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Gender and coping with HIV: A qualitative study of older childhood sexual abuse survivors living with HIV

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Abstract

People living with HIV often have complex identities and histories. Understanding how these experiences influences adherence to treatment and quality of life are critical to the HIV care continuum. The experiences of older adults living with HIV are uniquely embedded within biology and aging as well as gender. This study described the gendered strategies for coping with HIV among older adults who are childhood sexual abuse survivors. Audio-recorded semi-structured interviews were performed with 24 adults who are 50 years and older from a large immunology clinic in South Carolina. Thematic analysis approach was used to discuss key concepts, identify and reconcile codes, and name emergent themes.

Overall, the participants used a spectrum of coping strategies including spirituality, seclusion, social support, substance use, engagement in HIV care continuum, information acquisition and sharing, and cognitive reframing. Our findings suggest that the potential for growth and recovery is heightened if the interplay of HIV diagnosis, aging, coping, and mental health is considered. Health care providers should assess the ways in which individuals interpret their HIV diagnosis and other lived experiences in order to gain a better understanding of their patients' mental health. Knowledge of gender-based coping strategies used in HIV-relevant outcomes can be translated into more effective treatment plans to improve overall quality of life.

Keywords

Aging with HIV; gender differences; coping styles; older adults; Childhood Sexual Abuse

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Introduction

People living with HIV (PLWH) on treatment are living longer, contributing to the increasing number of older adults living with HIV (OALH). HIV infection and aging are both related to physical and psychological stress. Compared to younger individuals living with HIV and their noninfected peers, OALH experience more stressors, including higher prevalence and earlier onset of multimorbidity (Brown et al., 2019; Hosaka et al., 2019; Rodriguez-Penney et al., 2013; Bhatia et al., 2012; Smit et al., 2015). OALH are often members of already-stigmatized groups, living with the odium and discrimination related to their various identities and histories (Emlet, 2006; Logie, & Gadalla, 2009). A history of childhood sexual abuse (CSA) is prevalent among PLWH (Sikkema et al., 2008) and OALH (Brown et al., 2019), which is deleterious to health (Najman, Nguyen, & Boyle, 2007; Fields et al., 2008). The experience of CSA is correlated with poor mental health, physical illnesses, poorer self-rated health, and higher odds of disability (Chartier, Walker, & Naimark, 2007; Rich-Edwards et al., 2010; Fields et al., 2008).

Traumatic experiences which are more common among PLWH may interfere with their total wellbeing (Cavanaugh et al., 2015; Brown et al., 2019). This population faces unique challenges in promoting and maintaining psychological and physical well-being. These challenges may also impact their coping strategies, which play a prominent role in maintaining overall health and impacts quality of life. In addition, the adjustment to the challenges of living with HIV can be impacted by the age, cultural, religious, and social factors which vary by gender (APA, 2022). For example, men and women perceive their ability to manage and react to stress in markedly different ways (APA, 2022). Women have also been reported to be relatively vulnerable regarding living and adjusting to HIV diagnosis compared to men (Higgins, et al., 2010). The mental health needs of women differ from men (Kennedy, 1995), so continued gender exploration of coping measures should be done to develop appropriate and effective interventions.

Some strategies including medication adherence, substance use, self-acceptance, disclosure, will to live, service, social support and spirituality had been identified related to coping with HIV among PLWH (Koch et al., 2022; Kaur et al., 2022, Wardell et al., 2018, Degenova, et al., 1994). However, few studies have examined strategies employed by older adults to cope with HIV (Vyavaharkar et al., 2007; Skalski, et al., 2013); and only one qualitative study has explored the coping strategies of OALH (DeGrazia, & Scrandis, 2015). Furthermore, there is paucity of literature that focuses on the coping strategies commonly employed by women living with HIV (WLHIV) vis-a-vis men living with HIV (MLHIV) in US. Herein, we described the gendered strategies employed by older adults to cope with their HIV.

Method

Participants

This qualitative study consisted of 24 OALH from a comprehensive immunology clinic in South Carolina. Individuals were eligible if they are living with HIV; 50 years or older; experienced CSA before 18 years of age; and lacked severe cognitive impairment. The participants were 50 to 67years; and comprised of 12 men, 11 women and 1 transgender

woman. The participants were 16 Blacks, 6 Whites, 1 Native Hawaiian/Pacific Islander, and 1 American Indian/Alaskan Native. Furthermore, 12 of them identified as heterosexual, 9 as gay/lesbian and 3 as bisexuals. Nearly half of them (11) had attended some college, and 13 had a yearly income less than \$10,000.

