

# Community-Driven Health Priorities for Healthy Aging With HIV

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## Abstract

Palm Springs, CA, is a retirement community with the highest prevalence of gay men living with HIV older than 50 years in the United States. Through a community–academic partnership, we explored the major health issues, resiliencies, and priority research topics related to HIV and aging. We conducted five community facilitated focus groups with different stakeholders, including two focus groups with older adults living with HIV, one with their caregivers, one with HIV-focused community-based organizations, and a joint focus group with researchers and HIV care providers. Using the rigorous and accelerated data reduction technique, five major themes emerged, which included long-term side effects of medication, social determinants of health, mental health, resiliencies, and involving community in research. These data are important for developing effective interventions, conducting useful and impactful research, and providing health care providers with the tools and knowledge to provide optimal care.

**Key words:** aging, HIV, community, health priorities, resilience, focus groups

In 2015, nearly 35 years after the HIV epidemic was first recognized, it was estimated that more than 50% of people living with HIV (PLWH) in the United States were 50 years and older (Effros et al., 2008; Guaraldi & Palella, 2017). By 2020, this proportion is expected to increase to approximately 70% (Centers for Disease Control and Prevention, 2016; Diverse Elders Coalition, 2014). Although HIV was once regarded as a death sentence, the development of combination antiretroviral therapy (cART) in the 1990s transformed HIV into a largely manageable, chronic condition. As a result, PLWH have a near normal life expectancy in resource-rich settings (Centers for Disease Control and Prevention, 2018; Harrison, Song, & Zhang, 2010). The

probability of long-term survival continues to increase with improving cART and other therapies (Centers for Disease Control and Prevention, 2018; Guaraldi and Palella, 2017). Older adults (ages 50 years or older), living with and without HIV, also remain sexually active and do not always have protected sex—approximately 18% of new HIV diagnoses are among people older than 50 years (Centers for Disease Control and Prevention, 2017). The combination of all these factors contributes to the growing proportion of older adults living with HIV. As PLWH age, they experience an array of new difficulties (e.g., higher rates and earlier onset of comorbidities, mental health issues, geriatric syndromes, ageism, and stigma; Wing, 2016). Although PLWH typically experience far fewer, life-threatening, acute illnesses than before the advent of cART, they are burdened with issues specific to the unique interaction between HIV and the aging process (Bhatia, Ryscavage, & Taiwo, 2012; Rodriguez-Penney et al., 2013).

## The Challenges of Aging With HIV

Generally, PLWH experience a higher number of comorbidities (average of three) than those without HIV (Havlik, Brennan, & Karpiak, 2011; Schouten et al., 2014; Smit et al., 2015). Common comorbidities include cardiovascular disease (Feinstein et al., 2016; Martin-Iguacel, Llibre, & Friis-Moller, 2015), osteoporosis (Prieto-Alhambra et al., 2014; Walker Harris & Brown, 2012), and renal disease (Ando, Tsuchiya, & Nitta, 2012). Research also suggests an increased risk of diabetes (Guaraldi et al., 2011; Vance, Mugavero, Willig,

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Raper, & Saag, 2011) and certain types of cancer, such as anal cancer, liver cancer, lung cancer, and Hodgkin lymphoma (Silverberg et al., 2015; Yanik, Katki, & Engels, 2016). Studies have also shown a high rate of geriatric syndromes among older PLWH, including frailty, difficulty with activities of daily living, and neurocognitive impairment (Greene et al., 2015; High et al., 2012). Indeed, many adults aging with HIV must confront the challenges associated with the onset of illnesses typically experienced by people who are many years older (Havlik et al., 2011; Karpiak & Havlik, 2017). The health problems experienced by older PLWH are exacerbated by and occur in tandem with social (e.g., ageism, stigma, social isolation, and the erosion of social support) and emotional (e.g., depression) challenges (Erosheva, Kim, Emler, & Fredriksen-Goldsen, 2016; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Halkitis, Krause, & Vieira, 2017).

