EXAMINING THE RISKS AND RESILIENCE OF OLDER ADULTS LIVING WITH HIV/AIDS: QUALITATIVE COMMUNITY-BASED PARTICIPATORY RESEARCH STUDIES IN SOUTHERN NEVADA

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Abstract

Since the height of the HIV pandemic in the 1980s, medical interventions have significantly increased the life expectancy of people living with HIV/AIDS (PLWH) and made HIV/AIDS a livable, chronic health condition. Because of this, PLWH have been living longer lives and thriving with the help of HIV sector healthcare and service providers. However, with their longer life expectancy, older PLWH have been experiencing other health challenges. One such challenge is the risk of developing HIV-Associated Neurocognitive Disorder (HAND), which is a condition that affects up to 50% of PLWH at some point in their lifetime, with middle-aged and older PLWH being most at risk. In this three-paper dissertation, the awareness and knowledge of the specific risk of PLWH developing or experiencing neurocognitive challenges as they age as a result of HAND among relevant study participants (i.e., middle-age and older PLWH and their HIV sector providers) from Southern Nevada are examined and discussed in the first two papers. Looking beyond the risks aging PLWH face, the third paper of this three-paper dissertation takes on a more strengths-focused approach to examining the circumstances and experiences of study participants. It directs its attention to the inherent resilience of PLWH, specifically the resilience of middle-aged and older men who have sex with men (MSM) living with HIV/AIDS, the subpopulation of PLWH that has inarguably been impacted the most and the longest by HIV/AIDS since the global pandemic started in the 1980s.

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Chapter 1: Introduction

Since the advent of combination antiretroviral therapy (cART) in the 1990s, people living with HIV/AIDS (PLWH) have been living longer lives and thriving more with the support of dedicated HIV sector healthcare and service providers from different healthcare institutions and community-based organizations (Trickey et al., 2023). With this longer life expectancy resulting from the widespread availability of cART, particularly in developed countries, HIV/AIDS has become a livable, chronic health condition. However, it is important to note that PLWH living longer lives have begun experiencing other health concerns that come with aging while living with the virus (Rosenthal & Tyor, 2019). This makes apparent the need for increased research on healthcare access and relevant support services from the HIV sector in order to robustly support aging PLWH.

HIV-Associated Neurocognitive Disorder

One such growing health concern among aging PLWH is HIV-Associated Neurocognitive Disorder (HAND), which is a condition that affects attention, learning, memory, language, sensorimotor abilities, and executive functioning (Simioni et al., 2010). Research has shown that as much as 50% of PLWH are expected to experience signs and symptoms of HAND at some point in their lifetime, even if they are regularly taking their prescribed HIV medications (Heaton et al., 2011). HAND is a spectrum of neurocognitive challenges that ranges from asymptomatic neurocognitive impairment, where symptoms are barely noticeable, to the most severe form called HIV-Associated Dementia. Studies have documented that even mild to moderate forms of HAND significantly affect instrumental activities of daily living, quality of life, and medication adherence (Alford et al., 2021; Wei et al., 2020). Moreover, living with HIV/AIDS has also been documented to increase the risk of developing other concomitant health conditions such as heart disease, diabetes, and obesity, which syndemically interact with HAND in ways that lead to significant challenges among PLWH (Rosenthal & Tyor, 2019).

Resilience to HIV/AIDS

Resilience, on the other hand, has been found to not only be protective against overall HIV risk, but also critical to promoting the access of PLWH to key healthcare and community services (Green & Wheeler, 2019; Halkitis et al., 2017; McNair et al., 2018). Additionally, resilience has been reported to mitigate the impacts of living with HIV/AIDS as an overall life stressor, a factor that can lead to depression and other disabilities (Fang et al., 2015; Fredriksen-Goldsen et al., 2013; Zhang et al., 2015). A focus on HIV/AIDS resilience has helped ameliorate the overwhelming deficits-based focus of prior HIV/AIDS prevention studies, an effort that has been promoted by researchers advocating for more strengths-based research that emphasizes the positive traits of many PLWH (McNair et al., 2018; Woodward et al., 2017). Strengths-based research specifically focuses on protective factors rather than pitfalls and risks, and examines both positive microsystem level individual traits and macrosystem level community resources (Colpitts & Gahagan, 2016; Woodward et al., 2017; Zhang et al., 2015). The focus on positive traits and empowerment is crucial to research addressing health concerns of minority and other underserved populations so that it could help reverse damaging rhetoric and discourse that focus on weaknesses and vulnerabilities of PLWH instead of their strengths.