Data collection

Information was shared through flyers and the clinic staff approaching potential participants. Individuals interested in participating were directed to contact the research team and were screened for eligibility. Interview questions were created by a multidisciplinary team with expertise in HIV, adverse childhood experiences, public health, sociology, and epidemiology. Some of the question topics included general/overall health, aging with HIV, coping, barriers and facilitators of ART adherence, and CSA experiences. Sample questions included: ‘What are the main source of stress in your life? How does that affect your health behavior and your overall health?, ‘How do you deal with the stress?’. In-depth interviews were conducted from October 2019 to February 2020 by two research assistants, trained in qualitative interviewing techniques. The interviewers employed a semi-structured in-depth interview to explore the strategies to cope with HIV. Interviewers used probes and open-ended questions (e.g., *tell me more about that*) to encourage participants to offer more detail. Participants were assigned an ID number to assure confidentiality. The interviews lasted 31 minutes on average and were conducted in a private room at the clinic or on-campus. Participants received a \$20 gift card for their time.

Data Analysis

Interviews were audiotaped and transcribed using otter.ai (Los Altos, CA). Data were analyzed using inductive coding and thematic analysis (Saldaña, 2021). The authors began by reviewing the transcripts and correcting errors. Four authors independently coded the interviews using line by line coding; and independently collapsed the codes and created a preliminary list of themes. To enhance rigor of the analytic process, the research team held regular analysis meetings to discuss and reconcile any discrepancies in coding and theme development. The interrater reliability between coders indicated an acceptable level of agreement ($r = 0.70-0.80$). Additionally, to attend reliability of coding, findings were cross-referenced with the literature.

Result

The majority of the participants have lived with HIV for more than 20 years. A good number of the participants described their health as poor and shared the burden of having multiple chronic illnesses. Participants’ responses reflected a range of coping strategies with 8 major themes emerging: spirituality, seclusion, self-distraction, social support, substance use, cognitive reframing, engaging in HIV care, information acquisition and sharing.(Table-1)

Spirituality:

Spirituality is a common coping resource which was described as reaching a variety of sacred or existential goals in life. More WLHIV (three-quarters) talked about how their beliefs in God and the frequency of spiritual behaviors (e.g., prayer, church attendance) had

helped them to manage their challenges. Receiving and engaging in any type of spiritual activity provided a sense of peace and helped them imbue purpose in life. One woman living with HIV (WLHIV) described:

I guess it's my faith. I just relying on the Lord and going to church and doing a lot of Bible studies and really kind of putting everything in His hands.

For some participants, the peaceful and comforting feelings they experienced were related to taking their medication to the church. One woman shared:

As I was sitting down on the bed, I say I'm taking my medicines to church with me. So, I took my medicines and went to church. Every time I went to church, I held on to my medicines. I ask God to welcome me back in my home and ever since then I have no problem with it.

Seclusion:

Perceptions of people's awareness of their diagnosis and attitude weighed heavily into their techniques for dealing with their diagnosis. Some participants used seclusion to maintain control over who they meet, socialize with and talk to about their HIV diagnosis. Compared to the MLHIV, more WLHIV seemed to fare with isolating themselves, withdrawing and limiting human contact.

Just staying by myself minding my own business dealing with it like that makes me alright. Peace of mind. I won't have to worry about what other people think. I gotta worry about nobody say, uh you nasty, you know, come on I don't have to worry about, I stay by myself. I don't bother nobody.

(WLHIV)

Some participants chose seclusion having learned through unpleasant experiences, and comments made about PLWH. Dealing with an HIV diagnosis included keeping their HIV diagnosis secret, hiding their medication, and limiting outdoor activities. Keeping to themselves constituted a strategy for avoiding stigma, discrimination and maintaining relationships. The woman said:

Well, right now I'm out of work. And I've just been sitting at home watching TV. That's all I do sitting at home watching TV and have no activities or anything. I'm too scared to go outside and communicate with people and so right now I'm just alone.

Self-distraction (exercising, watching TV/ listening to music):

Daily self-distracting activities were similar across gender and overwhelmingly characterized by the desire to avoid worrying about their status and to block the thought of HIV. These distraction techniques helped participants to gain control of their thoughts by distancing themselves from their HIV. The frequently practiced self-distracting behaviors were shopping, burying oneself in house chores, chatting, exercising, watching television, and listening to music.

One participant shared:

Meditate, soak in my bathtub, I do my exercise and try to entertain myself most of the movies. And family activities volunteering and keeping up with community events.