Depression is one of the most prevalent comorbidities among older PLWH (Halkitis et al., 2017; Havlik et al., 2011), which may be exacerbated by social challenges (Emler et al., 2013; Grov et al., 2010), particularly social isolation (i.e., loneliness) and lack of social support (Greene et al., 2018; Grov et al., 2010). Friends, many of whom are also living with HIV and in need of their own support networks, are commonly the main source of support, despite not always being in the best position to provide support to others (Brennan-Ing, Seidel, & Karpiak, 2017). Ageism and stigma also contribute to these social lacks, discouraging disclosure of HIV status and promoting ostracism and a self-defensive withdrawal from social ties and social engagement (Emler, 2016; Emler et al., 2013; Erosheva et al., 2016). These combined experiences can exacerbate physical and mental health conditions among older PLWH by inhibiting consistent access to care (Halkitis et al., 2017).

### **Community-Based Participatory Research and HIV Research**

Further research is needed to understand the ways older PLWH experience and cope with the challenges associated with aging. Community-based participatory research (CBPR) is an approach that emphasizes and ensures community participation in research and promotes co-learning, which equalizes power between research participants and academic researchers, transferring expertise between participants and academic researchers and sharing ownership in developing intervention and evaluating research outcomes and products (Rhodes, Malow, & Jolly, 2010; Wallerstein & Duran, 2010). HIV/AIDS research has a particularly long history of cultivating

collaborations between community members and academic researchers, which has been instrumental in aligning research priorities with the needs of populations most impacted by HIV to improve their health and well-being (Rhodes et al., 2010).

HIV research has used CBPR with a variety of populations and in various settings, such as online communities of men who have sex with men (Rhodes et al., 2011), Latinas and immigrant Latino men who have sex with men living in rural communities (Rhodes et al., 2012, 2013), and African American gay men living with HIV (Hergenrather, Geishecker, Clark, & Rhodes, 2013). Some CBPR has been conducted with older adults living with HIV in the context of developing recommendations and clinical practice guidelines for rehabilitation (Solomon, O'Brien, Baxter, MacLachlan, & Robinson, 2016; O'Brien et al., 2014). Overall, however, there is very little research using CBPR to understand the ways that older adults experience and cope with challenges associated with aging with HIV.

### **Setting**

Palm Springs, CA, is a popular retirement community in the Coachella Valley, particularly among older gay men living with HIV. The Coachella Valley, part of Riverside County (the 11th largest county by population size in the United States), has a population of approximately 350,000 residents (Lowe Institute of Political Economy & Inland Empire Center, 2016). Of the 1,283 PLWH in Coachella Valley, more than half (63%) are 60 years or older (Riverside University Health System, 2017). The incidence estimates of HIV in the Coachella Valley range from 3.5 to 177.6 cases per 100,000 people—substantially higher than California's overall HIV incidence estimate of 16.7 cases per 100,000 people (Centers for Disease Control and Prevention, 2017; Health Assessment Resource Center, 2014; Riverside University Health System, 2017). Given the number of older adults living with HIV, Palm Springs (and the Coachella Valley) presents an ideal place to investigate their experiences, coping strategies, and challenges. Our goal was to identify the major health-related themes surrounding HIV and aging among the major stakeholders (e.g., PLWH, their caregivers, their providers, community-based organizations [CBOs], and researchers) in the Coachella Valley.

### **Methods**

From January to February 2018, we conducted five focus groups with different stakeholder groups selected for participation due to their deep understanding, either

through lived experience or extensive community engagement, of HIV and aging. This included two focus groups with older adults living with HIV, one with nonmedical caregivers of older adults with HIV, one with HIV-focused CBOs, and one joint focus group of researchers (University faculty or other academic organizations) and health care providers with expertise in HIV and aging. Focus group questions explored three topics: (a) major health issues experienced by older adults living with HIV, (b) resiliencies allowing people to age successfully with HIV, and (c) top priority research topics surrounding HIV and aging in the Coachella Valley. These focus group sessions were 60–90 minutes in length and recorded for analysis. All participants received \$50 for participation.