Manuscripts

In this three-paper dissertation, the awareness of the specific risk of aging PLWH developing or experiencing neurocognitive challenges as a result of HAND among relevant study participants from Southern Nevada is assessed. More specifically, the first two papers examine the knowledge of HAND, perspectives, and lived/work experiences of study participants from Southern Nevada who are, in paper 1, middle-aged and older PLWH, and in paper 2, HIV sector healthcare and service providers. These two papers also discuss the salience of the influence and impacts of different social determinants of health, which becomes an important focus in the papers' discourse.

Next, looking beyond HAND as one of the more critical health risks PLWH may face as they age, the third paper takes on a strengths-based approach to examine the circumstances and experiences of aging PLWH. The third paper specifically evaluates factors that build the resilience of middle-aged and older men who have sex with men living with HIV/AIDS (MSMLWH), the subpopulation of PLWH that has been impacted the most and the longest by HIV/AIDS since the 1980s ((Liboro, Yates, Bell et al., 2021). This third paper is an examination of the facilitators and challenges to the resilience-building of Southern Nevada middle-aged and older MSMLWH, explicitly drawing from a social determinants of health perspective.

A major commonality among all the three research papers of this dissertation is the use of the community-based participatory research (CBPR) approach in the studies they each describe. CBPR is not only a research method but also an overall approach to building community-wide knowledge, fostering learning, empowerment, and encouraging long-term positive change (Wallerstein & Duran, 2006). We conducted our research by collaborating with relevant community-based organizations and establishing working relationships with both individual stakeholders and the larger community. Additionally, we furthered our research goals of spreading valuable knowledge by encouraging stakeholders to take an active role in the research affecting them. This approach develops opportunities for increased collaboration, learning, and equitable access to knowledge often gatekept by standard academic approaches (Wallerstein, 2021). Further, the CBPR approach allows complex research topics like HIV/AIDS that intertwine health and social issues to be viewed from multiple perspectives, specifically in this case, through the perspectives of PLWH, their providers, and the community-based organizations delivering needed HIV/AIDS programs and services (Rhodes et al, 2010).

The first paper focuses on PLWH and their lived experience related to HAND. Much of previous research has focused on the clinical aspects of HAND, but with this qualitative CBPR study, we sought to extend the research knowledge base by examining awareness and knowledge of HAND, specifically in Southern Nevada. With 15 semi-structured interviews, our open-ended questions focused on awareness of HAND, knowledge of HAND, and access to local resources that help address issues related to HAND. After conducting thematic analysis, we found that PLWH had limited awareness and knowledge of HAND, and that, even with ample resources available in Southern Nevada, PLWH struggled to access these resources due to various factors. We also utilized a social determinants of health perspective in this manuscript as it highlights the many challenges PLWH are facing in the Southern Nevada setting.

In the second paper, we extend this awareness research to the context of healthcare and service providers who are critical to managing a chronic health condition like HIV/AIDS. In the study described in the manuscript, we sought to explore the knowledge and awareness of HIV sector healthcare and service providers in Southern Nevada. With 12 interviews, we conducted thematic analysis to identify major themes and subthemes which centered on: (1) provider awareness and knowledge, and (2) prospective provider roles. Providers varied in their knowledge and experience, and many providers had some outdated knowledge regarding HIV-Associated Dementia. Lack of knowledge was revealed to be a barrier to providing care, but many providers continued their education and engaged in other forms of professional development. Subthemes for prospective provider roles included early detection, direct and practical support, and appropriate and timely referrals. In this manuscript, we sought to provide insight into the knowledge and work experiences of the healthcare and service providers who work closely with PLWH and are in ideal positions to educate and intervene.

In the third and final paper, we looked to balance the deficits-based focus of the first and second manuscripts with a strengths-based approach. Specifically, we conducted a qualitative

CBPR study to interview 16 middle-aged and older MSMLWH on the facilitators and challenges to building their resilience to the clinical and social impacts of living with HIV/AIDS. Robust social networks and social support from family, both blood relatives and chosen family, were strong facilitators to building resilience. Key challenges included the lack of a central hub for HIV care in Southern Nevada and continued HIV stigma. As with the first two manuscripts, this paper also used a social determinants of health perspective to examine health disparities faced by PLWH in Southern Nevada. While this manuscript does have a strengths-based focus, the inequities experienced by marginalized populations must be examined and addressed as they are important factors that impact the overall well-being of middle-aged and older MSMLWH.