(WLHIV)

An interesting effect of the self-distracting behavior is that it has helped them to live a healthy lifestyle, and adhere to their HIV treatments, as shared by two MLHIV:

Exercising makes me feel good because it relieves stress. Jogging or something to lets out some of that tension. Drink plenty of water.

Listening to music, exercising, eating healthy, go into groups, being around positive people, being around just general people that wants to live not people that have negative ideas and mind.

Social support:

Social support is an important coping strategy used commonly by both genders. Knowing that someone cared about them helped relieved the stressors associated with living with HIV. Participants received social support from family, friends, church members, providers, and HIV support group. Social support came in a variety of ways such as emotional, informational, and support to adhere to treatment.

I have a mother that loves me dearly. I have a partner that lives for me. So yes, I have people outside my family that count on me for certain things.

(WLHIV)

Some participants worried about losing their social networks due to their status and age, as their immediate community provided them the critically needed supports. Sharing thoughts and feelings with trusted others helped relieve psychological stress.

A lot of times it takes talking to somebody and being honest about things that are going on in your life just as a venue to an outlet. Talking about it. Because you get the vent, you get to get things off your chest, you get to express how you feel, and it releases a lot of, you know, tension. For me anyway”

(MLHIV)

Substance use:

Some participants expressed using substances such as alcohol, marijuana, and cocaine. This was common among MLHIV. These substances were used to suppress thinking about their status and to deal with some negative experiences. Though substance use can result in suboptimal engagement in the HIV care continuum, many participants who reported substance use said it does not interfere with their ART adherence and engagement in care. One man explicitly stated.

Sometimes I do, like some mornings I get up I can't hardly put one foot in front of the other. And I know when I get all these, you know, how you get all these thoughts in your head and unravels, and you can't get rid of them. Yeah, I use the marijuana to help me cope and think more clearly sometime. Yeah.

Another male respondent highlighted his awareness of the possible consequences of substance use on his health.

Oh, I guess I drink, I mean, I know I need not be drinking as much as I do but I drink every day. It helps me deal with being HIV positive you know what I'm saying, I just keep on having to drink than to keep thinking about it.

Engaging in HIV care:

More than half of the participants mentioned adhering to their ART and keeping their appointments to deal with the disease. Participants engaged in HIV care to lessen the fear of dying from the disease, the physical signs of HIV-infection, and prevent recurrent illness. Knowledge of the importance of ART adherence was high among respondents, as they were keenly aware of the risk and implications of non-adherence.

I just make sure I take my meds every day. And like I said try and eat healthy and live a healthy lifestyle

(WLHIV)

Some participants further shared their confidence in ART and that taking ART as prescribed reduced their worries about the effect of the virus on their health.

As long as I take that once a day, tablet, it keeps my confidence build up, because I know it's doing what it's supposed to form a viral load and keeping me healthy.

(MLHIV)

I basically just accept the fact that I have it and try to take medicine as I supposed to and going to the doctor within three or six months.

(MLHIV)

Information acquisition and sharing:

Some participants found comfort in seeking information about HIV and/or sharing their knowledge. This coping style was particularly common among WLHIV. Respondents who used this strategy has either openly disclose their HIV status to family and friend or are active members of an HIV support groups. The interpersonal information exchange is heightened by the need to educate their family, friends, and community to reduce stigma and increase support for PLWH. One woman shared:

First, it was more like a shameful thing you know, but the more I learned about it, the more I see more people dealing with it as much as I am. To me, the more I educate younger people. I try to tell my grandkids you know more about it. I mean, it's a part of life.

Some participants sort information on HIV to dissuade their worries. This helps them to adopt a more positive view of their health. One woman stated:

Doing research, keeping up on my meds, knowing what matters, what affects me and what if I'm getting immune to it? Do I need to switch to different ones? And making sure I keep my diet plan as much as possible more fruits and vegetables.

Cognitive reframing:

Both genders coped by believing that their HIV diagnosis happened for a purpose. The participants added that they have accepted their HIV diagnosis, acknowledged their present circumstance, and continued to learn to live with it. Positive reframing helped the participants to build positive attitudes, and approach living with HIV with courage. They used positive self-talk and feeling grateful to be alive. Two participants shared:

I don't have a difficult time living with HIV. I really don't because I have fully accepted that. I'm on my medicine and I'm undetectable.

(WLHIV)

Mentally just always encouraging and always looking for the optimistic part, the positive part of life and living there's a big plus, lot of us have died. So, I'm doing a lot better than most.