Following CBPR principles, study materials were created through a collaborative process involving the research team, including older adults living with HIV, a 10-person steering committee of stakeholders from the groups listed above, and a 10-person community advisory board of PLWH. Materials included a verbal consent script, outreach flyers, a five-question demographic survey questionnaire, and the focus group questions (Table 1). Inclusion of a question focused on resiliencies

was viewed as particularly important by PLWH. Several community members were trained by the research team to facilitate these focus groups, and field notes were recorded to supplement the audio recordings. Participants were recruited using a study flyer distributed at community events, by word of mouth, and through our steering committee and community advisory board networks. To maintain confidentiality of HIV status, participants were not asked to self-identify their stakeholder group at the time of recruitment; rather, they were asked to e-mail or call the study coordinator with that information. This met an important criterion for our steering committee and community advisory board composed of PLWH who helped design the study.

### Qualitative Analysis

The rigorous and accelerated data reduction (RADaR) technique by Watkins (2017) was used for systematic analysis of the focus group transcripts. The RADaR technique consists of five steps intended to organize and reduce the data to yield final themes and exemplar quotes. In Step 1, audio recordings were transcribed verbatim, and data transcripts were formatted to include

**Table 1. Focus Group Questions for HIV and Aging Stakeholders**

Question set A: health issues	1. What are the top 3 major health issues affecting people who are aging with HIV? a. Probe: health can be physical, mental, environmental stressors, or something else
Question set B: resiliencies	1. What are some of the resiliencies that allow people to age healthily with HIV? Resiliencies are positive things like strengths, coping mechanisms, or adaptation. a. Probe: growth, adaptation, expand
	2. What are some of the resources that you draw upon to navigate your health?
	3. What are some of the choices that people have made to live healthily a. Probe: what behaviors?
Question set C: research	1. What should be the top priority topics for research on HIV and aging in the Coachella Valley? a. Probe: how important is XX issue to you?
	2. How should these priority research topics be chosen? a. Probe: by budgets, by those aging with HIV, by scientists
	3. What topics do you think are understudied that could benefit people who are aging with HIV?
	4. What are the problematic aspects of research participation?
	5. What are the aspects of research that you would like to learn more about? a. Probe: for example, some people might like to learn more about informed consent or clinical trials or confidentiality of data or what my rights are as a participant or how to get involved in a community advisory board or what to do if I am injured in a study
	6. What are the topics of research you would like to get training in?

line and page numbers and double-checked for anonymity to maintain participant confidentiality. The focus group transcripts were incorporated into one all-inclusive table, organized by focus group, page, and question numbers, completing Step 1 of the RADaR technique. Two analysts (A.C., M.D.) individually reviewed the all-inclusive spreadsheet and considered the topics discussed, developing the overarching research question: “What are the major health priorities for HIV and aging among key stakeholders?” In Step 2, the same two analysts separately and then collectively eliminated data irrelevant to the overarching research question. As the text was reviewed, particularly, helpful quotes for answering the overarching question were noted and highlighted. These quotes were validated by our steering committee members and shared with our stakeholders. In Step 3, these notes helped the analysts create themes and subcodes. Step 4 repeats Step 2’s elimination of data, first individually and then together. Analysts reached consensus for each quote before officially keeping it in or removing it from the Step 4 table. In Step 5, analysts returned to the overarching research question to ensure all remaining quotes answered the question through the emphasized themes and codes. A final table was made, separating each quote by theme and further identifying quotes by focus group origin, line number, and assigned code.

### **Ethics Approval**

We received expedited approval from the University of California, Riverside, Institutional Review Board. All participants provided verbal consent to participate, preventing a paper trail that could connect their identities to their responses.

## **Results**

### **Participant Characteristics**

A total of 46 people participated in the focus groups, including 18 older adults living with HIV, 12 nonmedical caregivers, 8 CBO representatives, and 8 researchers or HIV providers. Participants’ mean age was 59 years (range, 30–76 years). The majority of participants were White non-Hispanic (80.4%) with 15.2% identifying as Hispanic and 4.4% either Black or multiple races. Participants were also largely male (89.1%), with four identifying as female and one as transgender. The majority (76.1%) of participants attended a 4-year University or graduate school, whereas the rest were high school graduates or attended some college.

