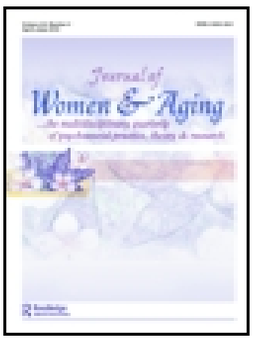

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"We are becoming older women and then we have two stigmas": voicing women's biopsychosocial health issues as they age with HIV

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ABSTRACT

In April 2019, nine older women (age 50+) living with HIV in Palm Springs, California, participated in a 90-minute focus group to identify their major health issues, strengths, and HIV and aging-related health priorities. Using the rigorous and accelerated data reduction (RADaR) technique, we identified four major themes: (1) mental health, (2) HIV comorbidities, (3) social determinants of health, and (4) resiliencies. These results reinforce the need to conduct additional research focused on women aging with HIV, an understudied population that requires more effective, tailored interventions to promote better quality of life and healthy aging.

KEYWORDS

Aging; health priorities; HIV

Introduction

The development of effective combination antiretroviral therapy (cART) resulted in a dramatic increase in life-expectancy among people diagnosed with HIV. Indeed, nearly 50% of people living with HIV (PLWH) are 50 years of age or older (Centers for Disease Control and Prevention, 2019; Guaraldi & Palella, 2017). By 2030, this proportion is expected to rise to 70% (Smit et al., 2015). While PLWH now experience fewer life-threatening acute illnesses than before the development of cART, research shows that older PLWH (i.e., aged 50 and older) face a unique combination of challenges associated with the interaction between the aging process and HIV.

Older PLWH experience high rates and early onset of comorbidities, mental health and psychosocial issues, geriatric syndromes, and HIV and age-related stigma – all of which negatively impact older PLWH's everyday lives (Bhatia et al., 2012; Brown et al., 2019; Hosaka et al., 2019; Rodriguez-Penney et al.,

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2013). Higher rates of age-associated comorbidities among older PLWH include cardiovascular disease (Feinstein et al., 2016; Martin-Iguacel et al., 2015), osteoporosis (Prieto-Alhambra et al., 2014; Walker Harris & Brown, 2012), and neurocognitive disorders (Greene et al., 2015; High et al., 2012), and are at least partially due to chronic inflammation associated with HIV (Castillo-Mancilla et al., 2016; Deeks, 2011; Schnall et al., 2019). Studies also suggest that prolonged use of cART negatively affects physical health, because it may increase the incidence of comorbidities (Cahill & Valadez, 2013). Additionally, compared to the general population, PLWH have up to three times the rate of depression – one of the most common comorbidities among older PLWH (Brown et al., 2019; Do et al., 2014; Halkitis et al., 2017; Havlik et al., 2011; Marg et al., 2019). High rates of depression among older PLWH are likely linked to and worsened by high rates of social isolation and low levels of social support (Greene et al., 2018; Grov et al., 2010; Yoo-Jeong et al., 2019), both of which are related to fragile social networks among older PLWH, mostly consisting of friends living with HIV, and the loss of friends due to illness (Brennan-Ing et al., 2017; Brown et al., 2019; Emlet, 2006). Research shows that HIV and age-related stigma also contribute to high rates of depression, social isolation, and the lack of social support among older PLWH (Emlet, 2017, 2016; Emlet et al., 2013; Erosheva et al., 2016; Yoo-Jeong et al., 2019). Due to the combination of physical, mental, and psychosocial challenges associated with aging with HIV, older PLWH often experience reduced quality of life (Kteily-Hawa et al., 2019).

While men are disproportionately represented among those infected and aging with HIV, by the end of 2016, women comprised over 22% of all persons aged 50 or older living with diagnosed HIV in the United States (Centers for Disease Control and Prevention, 2018). The increasing life expectancy among those living with HIV and taking effective cART suggests that the prevalence of HIV among women aged 50 and older will continue to rise (Rodger et al., 2013). However, the disproportionate representation of incident infection and prevalence of HIV among men has resulted in far less empirical research focused on women living with HIV (WLWH), especially older WLWH, compared to men living with HIV (MLWH) (Goldstein & Walensky, 2019). Thus, while much research has uncovered the unique challenges associated with aging with HIV, little research has examined women's experiences aging with HIV (Durvasula, 2014; The Well Project, 2018). However, a small but growing body of literature suggests older WLWH may face different burdens than both their younger counterparts and older MLWH, and that certain burdens may be more outsized for older WLWH (Durvasula, 2014).