Positionality Statement

Conducting interviews is an intimate and personal process, so it was important to me to feel comfortable making connections with our participants. I knew, prior to beginning this research, that many of our participants would be gay men and, as a gay man myself, I felt comfortable making that connection. On the other hand, Southern Nevada is a very diverse place, and our participants in manuscripts one and three were middle-aged and older, so I knew that as a young, White Hispanic man, some participants might view me as “other”. As a CBPR scholar working in collaboration with our Community Health Advocacy for Minority Populations, Immigrants and Other Newcomers, and their Mental Health research lab team, I am particularly aware of the power differentials that participants may feel coming into an interview with me on the other end. I maintained my best efforts to keep the interview environment neutral but still warm, open, and inviting. A few participants mentioned my young age, but generally in a positive light. For example, at the end of one particularly memorable interview, a participant mentioned to me how happy they were to see a young person taking interest in the health of older PLWH. This was a powerful moment for me that solidified the importance of this work, and a reminder of how my privileged position serves as an opportunity to do meaningful work.

Chapter 2:

Awareness and Knowledge of HIV-Associated Neurocognitive Disorder Among Middle-Aged and Older People Living with HIV/AIDS in Southern Nevada: Implications for HIV/AIDS Community-Based Education Programs

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Abstract

Although a significant amount of clinical and biomedical research has been conducted to study the condition known as HIV-Associated Neurocognitive Disorder (HAND), there has only been scant research done to assess the awareness and knowledge of this public health concern among middle-aged and older people living with HIV/AIDS (PLWH), particularly as community-based service users. HAND is a condition that may affect as much as 50% of PLWH and is characterized by challenges affecting their attention, learning, memory, language, sensorimotor skills, and executive functioning, all of which could impact their quality of life. Our qualitative community-based participatory research study sought to address this research gap by examining the awareness and knowledge of HAND among relevant stakeholders in Southern Nevada, USA. We conducted 15 semi-structured interviews with middle-aged and older PLWH to examine their awareness and knowledge of HAND, and their access to pertinent local resources. After conducting a thematic analysis of our interviews, we identified two overarching themes: (1) limited awareness and knowledge of HAND among PLWH, and (2) Southern Nevada social determinants of health. Our findings revealed there was considerable room for improvement in the levels of awareness and knowledge of HAND among our participants. These findings underscored the importance of raising awareness and knowledge of HAND among PLWH through community-based education programs so that they could better anticipate the possible impacts of HAND on their daily lives and learn how to address these impacts utilizing community-level resources. Although participants reported having ample resources available to them, they also conveyed the difficulties they experienced accessing these resources, which were spread across the sprawling Southern Nevada region. In this article, we discussed the subthemes and implications of our findings, as well as our recommendations for enhancing existing community-based education programs, access to needed resources, and related future research.

Keywords: awareness and knowledge; education programs; HIV-Associated Neurocognitive Disorder; people living with HIV/AIDS; Southern Nevada

Introduction

Research has documented that the life expectancy of people living with HIV/AIDS (PLWH) has markedly increased due to significant advances in medical treatment since the 1990s, particularly among those who have been diagnosed early and who have ready access to current antiretroviral therapy (Trickey et al., 2023). As HIV/AIDS has become a chronic, manageable condition since the advent of antiretroviral therapy, researchers and scientists have gradually uncovered and recognized the effects and health risks of living with HIV/AIDS and being on long-term antiretroviral therapy (e.g., metabolic complications, cardiovascular disease, obesity, liver toxicity) (Cahill & Valadez, 2013). Studies have shown that PLWH on many years of antiretroviral therapy have experienced widespread cognitive impairment with prevalence rates ranging from 21% to 86% (Wei et al., 2020). As much as 50% of PLWH can be expected to experience neurocognitive challenges at some point in their lifetime due to the condition known as HIV-Associated Neurocognitive Disorder (HAND), even with regular intake of prescribed medications (Heaton et al. 2011).