### **Major Focus Group Themes**

The five major focus group themes identified were (a) the long-term side effects of medication, (b) social determinants of health, (c) mental health, (d) resiliencies, and (e) involving the community in research. Subcodes included accelerated aging, stigma, depression, community/social support, and research barriers. See Supplemental Digital Content 1 (Table 2, <http://links.lww.com/JNC/A2>) for a complete list of exemplary quotes for each theme.

**Long-term side effects of medication.** This theme encompasses worries and anxieties regarding the possible side effects of extended (years to decades) use of antiretrovirals and other HIV-related medications. Many participants shared that they have been using these medications since the late 1980s and early 1990s and expressed concerns that long-term use of these medications might be responsible for accelerated aging, organ damage, and other health issues. Many participants were among the first persons with HIV to take antiretroviral medications and have continued throughout their lives to be the first to use new medications to manage HIV and its comorbidities. As one 69-year-old Hispanic male explained, “*I’ve been on drugs for so long ... what’s the price we’re gonna pay for living this long and taking these drugs, and the effects they’re gonna have on parts of our bodies.*” Similarly, a 62-year-old White male stated, “*Recently, I got my labs. My creatinine numbers had spiked up. I don’t know if it’s due to one of the new medications in my regimen, but it indicates a possible kidney issue, that’s causing me a lot of anxiety.*”

**Social determinants of health.** This theme addresses the significance of housing, access to insurance and competent medical care, and financial stability for PLWH. The importance of these social determinants of health was reported by participants to be amplified among those aging with HIV, which includes “the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness,” as defined by the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (Centers for Disease Control and Prevention, 2014). In particular, financial and housing stability were important issues facing participants. As one 69-year-old Black transgender participant stated, “*A lot of folks may be living relatively close to the edge in terms of financial stability. And having some support to prevent people from just falling off the [financial] cliff is a good thing. That’s why we have an emergency fund for the trans community... [to] keep people from falling into the abyss.*” In addition, many participants stated adherence to their medication



regimen was challenging without being able to frequent a medical facility that respected their experiences. A 57-year-old Hispanic male caregiver voiced,

*“A lot of places that I’ve been to, some places were really bad ... I went to a doctor and she was not great at all. I felt stigmatized, I felt really bad about myself. I felt dirty, and they made me feel that way. There was a big difference in how they treated people and that made a difference in how I felt about myself.”*

Thus, limited access to stigma-free and therefore competent medical care is a barrier to successfully aging with HIV.

Among this older population, food security was also a pressing matter. For instance, one 76-year-old White male stated, *“I eat at [the senior center] probably at least three or four times a week. It’s \$3, it’s very inexpensive,”* whereas a 66-year-old White male stated, *“Thousands of people who get help by the AIDS assistance program giving us the grocery store coupons to go get actual food. And that’s a very real tangible benefit for many people.”*

**Mental health.** Numerous participants recounted feelings of depression or isolation that resulted from lack of social support, including the lack of a sense of community or family ties. A 76-year-old White male discussed a recent situation with a friend who was depressed,

*“I go over to this condo and he’s on the bedroom floor, and he hadn’t eaten in 3 or 4 days. And he couldn’t even get off the floor. We ended up having to call an ambulance and then transport him to the hospital ... I still check on him every once in a while but he has two sons, they don’t care about him, and he just got depressed and stopped eating.”*

Other participants reported depression due to grief over the loss of partners and friends, described by the same 76-year-old White male: *“Isolation from all your friends who’ve died. My partner and I are nearly, I’m over 70, he’s nearly 70 and we have no close friends. They all died ... everybody is dead.”* Another 76-year-old White male similarly expressed, *“Another aspect of grief: coping. I’ve had several people say ... everybody I know is dying. They’re not dying of AIDS but they’re dying.”*