Some research suggests that mental health issues are particularly pronounced among older WLWH. WLWH have higher rates of depression than other subpopulations (Arseniou et al., 2014; Brennan et al., 2013;

Durvasula, 2014), which is linked to experiences of social isolation and social support. Some studies have found that older WLWH experience lower levels of social support compared to younger WLWH, as well as a high rate of social isolation (Kteily-Hawa et al., 2019; Siemon et al., 2013). While women often have larger social networks than men, the social support derived from such networks can be complicated by associated demands, such as caretaking responsibilities (Cao et al., 2019; DeGrezia & Scrandis, 2015; Durvasula, 2014; Ouedraogo et al., 2019). Older WLWH may be responsible for caring for their partner/spouses, elderly parents, as well as assisting adult children with caring for their grandchildren. Such care work can interfere with self-care and exacerbate mental and emotional health issues (Cao et al., 2019; DeGrezia & Scrandis, 2015; Durvasula, 2014). Mental health issues among older WLWH are also likely amplified by experiencing higher levels of HIV-related stigma compared to older MLWH, which can be a barrier to receiving HIV-related care (Brennan et al., 2013; Emlet et al., 2013; McDoom et al., 2015; Siemon et al., 2013).

Research suggests that women experience high levels of HIV-related stigma because they are perceived as deviating from gendered cultural expectations. While women are expected to be caregivers, mothers, and nurtures, WLWH are perceived as dirty, diseased, sexually deviant, and irresponsible, and, therefore, unable to adequately fulfill culturally prescribed gendered ideals and expectations (Colbert et al., 2010; Psaros et al., 2012; Wagner et al., 2010). In this way, the stigma experienced by WLWH is multidimensional and occurs at the intersection of gender, culture, and HIV status (Rice et al., 2018; Siemon et al., 2013). In addition to gender, the intersection of race/ethnicity, class, and other dimensions of social identity, such as age and sexual orientation, are also important for understanding experiences of stigma among WLWH (Rice et al., 2018). Moreover, the intersectional nature of stigma means that WLWH's experiences of stigma extend to multiple levels of social interaction and society, including interpersonal, community, and structural levels from an array of sources (e.g., family, friends, health clinics, etc.) (Rice et al., 2018; Turan et al., 2017).

The intersection between HIV and menopause is also an important contributor to the unique experiences among older WLWH. In addition to evidence that WLWH experience earlier onset of menopause and more menopausal symptoms, menopausal symptoms can imitate or disguise HIV, complicating timely and appropriate HIV-related treatment (Andany et al., 2016; Bull et al., 2018; Durvasula, 2014; Sundermann et al., 2019). The interaction between HIV, cART, and hormonal changes associated with menopause also increases older WLWH's risk of developing age-associated comorbidities, including cardiovascular disease, osteoporosis, and stroke (Kendall et al., 2014). Moreover, treating menopausal symptoms through hormone replacement therapy is also complicated by cART, potentially

increasing the risk of stroke, cardiovascular disease, breast cancer, and pulmonary embolism (Sundermann et al., 2019).

Overall, research on the lived experiences of older WLWH is lacking. Given the increasing prevalence of older WLWH, such research is sorely needed to inform the development of effective, comprehensive, and tailored interventions (Frazier et al., 2018). Specifically, further research is needed to understand the ways older WLWH experience and cope with the associated challenges of aging with HIV (Durvasula, 2014). Toward this end, the present study uses qualitative methods to understand the challenges, coping strategies, and experiences of older WLWH.

Setting

One of the oldest populations of PLWH in the United States resides in the Coachella Valley (CV) of California's Riverside County, which is also home to Palm Springs. The average age of PLWH in CV is 51 years and nearly two-thirds (63%) of PLWH in CV are 60 years or older (Gardner AT, 2017), which is partially due to the large migration of PLWH to this retirement community. As such, CV (and Palm Springs) is a fitting locale to investigate the experiences of older WLWH.