(MLHIV)

Constructing meaning of their HIV status allowed them to avoid feeling angry or self-pity. This was expressed in statements such as,

It causes me to have other issues with my health and I know if I haven't had HIV, there are somethings I probably wouldn't deal with. But then at the same time I'm getting old and everybody has health issues, so just have to pick and choose. You're better than what you want to deal with it. I can sit around ... and complain and cry or I can just live my life.

(MLHIV)

One participant positively reframed her diagnosis with intention that the cure would be discovered sooner.

Knowing that one day it'll be a cure for it. So, I don't get upset. Is it, they got a cure coming? And my levels are low. As long as I know I'm doing what I have to do I will be alright.

(WLHIV)

Discussion

This study reinforces the importance of overall quality of life with HIV. Our results indicate that OALH use a wide range of coping mechanisms to manage their complex needs. Men and women used almost all the coping styles, but some coping strategies were commonly used by either men or women. For example, WLHIV were more likely to use spirituality, self-isolation and information acquisition and sharing than MLHIV. Furthermore, the results suggest that these coping strategies may interact or overlap with each other, such as in the case of bringing their medication to church, self-distraction through exercise, as well as in maintaining strict medication adherence. This array of coping styles is logical, given that individuals in this population often face multiple challenges. In line with our study, Heckman and colleagues found that adults living with HIV use multiple coping strategies,

some which were similar to the strategies used by our participants (Heckman et al., 2011; Hansen et al., 2013).

Spirituality was most frequently reported by WLHIV and was extremely important in their lives. Women often use faith and seek resilience through God to deal with chronic illness (Dalmid et al., 2012; Rudaz, et al., 2019). A study of WLHIV in U.S found that spirituality was an extremely important part of their HIV journey and provided them the ability to keep going (Dalmid et al., 2012). Our participants reported that these coping measures (spirituality, information acquisition and sharing, social support) provided a larger sense of purpose, allowed them to focus on their values and to keep challenges in perspective as they arose. Social support is another important coping strategy, most especially for OALH, who have fragile social networks (Brown et al., 2019; Brennan-Ing et al., 2017). Support from family and friends is a common coping measure by PLWH (Heckman et al., 2011). Like our participants, DeGrezia et al. (2015) found that obtaining support was paramount in OALH abilities to cope with HIV, and related stressors.

Substance use was another strategy used by our participants. Substance use is more common among people living with HIV; and this pattern remains true among older populations (Edelman et al., 2014; Skalski et al., 2013). In addition to substance use, seclusion was another coping measure. Limiting or avoiding human contact may reduce the experience of stigma or discrimination but can evoke stress and allow for the resurfacing of negative thoughts, resulting in more psychological distress and limited access to social support (Nöstlinger et al., 2015).

Inquiry into these coping strategies is valuable for several reasons. First, our study provided a glimpse at the subjective experiences of members of an often-overlooked population. Second, coping plays a large role in overall health and quality of life. Lastly, information on gendered differences in coping strategies can be used in developing psychosocial interventions and to conceptualize the best treatment plan for OALH.

Our findings suggest the potential for growth and recovery is heightened if the interplay of HIV, aging, other stressors, and coping is considered. Health providers should assess the ways in which patients interpret their HIV diagnosis and other lived experiences to help gain a better understanding of the patients' mental health. Clinical and supportive care for OALH should include an integrated focus on the number of comorbidities that accompany and complicate aging, HIV care and quality of life. Programs targeting OALH should incorporate assessment of the coping styles to help determine strategies that are beneficial or deleterious. There is need to adopt a developmental approach to adjustment for OALH who might be struggling not only with the challenging demands of illness but also with their aging.

Despite multiple strengths, our study had limitations. Our participants were selected using convenience sampling. Additionally, our sample was recruited exclusively from a large immunology clinic in southern US, a treatment center with great resources and personnel, our findings are limited and may not be generalizable to OALH who use other facilities. Our data was also obtained exclusively through self-report. This information will be

constructive in determining the long- and short-term effects of different coping skills, and in incorporating individual gender differences into our understanding of coping with HIV. More rigorous studies are needed on the nuances of gendered coping experiences and on the differences between genders in coping strategies with HIV. Future work should attend to the correlates, nuances, and precursors related to each type of coping identified in this study.

Conflicts of Interest and Source of Funding:

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Table 1:

Respondents endorsing each theme by gender.

Themes	Total	Women	Men
Spirituality	12	8	4
Seclusion	10	7	3
Self-distraction	13	6	7
Social support	10	7	7
Substance use	8	2	6
Engagement in HIV care	16	8	8
Information acquisition and sharing	8	6	2
Cognitive reframing	7	3	4

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