**Resiliencies.** The resiliencies theme represents strengths that have allowed participants to age successfully while living with HIV. Positivity, having a supportive community, and having friends were among the most important resiliencies reported. According to a 58-year-old White male,

*“There’s different people who are isolated and separated and lonely and don’t feel community support, and then there are people who are not like that ... [who have] many peers who*

*have survived with or without HIV, so these social networks are absolutely resiliencies. They rely on each other to understand each other, find support with each other, they’ve had common experiences that they’ve gotten to share.”*

One reason this sense of community support was deemed critical was the absence of family support for this population. As the same male participant stated,

*“The majority of gay men with HIV who are aging don’t have children. They don’t have extended families, which is an absolute major form of support for aging populations in the country that are heterosexual ... this is why community resources become so important because they don’t have family resources.”*

In addition, having pets was seen as an important resource for resilience. A 54-year-old White male affectionately stated, *“I recently got a cat and it has really put me on a schedule. And a positive, more positive feeling. I’m not as depressed as I was. She makes me laugh,”* whereas a 76-year-old White male reported, *“I have a little dog. I never thought I’d like a dog that much but it’s amazing how it does give you some sort of support.”*

A final core resiliency unique to this population was that, due to their extensive medical care history, community members possessed a high level of health literacy and knowledge that allowed them to be active participants in their medical care. A 55-year-old White male indicated,

*“I have a lot of straight friends with health issues who are, they don’t ask their doctors questions, they don’t look anything up on the Internet, they take whatever’s given to them. And the fact that we’ve been sort of trained to ask questions of our doctors ... that’s one of our resiliencies, that we’ve learned to be in charge of our health.”*

This was echoed by a 46-year-old White researcher who stated,

*“I haven’t met a person [in the community] who is not connected to care and insurance and who isn’t regularly seeing a doctor ... and the destigmatization—I mean people will be talking at Starbucks about their HIV status, meds, T-Cell count.”*

**Involving community in research.** This research theme highlighted the importance of involving community members in HIV and aging research, with members having a voice in deciding research priorities, including (a) how topics are selected, (b) who selects the topics, and (c) where the research takes place. It also included participants’ concerns about typical research methods. Because many of the participants were involved in research since the beginning of the epidemic, participants were

adamant that any research implemented should include their contributions as more than participants. As one 69-year-old Hispanic male verbalized,

*“We should choose or decide. We’re the ones that are here, we’re here to give our opinion. And you know, as best as it is, what we think is important to us as a group should be studied.”*

In contrast, a 76-year-old White male stated, *“I think a lot of studies, because they have to be so specific in what they’re looking after excludes a lot of us in the process.”* Confirming the importance of conducting CBPR research with this community, a 48-year-old White male researcher said,

*“research organizations have a commitment to the community, staying in the community. Rather than coming in, poaching research subjects, and leaving. So that [researchers] get their journal articles published but without any sort of sustained work in the community.”*

There was also a call for improved communication between researchers and participants. This included being made aware of the studies occurring in the community. One 63-year-old multiracial male said,

*“nobody tells me [about the studies] and there’s no place I can go to find out about them unless I actively go from here, to here, to here to here to look for them.”*

Other participants expressed concern about being participants in research but not being privy to the results. The same 63-year-old male reported,

*“I need to know the applicability of [a study’s] data to my daily life. How does that data apply to me as a human being, apply to my community, what does it inform in terms of what I need to watch out for, things I need to think about? Having a study in a book is great. But if I don’t have any way to access that data in a way that’s meaningful for me ... then I can’t proactively manage my health.”*

## Discussion

Using CBPR methods, this study sought to better understand the ways that older adults living with HIV experience and cope with challenges associated with aging with HIV. One of the main challenges that participants highlighted was concern about the long-term side effects of HIV-related medications (e.g., cART). A core component of this theme was acknowledgment that participants were the first generation to have taken these drugs for multiple decades, and as a result, there is little information about the long-term consequences. Thus, participants’ anxieties about the effects of their medication regimen on their bodies resulted from a lack of data in older adults

living with HIV. Without a clear understanding of the long-term effects of their medications, participants often worried that their medications could be responsible for perceived changes in their health, such as accelerated aging and damage to their biological systems. Other research has also found that older PLWH are concerned about the consequences of long-term HIV-related medication use and that there is a lack of information in this area (Solomon, O’Brien, Wilkins, & Gervais, 2014).