Materials and methods

This study used a community engaged approach (Karris et al., 2019; Subica & Brown, 2020). Consistent with best practices for community engaged research, we used snowball sampling with help from a community advisory board of PLWH (Karris et al., 2019; Subica & Brown, 2020). Through this sampling strategy, 12 WLWH aged 50 and older were recruited to participate in a focus group regarding experiences aging with HIV – nine of whom ended up participating on April 18, 2019. Three of the prospective participants did not show up on the date of the focus group. Prior to the start of the focus group, participants completed a brief demographic questionnaire that collected their age, gender identity, racial/ethnic identity, and level of educational attainment. Each participant was assigned a unique number that was associated with their demographic data and corresponded to where they sat in the focus group space. Participants' anonymous demographic data were used to help contextualize their verbal responses.

Focus group questions were designed by PLWH and encompassed three main areas, including major health issues (e.g., "what are the top major health issues affecting people who are aging with HIV?"), sources of resilience that promote healthy aging with HIV (e.g., "what are some of the resiliencies that allow people to age healthily with HIV?"), and priority research topics related to HIV and aging (e.g., "what should be the top

priority topics for research on HIV and aging in the Coachella Valley?"). The 90-minute focus group was audio-recorded and facilitated by two trained community members living with HIV.

Research ethics

This study was approved by the Institutional Review Board of the University of California, Riverside. All participants provided informed verbal consent, which prevented a paper trail that could connect their responses to their identities, and were compensated with 50 USD for their time and efforts.

Analysis

Data were systematically analyzed using the rigorous and accelerated data reduction (RADaR) technique (Watkins, 2017). The outcomes of the RADaR technique are major themes and illustrative quotes that accompany each theme. There are five steps in the RADaR technique that work to narrow down the data and yield results.

The first step required organizing all data transcripts in a similar format. Two analysts (F.C. and G.R.) transcribed the audio recording of the focus group and formatted the transcript to include page and line numbers. Participants remained anonymous during this process by using their assigned numbers to document their responses. The second step involved creating an all-inclusive data table. Using Microsoft Excel, text from the transcript was copied and placed into its respective column. The columns in this table included page number, question number, participant's response, and notes. After the table was completed, the team produced a comprehensive research question to follow throughout the analysis process. The research question developed was: "What are the major health priorities for women who are aging with HIV?" In step three, the all-inclusive data table was reduced into a "Phase 2" data table by removing data that did not correspond to the project's research question. The remaining data were further examined, and salient segments of text were highlighted and annotated to generate codes that helped yield the major themes. Step four of the RADaR technique involved further condensing the previous data table and thus creating a "Phase 3" data table. Reducing the chunky texts created a clearer presentation of the ideas and concepts interpreted by the analysts. The Phase 3 table contained text that was used to demonstrate themes, therefore it was best to only have the most relevant data. Codes were assigned to the remaining data on this table. The final step in this process was putting together the project deliverables, in which the Phase 3 data table was used to produce the final themes. Each theme was illustrated by exemplary quotes.

Results

Participant demographics

Participants' ages ranged from 50 to 68 years, with an average of 57 years. Eight participants identified as cis-women (n = 8) and one identified as a transgender woman. Participants were racially/ethnically diverse. Three participants identified as non-Hispanic White, three as Black, one as Hispanic White, one as Asian, and one as multiracial. Most participants had some post-secondary education. One participant attended graduate school, two attended a four-year university, three attended some college, two were high school graduates, and one did not obtain a high school diploma.

Themes

The four major themes were: (1) mental health, (2) HIV comorbidities, (3) resiliencies, and (4) social determinants of health. See Table 1 for a complete list of exemplary quotes corresponding to each theme.

Mental health

Many participants discussed feelings of isolation and depression due to stigma over aging and body image as a woman in society. When asked about ways in which women aging with HIV cope with their situation and health, a 58-year-old multiracial woman responded:

> … remaining connected, not feeling so isolated cause, sorry, as we move forward, women aging and that are single, single and have HIV, it can be isolating, and you know we need that connectivity in order to be a little more happy in our lives and it's still a lot of negative stigma attached to that.

A few participants gave personal examples of times when they were out in public and had encounters that made them feel out of place and unwelcome. A 62-year-old Black woman admitted:

> I really am aging with this and I can cry … a lot of depression, a lot of social issues on how to interact with just people when you walk in the moment and they still telling AIDS jokes and you know you live with it for 30 years.

This is just one of the few ways that cause aging WLWH to feel anxious about sharing their status with others because it puts them in a vulnerable position. In addition, participants may also be in denial and not want to accept their situation. A 50-year-old White Hispanic woman stated, "*I avoid all these classes and stuff, never to learn, cause I really didn't want to sit there and know that I was sick.*" Thus, the issue of mental health represented a concerning health issue among participants.

