, guys are drawn to you and so then already, here comes the walls breaking down, because they are telling you that you're hot. It's like, it stinks, because you've busted your butt off working out. But then the benefits are great...it's the pat on the back you are looking for"	14
	Having a goal	"This time it is kind of like, I'll be finishing the 6th month right about Pride Fest. So it is like, Oh, good."	8
	Getting out of the house/staying busy	"I just know it gives me something to do."	6
Social/Environmental	Having a workout buddy	"Like I said, I've got some place to work out in my house. But having somebody to work out with would be a good motivator."	20
	Doctor's recommendation	"And my doctor is like, you've got to work on your core and stuff. So...I was like yeah, but they are getting me to do this. And they say it will help. And it has"	16
	Location/Availability	"if it's not going to be convenient, I'm not going to do it."	11

Main Theme	Category	Example	Count of unique theme is mentioned
	Something fun	"Yes. It is not just all the things that are going on around me, it is also that I've got to be enjoying it."	4
Physical	Recent weight gain	"I will stop for a while and then put on weight. And then you start getting fat and flabby and start thinking, ok, got to get back in the gym again. So it is sort of a sporadic thing for me."	14
Benefits of Exercise			
Intrapersonal	Increased Self efficacy	"... and I didn't think I could or even wanted to walk for 1/2 an hour. I was thinking 20 min. But then a 1/2 hour and then 40 min. then 50 min. I've never done that before. So it gave me ...encouragement that I could do it."	29
	Mood changes/decrease depression	"I am more positive, I can...I am more forgiving of the things that are going on and more grateful of the things that I have."	22
	Increased energy	"Well, running up and down the stairs after dogs and cleaning and all that fun stuff and being on my feet for 5 hours straight. That's fantastic. I mean, normally it was like find me a chair. I mean, now I have more energy"	16
	Improved body image	"Well, this past party dance, this past weekend, it was the first time my photograph was taken where I didn't want to slit my wrists."	13
	Sense of accomplishment	"It's that pat on the back you are looking for."	10
	Stress relief	"The best part about it for me, was once you get...you just go out in your own zone. You just erase all the...I have a lot of issues in my life with my parents and what not. And it just takes all that away. After you are on the treadmill for a few minutes, you know, it just erases. You go in your own zone and you just..."	7
Social/Environmental	Increased self confidence	"It's just...I think it pulled me out of always wanting to be alone. And I can actually go to the store and talk to a sales person."	18
	Others noticing changes in appearance	"I mean I've noticed my partner - my husband - will say, you are looking better. You are looking slimmer. He is noticing muscles on me."	9
	Improved relationships	"I got lots of nieces and nephews and two of them I go to [redacted] with all the time that have grown up with since they were babies. One just turned 18. She said I am a lot more fun. She said for awhile there, you were getting to be a real drag"	6
Physical	Muscle development	"I can't believe I got muscles coming up where I felt they didn't exist! Yeah. So legs are tightening up. They are just...you know. They are rock solid. My arms...you know, I've always had flabby arms and legs. And I can't believe the change. It is amazing."	8
	Overall being healthier	"It has improved my pulmonary function tremendously already. Enough so I'm not panting anymore. I mean, I used to live on my inhaler. But now I barely use it."	8
	Reduce Pain/Injury	"And I have neuropathy in my legs. And my legs ached and were cold. My feet were cold all the time. And I just thought maybe this exercise would help and it's helped considerably."	4