HAND is a spectrum of neurocognitive challenges that PLWH may experience in the domains of attention, learning, memory, language, sensorimotor abilities, and executive functioning (Simioni et al., 2010). Research has shown that even the mild to moderate forms of HAND could adversely impact the instrumental activities of daily living, adherence to medications, and overall quality of life of aging PLWH (Alford et al., 2021; Wei et al., 2020). Since the life expectancy of PLWH and the prevalence rates of HAND have remained consistent in the last two decades (Simioni et al., 2010; Trickey et al., 2023; Wei et al., 2020), HIV/AIDS sector clinics, community health centers, healthcare and service providers, and community-based not-for-profit agencies could expect that PLWH would need to access timely and appropriate care and support in order to control and manage the effects of HAND as they age. However, as in the case of many other chronic illnesses, sufficient awareness and knowledge of

HAND among PLWH is necessary to attain the benefits of the early detection of the signs and symptoms of HAND (Alford et al., 2021; Vastag et al., 2022).

Prior to the development of medical advancements in antiretroviral therapy and the greater availability of new medications across the globe, studies on the neurocognitive challenges of PLWH that generated awareness and new knowledge in the 1990s predominantly focused on HIV-Associated Dementia (Glass et al., 1993; White et al., 1997; Power & Johnson 1995). However, since the turn of the century, most modern research has paid more attention to the entire spectrum of HAND, with less research focusing solely on HIV-Associated Dementia at the severe end of the spectrum (Gouse et al., 2017; Rosca et al., 2021). Although a significant amount of clinical and biomedical research has been conducted to study HAND (Buckley et al., 2021; Cysique & Rourke, 2021; Johnson & Nath, 2022; Rosenthal & Tyor, 2019; Zenebe et al., 2022); to date, there have been scant studies that have examined the awareness and knowledge of HAND among PLWH (Gbordzoe, 2023; Ranuschio et al., 2022), particularly among middle-aged and older adults with HIV/AIDS who are at greater risk for developing neurocognitive challenges (Kellett-Wright et al., 2021; Vastag et al., 2022).

It would be critical to address this research gap and ascertain the levels of awareness and knowledge of HAND among PLWH so that a greater understanding of how much awareness and knowledge of HAND still needs to be raised and achieved, especially in communities that are potentially at-risk. Such an understanding would be useful and beneficial in the development, establishment, or improvement of community-based education programs that could prospectively help PLWH and their HIV sector healthcare and service providers anticipate and prepare for the impacts of HAND in the future. In order to address this research gap, we conducted a qualitative Community-Based Participatory Research (CBPR) study in 2022. The research aims of our collaborative study were to (1) examine the awareness and knowledge of HAND among middle-aged and older PLWH in Southern Nevada, and (2) explore our participants' perspectives and lived experiences related to their access to relevant resources in the region.

Materials and Methods

Partnership and Collaboration

Our qualitative CBPR study was conducted as part of a larger mixed-methods collaborative project with the LGBTQIA+ Community Center of Southern Nevada (The Center) dedicated to examining the awareness and knowledge of HAND among HIV/AIDS sector service users and providers. Serving as our primary community partner, The Center connected our research team with numerous Southern Nevada community-based agencies, AIDS service organizations, health clinics, and community health centers, for the purpose of obtaining greater meaningful stakeholder involvement. In the tradition of a genuine CBPR approach, our network of community partners and collaborators actively participated in many phases of our research project from the very beginning. They collaborated with us in determining our research focus, creating a community advisory committee, choosing our most appropriate research method, recruiting our study participants, developing suitable strategies to improve our participant recruitment, assessing and interpreting our findings from our data analysis, and disseminating our study findings and lessons learned to the rest of the Southern Nevada community. Through our established connections, not only were we able to recruit middle-aged and older PLWH in Southern Nevada to participate in our study interviews despite the challenges that we encountered during the peak of the COVID-19 pandemic, but we were also able to collaborate on the planning and conduct of the various crucial steps of our research process, which included the establishment of our research aims and questions, examination and ratification of our interview findings, and implementation of our knowledge mobilization plans and efforts (i.e., delivery of conference and community summit presentations, creation of a community report, and writing of manuscripts for peer-review and publication).