Table 1. Exemplary quotes from focus group participants.

Theme	Exemplar Quotes
Mental Health	… There is a lot of ignorance … stigma surrounding HIV. Still a lot of people have ridiculous concepts. *(58-year-old Multiracial woman)*
	I'm talking about sexual romance and how to deal with body image. We talk about a lot of medical stuff and that's good, but we are becoming older women and then we have two stigmas, and the research on that, I don't really get it. And body image issues … dating, body imagery, or if I look lean. You know, um, I'm telling you at first my mother and them should've told us some of this stuff that happens when you get older. *(62-year-old Black woman)*
	So, remaining connected not feeling so isolated 'cause sorry as we move forward, women aging and that are single, single and have HIV. It can be isolating, and you know we need that connectivity in order to be a little more happy in our lives and it's still a lot of negative stigma attached to that. *(58-year-old Multiracial woman)*
	… But the HIV and dryness and connecting with our body image. This is for older women, right? And um, I keep hearing how HIV is a chronic illness now, but there's a lot of issues that go with this. Chronic means that you are a part of me, right? And that is my understanding. Well I've been here 30 years, so it's pretty long for me … so with that, other issues like health, I am really anxious on my health issues. *(62-year-old Black woman)*
	We don't want to face it. That's a big barrier. Denial. *(50-year-old Hispanic woman)*
	What is the most important research in this room? Is it physical? Is it physical or is it emotional? Mine was emotional. I thought I was going to die 28 years ago. *(62-year-old Black woman)*
	I really am aging with this and I can cry … A lot of depression, a lot of social issues on how to interact with just people when you walk in the moment and they still telling AIDS jokes and you know you live with it for 30 years. What kind of research are we doing with a population that's under the bridge? That old women that are just kinda stuck in it, these are my answers. I want research showing us when, if that other shoe is gonna drop. 'Cause nobody can really say when your shoe is gonna drop. Which symptoms of thrash and this and that? What are some of the things that we should be kinda keeping our eye on? *(62-year-old Black woman)*
	They've never seen an old woman with HIV before. So, this is new for them and we have a lot of questions too. *(68-year-old White woman)*
	(68-year-old White woman)
HIV Comorbidities	I'm getting neuropathy, more neuropathy than I've been having. *(54-year-old White woman)*

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	(54-year-old White woman)
	Another issue is the long-term effects of the drugs. Long term effects, you know, that back problem with the particular drug that they had. [Lipodystrophy] right, so you wonder about that. *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	Um, things like dementia, lack of Vitamin D, brain distortion. *(50-year-old Black woman)*
	(50-year-old Black woman)
	The effects for women. The long-term effects of having HIV, if there's any particular secondary illnesses or things that come up with regards to women. *(58-year-old M*ultiracial woman)
	(58-year-old Multiracial woman)
	I think there's some women that still want to have babies. I'm saying some women. Pregnancy, yeah 'cause I think it's a miracle when an HIV woman has a baby. Gets pregnant and has the baby and is non-detectable. That's a miracle. *(54-year-old White woman)*
	(54-year-old White woman)
	HIV and cancer. When you work with women, a lot of things that people are coming down with- radiation exposure, cell phones, all that, but the effects of HIV and cancer in women. *(54-year-old White woman)*
	(58-year-old Multiracial woman)
	Living healthy with HIV, longevity-wise. *(50-year-old Black woman)*
	(50-year-old Black woman)
	… But I came to really identify health issues that we really don't talk about. We have been through a lot of these trainings. You guys know that. And we don't talk about the issues that could help us live on a day to day basis. And I know we take our meds, I take my osteoporosis meds … even if I don't have it, because I know about our bones. *(62-year-old Black woman)*