The interaction between HIV infection, aging, and side effects of cART is only beginning to be understood (High et al., 2012). Research suggests that elucidating the role of inflammation is key to understanding the complex interplay between HIV infection, aging, and long-term use of cART; however, the exact causes and clinical relevance of chronic low-level inflammation despite viral suppression remain uncertain (Deeks & Phillips, 2009; High et al., 2012). Moreover, debate continues about whether PLWH experience accelerated aging (Karpiak & Havlik, 2017). Research must continue to untangle the interactive effects of HIV infection, cART side effects, aging, and other biopsychosocial challenges. Medical providers of older adults living with HIV must stay abreast of key emerging scientific findings and communicate this information to patients to assuage their anxieties and/or provide coping strategies.

Other health challenges that emerged from the data were the importance of housing, access to stigma-free comprehensive medical care, and financial stability, which are elements of the social determinants of health as defined by the Centers for Disease Control and Prevention (2014). Participants emphasized that access to these structural resources was critical for their well-being and survival. Indeed, social determinants of health are particularly important for older PLWH because this population often lacks traditional support networks (e.g., spouses, children, other relatives) who help provide vital instrumental support, which includes various types of tangible help such as transportation and help with cooking and house cleaning (Greene et al., 2018). Our findings support other research that shows that older PLWH must contend with stigma, especially in health care settings, which can result in decreased engagement in health care (Davtyan, Farmer, Brown, Sami, & Frederick, 2016; Emler, 2016). Our findings suggest that older PLWH are more likely to access health care when medical providers and staff make them feel comfortable and supported—that is, when they do not feel stigmatized or discriminated against due to their HIV status, sexual orientation, or gender identity. Although much research demonstrates the impact of HIV-

related stigma (Cama, Brener, Slavin, & de Wit, 2015; Herrmann et al., 2013; Slater et al., 2015), there is less understanding of how HIV-related stigma impacts older PLWH, such as their access to health care. Research suggests that stigma may affect older PLWH differently than their younger counterparts because of the influence of ageism and its interaction with other forms of stigma, such as stigma related to sexual orientation, and/or gender identity (Emlet, 2017; Slater et al., 2015). Given the compounding and layering effect of living with multiple stigmatized identities (Emlet, 2017), future research is needed to understand the role and interaction of stigma and discrimination related to HIV status, sexual orientation, and gender identity on access to health care among older PLWH. This knowledge is important for developing interventions specific to older adults, such as provider training and practices aimed at decreasing barriers to health care access (Gelaude et al., 2017; Ion & Elston, 2015).

Participants' mental health concerns mainly focused on feelings of isolation, lack of social support, and uncertainty about the future. This finding is consistent with much research that shows that older adults living with HIV experience high rates of depression, which often results from or is exacerbated by fragile and/or shrinking social networks (key sources of social support) and feelings of loneliness and isolation (Brennan-Ing et al., 2017; Emlet, 2016; Greene et al., 2018). Other research also identified that older adults living with HIV express worry related to the uncertainty about how future care needs will be met, especially as close friends and/or family die or are otherwise absent (Solomon et al., 2014). Given high rates of depression among older adults living with HIV (Cahill & Valdez, 2013; Halkitis et al., 2017; Havlik et al., 2011), health care providers should routinely screen patients for depression, as well as social factors that may contribute to depression, such as isolation and loneliness. In this way, health care providers must understand that providing quality care for older adults living with HIV necessitates addressing comorbidities associated with HIV and addressing the role of social factors on patients' health (Halkitis et al., 2017).