Participants

We received the approval for our research protocol from the Institutional Review Board (IRB) of the University of Nevada, Las Vegas, prior to the conduct of our study (IRB protocol # 1657448-4). We recruited participants for our study interviews from the participant pool of middle-aged and older PLWH who completed the survey we previously conducted as part of our larger mixed-methods collaborative project with The Center, particularly the participants who indicated their interest in being contacted for future studies. Our inclusion criteria required that our participants (1) be 45 years of age or older, (2) currently reside in Southern Nevada, and (3) had been living with HIV/AIDS for at least one year. We were able to recruit and interview 15 participants until we reached the point of data saturation.

Our participants' ages ranged from 45 to 69 years old, and the time they had been living with HIV/AIDS ranged from 13 to 36 years. All our participants reported that they were currently on antiretroviral therapy and were under the care of a regular healthcare provider. In terms of their race and ethnicity, 10 participants identified as White (66.67%), four as black (26.67%), and one as Hispanic (6.67%). Nine participants identified as male (60%), and six as female (40%), with one of the participants identifying as transgender (6.67%). Nine participants identified as straight (60%), five as gay (33.33%), and one as bisexual (6.67%). To protect their anonymity, we assigned each participant a pseudonym upon recruitment, and used the participants' respective pseudonyms to identify them in this article. All participants provided express consent at the beginning of their recorded interviews, and were each given a $50 gift card at the end of their interview as compensation for their efforts and time.

Procedure and Materials

We conducted our confidential, one-on-one, semi-structured interviews with our participants over Zoom between January and April of 2022. Our interviews each lasted roughly one hour. Together with our community partners, we customized our interview guide questions so that we could gain a better understanding of our participants' awareness and knowledge of

HAND, how they learned about HAND, and how they accessed resources in Southern Nevada related to their concerns about neurocognitive challenges. In addition to specifically gather their background and sociodemographic information, we designed our interview questions to critically explore our participants' personal experiences on signs and symptoms potentially attributable to HAND, their discussions and interactions with their healthcare and service providers in relation to the possibility of developing or having developed HAND, their general knowledge of HAND, and where they obtained their knowledge. Our interview guide included general questions to encourage interview participants to open up about their day-to-day life experiences such as, "Could you please tell me about your experiences with any difficulties related to your memory, attention, learning, communication, decision-making, or problem-solving?" It also included more probing questions that helped us learn more about their awareness of HAND (e.g., "How long has it been since you have been aware of the existence of HAND as a condition that affects PLWH?"), or any strategies and community resources that they were familiar with that may help them address their neurocognitive challenges (e.g., "What kind of strategies do you use, if any, to overcome these difficulties?"). We purposefully left our questions open-ended to give our participants opportunities to elaborate and freely discuss their life experiences and possible neurocognitive challenges. We digitally recorded our interviews with each of our participants' consent, and later, de-identified and transcribed our interview data for analysis.

Analysis of Data

We analyzed our de-identified transcripts using the thematic analysis steps described by Braun and Clarke (2006). The first author and two senior members of our research team thoroughly reviewed our first seven transcripts to intimately familiarize themselves with the interview data, identified codes that emerged from the seven transcripts, and subsequently identified themes and subthemes from the same data set as separate initial coders. Afterwards, they gathered together and compared their themes, subthemes, and codes. They collaboratively defined, named, and agreed on the overarching themes and subthemes from the data set based on their separate analyses and collective deliberations. They then used these themes and subthemes to create a working coding manual, which our entire research team later used as a guide to analyze our remaining eight de-identified transcripts, and finalize our themes and subthemes.

Results

At the completion of the thematic analysis of our 15 interview transcripts, we identified two overarching themes, each with distinct sub-themes. Our two overarching themes included: (1) limited awareness and knowledge of HAND among PLWH, and (2) Southern Nevada social determinants of health. Below, we discuss each overarching theme along with their respective subthemes and representative quotes.

Limited Awareness and Knowledge of HAND Among PLWH

Under our first overarching theme, we identified two subthemes based on our participants' interview responses. These subthemes included: (1) acknowledging limited awareness and outdated knowledge, and (2) recognizing HAND signs and symptoms.