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	(62-year-old Black woman)
	Um, I would, I would like someone to research more into menopause. Um, migraines, tumors, cysts, ovarian cysts, things like that, and our HIV of course. *(50-year-old Black woman)*
	(50-year-old Black woman)
	My biggest health concern is … how do I know when the other shoe is starting to drop? Uh, well with HIV we don't, and it's because it's long term, we don't know … we knew symptoms when it was early. What symptoms should I be paying real attention to because the normal symptoms were talking about fibroids, I have that, but are those really connected to my age? You know I had anemia and HIV. What's the relationship of HIV to my physical being? *(62-year-old Black woman)*
	You don't even know, but all of us, well I do, wanna know all the time is this worse because of my kidney? Or is this actually with my HIV? Maybe nobody else wants to know, but I wanna know. And then which [chronic issues] are aggravated by my aging. *(62-year-old Black woman)*
	(62-year-old Black woman)
	Aging conditions aggravated by our aging bodies. *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	So, I started coming to these classes and now I think I'm finding out that I got neuropathy on this side. And I'm wondering what's gonna happen. I mean like is it going to go away if I take my medication? Or is it gonna get worser? Or is it gonna get … right, I'm kinda concerned. Is neuropathy affected by our hormones? *(50-year-old Hispanic woman)*
	(50-year-old Hispanic woman)
	And I would say dialysis and HIV, and sickle cell anemia and HIV, that right there would be fantastic. *(50-year-old Black woman)*
	(50-year-old Black woman)
	I have two. Once again, the study of living with sickle cell anemia and HIV. And the reproductive system as far as how we can prevent birth defects and vaginal issues with women, things like that I think to me seem to be understudied. And the outcomes of how our children were born. *(50-year-old Black woman)*

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	(50-year-old Black woman)
	I recently got a new doctor, because I've been having a lot of diarrhea issues and I don't know if it's from the cancer or the chemo or it could be from the long term HIV. *(54-year-old White woman)*
	(54-year-old White woman)
	I just have one suggestion. I think HPV should be up there. It's really not a wide-open thing. You really have to look for the information, so HPV should be there. *(50-year-old Hispanic woman)*
	(50-year-old Hispanic woman)
	I have to do chemo for the rest of my life, I mean just like taking my HIV meds 'cause my cancer is not curable. It's just that if you put it up for yourself then that's it, but it affects my immune system, my T cells and stuff they aren't very good, they're undetectable. Is there anything that they can study on that to help my T cells? I want my T cells to be good. *(54-year-old White woman)*
	(54-year-old White woman)
	Now it's just chronic. So, um, am I going to be expecting cancer and these different things because it's long term? *(62-year-old Black woman)*
	(62-year-old Black woman)
Social Determinants of Health	Lack of access to helpful choices for recreation, for things like swimming, and you know … The social aspect of our lives. A bit excessive. *(68-year-old White woman)*
	(68-year-old White woman)
	Financial hardship that affects how one wants to take care of oneself. We're limited. So, the economic stuff. *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	I'd like to see the effect of housing, good housing, supportive housing has on health outcomes. *(68-year-old White woman)*
	(68-year-old White woman)

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	Maybe research on how we can find some kind of funding or more services provided for women as we age whether we have HIV or not. But financial hardship does play a huge role in how our quality of life moving, moving forward. We can provide ourselves with help, cope and alleviate some of the depression and things that we feel as we age as women. Not having funding … there is women with bad financial hardship almost down to poverty level and how can we provide you know ourselves with the avenue of either having social prudence … ? *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	I've called several research [programs] and they don't [have] one for women. So, the lack of access. I've tried to get in research programs. *(62-year-old Black woman)*
	(62-year-old Black woman)
	Did somebody say environment? Like, smog, pollution, open areas, city areas for research. Like researching how do we survive in the environment? How you know what causes things to be worse? What causes things to be better? What environment should we be around to keep us going a little bit longer? *(50-year-old Black woman)*
	(50-year-old Black woman)
	Additional healthcare insurance coverage that provides for alternative ways of moving forward with women, but that help deal with women topics. Health issues that they don't provide for now. *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	I know I was taking, before I got sick, this natural hormone that only one doctor was providing here in the Valley [and it] was via shot in my hip. He tested blood and he developed a pellet. And I couldn't take regular hormones because I was a cancer survivor in a clinical trial, but my quality of life was not covered by insurance and for a shot it was about 400 dollars, 450 dollars, but it would last anywhere from 6 to 8 months depending on how your body would draw off of it, how much it needed … *(58-year-old Multiracial woman)*
	(58-year-old Multiracial woman)
	See those are the kind of things somebody just mentioned that we don't get that unless we ask or know. So, I guess open communication, I'm sure because gay white male have all this information and we don't have it. *(62-year-old Black woman)*