In the face of many challenges associated with aging with HIV, participants discussed several important sources of resilience. Resiliencies largely revolved around preventing and/or alleviating isolation and depression, such as the importance of friendships, community involvement, and access to resources provided by community organizations. Participants noted that access to social support through friends and/or community organizations provided both instrumental and emotional support—

both of which are important for maintaining good health and well-being. This finding supports other research that shows the positive impacts of social connectedness on the physical and mental well-being of older adults living with HIV not only through friends and family but also through support groups or other social engagement, such as through volunteering or using community organization resources (Emlet, Tozay, & Raveis, 2011). Given this research, medical providers should consider linking patients aging with HIV to sources of social support beyond friends and family, such as nearby community organizations or volunteer opportunities.

Participants also discussed pets as an important source of resilience and emotional support. To our knowledge, the impact of pets on the physical and mental well-being of older adults living with HIV has not been examined. However, some research has demonstrated the positive effects that pets can have on individuals' lives. For example, research shows that pets can motivate people to engage in physical activity (Dall et al., 2017). Pet ownership can also provide a gateway for friendship development and interaction (Wood et al., 2015). Research also shows pets as sources of social and emotional support (Bryan et al., 2014). Other research shows that pet ownership is associated with decreased feelings of loneliness among older adults (Stanley, Conwell, Bowen, & Orden, 2014) but that effect may be dependent on gender and other sociodemographic characteristics, such as health status (Pikhartova, Bowling, & Victor, 2014). Future research should examine the impact of pet ownership on feelings of loneliness, depression, and social support among older PLWH specifically. Understanding all sources of resilience among older adults living with HIV is important for developing interventions so that health care providers can suggest evidence-based strategies for managing the numerous burdens associated with aging with HIV.

The final theme that emerged was the importance of engaging and involving older adults living with HIV in helping to shape research studies on HIV and aging. Participants from all of the groups (i.e., older adults living with HIV, caregivers, CBO representatives, researchers, and HIV providers) identified desires for research that was consistent with CBPR, especially the minimization of the power differential between researchers, participants, and community members. Participants emphasized the importance of establishing partnerships between communities and researchers and the need for researchers to share their findings with the community and explain what the findings meant for their day-to-day lives. Participants also stressed that research must include their input. Our findings support previous research that found that older



adults living with HIV prefer greater use of research strategies employed in CBPR (Nguyen, Brown, Taylor, Estevez, & Loftus, 2017). Also, our findings extend previous research because our findings within this theme emerged across all of our participant groups and were not limited to older adults living with HIV.

Our findings show that many older adults living with HIV are knowledgeable about the research process and can offer useful advice for how researchers can conduct impactful and equitable research that empowers participants and community members. Accordingly, future research on older adults living with HIV would benefit from relying on CBPR methods and should include all key stakeholders in the research process.

This study has several limitations. First, the majority of participants were White, male, and college educated; therefore, these findings may not be generalizable to other racially/ethnically and socioeconomically diverse populations in addition to women and the transgender community. Furthermore, individuals who were recruited and decided to participate may have been already active in the community, and those who were isolated may not have provided their voice here. Using more dynamic recruitment measures might include more diverse participants. Some participants expressed concern about the lack of research in other areas of the Coachella Valley outside of Palm Springs. Specifically mentioned was Eastern Coachella, which has more migrant farm workers and incarcerated people and their families. Finally, the total number of participants in this study was 46 people from various stakeholder groups, and their views may not be representative of the entire HIV and aging community.

## Conclusions

More research is needed to understand aging among diverse populations of older adults living with HIV. Few studies have investigated people's lived experiences of aging with HIV and even fewer have done so using CBPR methods. This study showed that important health concerns for older PLWH centered on worries about the long-term side effects of medications, social determinants of health (e.g., access to housing, medical care, financial stability), and mental health (e.g., depression, loneliness, isolation). Despite the significant burdens associated with aging with HIV, participants described numerous sources of resilience, including social support from friends, family, and community organizations, as well as emotional support provided by pets. This study also showed that participants valued research strategies consistent with CBPR. Understanding the lived experiences of PLWH

and their sources of resilience is important for developing effective interventions, conducting useful and impactful research, and providing health care providers with the tools and knowledge to provide optimal care.

## Disclosures

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