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	Well, but I think it's great that you are having this group because there is a lot of room, that like, I don't understand. I don't understand … ya know and I know the big community and I have nothing against my friend, but they know a lot more than I do and we need to know. Us women need to know. I need to know. *(54-year-old White woman)* *(54-year-old White woman)*
	I think about gender. I mean with the meds, because men are men. Women are totally different. We have different [re]productive … and I'm not making fun of the men that like to dress up like women or anything, but they don't have the body parts. I'm saying we have women stuff, they have … wouldn't it be, like medicine would be better for us if they come out with something like that? *(54-year-old White woman)* *(54-year-old White woman)*
	How about research on immune systems and how to boost them? How about more research on how do we boost our immune systems moving forward? And if health care will they provide for it, to boost our immune systems? *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)*
Resiliencies	Female relationships like in a group with the chairs. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)*
	Well, support groups. Females that share the same situation. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)*
	Family, positive family, and proper health care. *(50-year-old Black woman)* *(50-year-old Black woman)*
	Artistic outlets like to be creative, like creative workshops that express [yourself]. Or exercise, yoga, stuff like that. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)*
	Pampering myself. And I find that music helps me stay motivated too. Comedy, always comedy when I'm feeling some type of way. I keep laughter in my life. *(50-year-old Black woman)* *(50-year-old Black woman)*
	I stay away from drugs and alcohol. Staying sober, yeah. *(54-year-old Wh*ite woman)

(*Continued*)

Table 1. (Continued).

Theme	Exemplar Quotes
	(54-year-old White woman) I go to the bookstore and read a bunch of books on health and holistic alternative medicine … incorporating it, so using both in a balanced way. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)* I use the internet and I talk to my doctor and my nurses all the time. *(50-year-old Black woman)* *(50-year-old Black woman)* Umm, we come to the lady's groups and they always have HIV workshops that we can ask questions about health issues, about what's going on with new medicine and what not, and the community, so I would definitely say workshops are very informative. Health workshops. *(50-year-old Black woman)* *(50-year-old Black woman)* … And I mean I do drink socially, but I try to take care of my body and I try to keep as much out of it as I can to make it last a little longer … *(50-year-old Black woman)* *(50-year-old Black woman)* Creating a very non-stressful, peaceful environment. And people around you … it's strange that people bring joy into your life … Environment whether it be home, wherever, yeah work, both. [Having] positive people. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)* Um, today I, uh, because they took me to the wrong place today, tried changing it, and I kinda snapped on the phone so I was thinking changing my behaviors, my attitude towards peoples. *(54-year-old Whit*e woman) *(54-year-old White woman)* Giving back to the community, whether it be with children or with older people, they tend to appreciate commitment, helping them. *(50-year-old Hispanic woman)* *(50-year-old Hispanic woman)* I'm thinking incorporating alternative medicine or ways, or meditation, or just a lot of different avenues where you can … gives us a quality of life so that we can remain connected to each other. It's not all the time do people find dating. You know dating, it's not all about that. It's really more connections with people, small groups, moving forward that really helps makes a difference in our mental clarity and health. Moving forward which affects our physical. *(58-year-old Multiracial woman)* *(58-year-old Multiracial woman)*

HIV comorbidities

This theme encompassed participants discussion of concerns related to major health issues that occur alongside, and often interact, with HIV. As a 52-year-old White woman explained, *"I have to do chemo for the rest of my life, I mean just like taking my HIV meds because my cancer is not curable."* Another comorbidity that was repeated by several participants was osteoporosis. In an effort to try to keep healthy, a 62-year-old Black woman stated, *"And I know we take our meds, I take my osteoporosis meds … even if I don't have it, because I know about our bones."* Many participants also had concerns over hormonal changes associated with aging and menopausal symptoms that may be altered due to HIV and other chronic illnesses. A few participants also discussed other common HIV comorbidities, such as kidney failure and neuropathy. For example, a 50-year-old Hispanic woman wondered about the possible connection between hormonal changes and her newly discovered neuropathy:

> So, I started coming to these classes and now I think I'm finding out that I got neuropathy on this side. And I'm wondering what's gonna happen. I mean like is it going to go away if I take my medication? Or is it gonna get worser? Or is it gonna get … right, I'm kinda concerned. Is neuropathy affected by our hormones?

Similarly, a 62-year-old Black woman expressed a desire to better understand whether there was a connection between her kidney failure, HIV, and aging:

> You don't even know, but all of us, well I do, wanna know all the time is this worse because of my kidney? Or is this actually with my HIV? Maybe nobody else wants to know, but I wanna know. And then which [chronic issues] are aggravated by my aging?

Social determinants of health

The World Health Organization defines social determinants of health as "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" (World Health Organization, 2008). Social determinants of health encompass policies, economics, insurance, housing, and access to resources. Along these lines, many participants made statements about the structural barriers they face as women aging with HIV. A 68-year-old White woman indicated that there was a "*lack of access to helpful choices for recreation, for things like swimming, and you know … the social aspect of our lives."* Some participants discussed facing larger hardships, such as medical expenses not covered by their health insurance. A 58-year-old multiracial woman explained the need for:

> Additional healthcare insurance coverage that provides for alternative, you know, ways moving forward with women, but that help deal with women topics. Health issues that they don't provide for now.

Resiliencies

This theme is comprised of the various coping strategies that allowed participants to healthily age while living with HIV. Participants most frequently cited the importance of having a positive system of social support. Discussing sources of resilience, a 58-year-old Multiracial woman said, "people around you … it's strange that people bring joy into your life … [Having] positive people." Support groups were also important sources of social support and places where participants received information about HIV. A 50-year-old Black woman explained:

> We come to the ladies groups and they always have HIV workshops that we can ask questions about health issues, about what's going on with new medicine and what not, and the community, so I would definitely say workshops are very informative.

Sources of resilience also included artistic outlets, recreational activities, self-care, and community engagement. In conjunction with social support, another popular source of resilience was turning to alternative medicine to explore other means of living healthy. A 58-year-old multiracial woman stated:

> And I'm thinking incorporating alternative medicine or ways [of] thinking, or meditation, or just a lot of different avenues [which] gives us a quality of life so that we can remain connected and things like that to each other … It's really more connections with people, small groups, moving forward that really helps makes a difference in our mental clarity and health.

Discussion

This study sought to better understand the experiences, challenges, and coping strategies of older WLWH, who are historically underrepresented in HIV research. Participants' main health concerns centered on mental health and related psychosocial issues – namely, social isolation and stigma linked to living with HIV as a woman – as well as other common HIV comorbidities, including cancer, osteoporosis, kidney failure, and neuropathy. Participants also discussed menopausal complications related to living with HIV. Additionally, participants described many structural barriers that inhibited healthily aging with HIV, such as financial strain associated with out-of-pocket medical costs, as well as a lack of access to recreational and social activities that would improve the quality of their lives, all of which are elements of social determinants of health. To cope with the myriad challenges of living with HIV, participants most frequently cited social support as a major source of resilience.

The prevalence of perceived stigma and its impact on mental health, including depression, has been well documented among PLWH in general, including older PLWH, though much less so among older WLWH (Rubtsova

et al., 2017). Our findings support and extend previous research by highlighting the prominence of stigma, depression, and related psychosocial issues, such as social isolation, among older WLWH. Given the layered, compounding, and intersectional nature of stigma among those with multiple stigmatized identities, understanding older WLWH's experience of stigma – and its relationship to their mental health and level of social engagement – is particularly important because stigma likely manifests in different ways for older WLWH compared to both their younger counterparts and older MLWH (Emlet, 2017; McDoom et al., 2015; Rice et al., 2018). For example, in addition to experiencing stigma related to HIV-infection, participants described feeling stigma related to body image, which is considerably influenced by gender identity and associated cultural expectations. Indeed, dissatisfaction with one's body is widespread among women, but may be amplified among older WLWH due to the bodily changes that accompany cART (e.g., lipodystrophy), aging (e.g., wrinkles, other body marks), and the interaction thereof (Alencastro et al., 2017; Santos et al., 2005). Thus, consistent with the concept of intersectional stigma, older WLWH's experience of stigma is likely related to their intersectional identities as older, women, and PLWH, and the interaction of those and other identities (Rice et al., 2018; Sangaramoorthy et al., 2017). As such, older WLWH's unique experience of stigma may also result in distinct impacts, such as adherence to cART and access to health-care services. Previous research has demonstrated the impact of perceived HIV-related stigma on access to health-care services among older PLWH (Emlet, 2017), though addressing older WLWH's experience of stigma and related barriers may require tailored interventions (Durvasula, 2014; Rubtsova et al., 2017). More research is needed to understand older WLWH's perceived stigma and its various impacts at interpersonal, community, and structural levels (Turan et al., 2017).

In addition to depression, participants' concerns regarding other HIV comorbidities supports previous research demonstrating certain types of cancers, kidney failure, osteoporosis, and neuropathy as among the most common types of comorbidities in older PLWH (Marg et al., 2019; Wing, 2016). Participants also described concerns regarding the relationship between menopause and HIV, which illustrates the importance of understanding older WLWH's experiences aging with HIV as distinct from both their younger counterparts and older MLWH (who, for example, have not yet, or will not, experience menopause, respectively). The complex, bidirectional relationship between menopause and HIV is only beginning to be understood (Andany et al., 2016). More research is needed to fully elucidate the interaction between HIV, cART, and menopause, as well as its effects on the lives of older WLWH. Thus, medical providers of older WLWH must stay abreast of emerging empirical evidence and communicate this

information to patients to reduce their anxieties and/or provide tools to help patients manage the interaction.

Many participants described health challenges tied to important social determinants of health, including financial stability and access to affordable, stigma-free medical care tailored for WLWH. Participants stressed that access to such resources was important for their physical and mental well-being. Further understanding social determinants of health among older WLWH is particularly important because some may be more pronounced compared to older MLWH. For example, research suggests that older WLWH may be less likely to have a partner/spouse and therefore more likely to rely on a single, often fixed income, thereby increasing financial barriers to health care and other resources important for healthy aging with HIV (Durvasula, 2014). Relatedly, PLWH often lack support networks that are typically sources of instrumental support, such as assistance with cooking, cleaning, and transportation (Brennan-Ing et al., 2017; Greene et al., 2018). Interventions must consider these structural barriers in order to effectively address older WLWH's needs.

Finally, most participants described informal (e.g., friends) and formal (e.g., support groups) types of social support as major sources of resilience, which allowed them to cope with the myriad challenges associated with aging with HIV. Some participants also described engaging in meaningful activities (e.g., artistic and spiritual practices) as sources of resilience, which has also been found in previous research on older WLWH (Psaros et al., 2015; Warren-Jeanpiere et al., 2014). Much research has shown social support as vital for maintaining and improving the health and wellbeing of, and likelihood of successful aging among, older PLWH (Brennan-Ing et al., 2017; Brown et al., 2019; Greene et al., 2018; Marg et al., 2019). While little research has examined the social support networks of and their effects on older WLWH, the extant body of literature on older PLWH shows that social support among older PLWH is associated with greater engagement in HIV care and treatment adherence, lower levels of depression, lower levels of perceived stigma, more positive perceptions of body image, and overall more positive health outcomes (De Oliveira et al., 2019; ; Emlet et al., 2019; Greene et al., 2013; McDoom et al., 2015; Santos et al., 2005). Thus, medical providers should assess older WLWH's level of social support, positively reinforce accessing support from friends and family, and connect them to other sources of support, such as community organizations and support groups.

This study is not without limitations. First, the data came from a small sample of mostly college-educated women between the ages of 50 to 68 years in Palm Springs. Therefore, findings may not be generalizable to other populations of PLWH, those living in other geographic regions, or to WLWH in older age groups (e.g., ages 75–84 and 85+). Second, our

recruitment strategy may have yielded participants who were active in the community and possibly from similar social networks. Thus, the voice of socially isolated older WLWH and those in different social networks may not be represented here. Third, women's biopsychosocial issues may vary depending on the amount of time since their diagnosis. For example, women diagnosed 20 years ago may have different or perhaps more effective coping strategies than women more recently diagnosed. However, the present study did not consider participants' time since diagnosis. Finally, the present study did not ask about participants' sexual orientation. As such, we could not address any differences between heterosexual and women of other sexualities.

Conclusion

Despite its limitations, this study drew upon the lived experiences of older WLWH, an understudied population, and contributes vital knowledge regarding their challenges, coping strategies, and experiences aging with HIV. Additionally, our community engaged approach allowed participants to respond to interview questions created by PLWH (including WLWH) for people aging with HIV. Moreover, the focus group was facilitated by WLWH who understood participants' lived experiences better than researchers without HIV. Taken together, this study is an example of a true community engaged approach in research. Through this approach, we showed that important health concerns for older WLWH centered on mental health and related psychosocial issues (e.g., depression, social isolation, multiple intersecting stigmas), common HIV comorbidities (e.g., osteoporosis, the interaction between menopause and HIV), and social determinants of health (e.g., structural barriers to health care and other resources). In order to cope with the many challenges associated with aging with HIV, participants emphasized the importance of social support as a major source of resilience. As the population of older WLWH continues to grow, more research is needed to understand their experiences, challenges, and sources of resilience in order to develop effective, tailored, and comprehensive care and treatment.

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