Acknowledging Limited Awareness and Outdated Knowledge

Many of our participants readily acknowledged that they were aware of the fact that HIV/AIDS could affect their neurocognitive functions, particularly because of their awareness of the condition known as HIV-Associated Dementia (HAD). At the time of their interviews, all of our participants had been living with HIV/AIDS for at least a decade, and at some point, while receiving care and shared information over the years, had heard of how HIV/AIDS can cause dementia in PLWH. For example, Andrew (59 years old, straight, White man living with HIV/AIDS for over 15 years) reported, “I knew HIV could significantly affect your memory and cause dementia but I didn't know about this [actual] condition, HIV-Associated Neurocognitive Disorder. I've never heard of it before.” Peter (48 years old, gay, White man living with HIV/AIDS for over 25 years) similarly expressed his familiarity with HAD and even shared that he had some working knowledge of it based on what he's seen and heard from the community:

> I've been positive nearly 30 years. When I was first diagnosed, there was a lot of HIV-associated loss of memory [leading to dementia], loss of sight, um, and, Kaposi's sarcoma. So, there was a lot of different things that I was exposed to or expecting that I would experience because, at that time, treatments weren't necessarily what they are today. There's a lot less dementia now.

Although most of our participants had some awareness of or familiarity with the possibility that HIV/AIDS could affect the brain health of PLWH, the only information that most of them could acknowledge they knew for certain was that PLWH could develop dementia because of HIV/AIDS, especially if PLWH were not regularly on prescribed medication. Our participants revealed that this was outdated knowledge that they gained much earlier during the first three decades of the HIV/AIDS pandemic.

Recognizing HAND Signs and Symptoms

During the course of their interviews, many participants began to recognize that over the years they could potentially have been experiencing signs and symptoms that could have been due to HAND. Since they were largely unaware that the neurocognitive deficits that could result from HAND could be milder, subtler, and more insidious than the well-known, more obvious, and alarming manifestations of dementia due to HIV/AIDS, they routinely attributed their day-to-day neurocognitive challenges to other causes that seemed more plausible to them. When they experienced memory loss or difficulties with concentration, many participants attributed these symptoms to natural aging. Peter emphasized that he consistently kept his medical appointments, took his medications, and followed all of his doctor's instructions. This was why it did not occur to him that his symptoms could potentially be related to HIV/AIDS. He explained:

> The first thing that automatically comes to mind is that I am just getting older, you know. I am pushing 50 now…I have actually never really thought that any

> of these changes could be a result of HIV. I see the doctor every six months, I monitor my CD4 count and viral load, and everything looks good. So, I have never really thought that HIV could even be the reason for my symptoms.

Aside from aging, other participants attributed their neurocognitive challenges to different medical conditions or their significant history of problematic substance use. Jessica (45 years old, bisexual, White woman living with HIV/AIDS for over 15 years) candidly shared her experiences, which she always believed were the cause of her neurocognitive challenges, “Because I used to do drugs, it’s lingered in my system over the years. So, everybody always just associated my difficulties concentrating with my drug use. Nobody ever looked into it and said maybe it’s my HIV.”

Additionally, most participants did not recognize that other neurologic challenges they experienced could also be attributable to HAND, and that HAND did not always manifest as cognitive issues. For the longest time, Larry (68 years old, gay, White man living with HIV/AIDS for over 25 years) not only always blamed his difficulties multitasking on possible prescribed drug interactions, but he also ascribed his gait disturbances and poor coordination to medication side effects, “It’s with small things, like starting the car. Just a simple thing, turning the key, and stepping on the gas at the same time, but it’s getting harder to do for some reason. I thought it must’ve been my meds.” In his interview, Larry was surprised to learn that changes in sensorimotor abilities could also result from HAND.

Other participants also experienced changes in their sensorimotor abilities that they believed impacted their activities of daily living and quality of life but never thought were a result from living long-term with HIV/AIDS. Completing chores and other daily tasks at times became a problem, putting additional strain on PLWH who already have issues managing their doctor’s appointments and availing of community resources. Gary (52 years old, straight, Hispanic man living with HIV/AIDS for over 15 years) discussed his difficulty running groceries into the house due to his slowed movements:

> Even just going to the market. I am bringing things up from the car. If I do a big shop, I have to literally spread it over two to three days because there is no way that I could move fast enough and take everything up with me in one go.

Andrew felt that his quality of life had been severely impacted over the years because he needed to adjust his hobbies to something more manageable as his symptoms started to restrict his regular activities. He revealed, “I’d still like to ride a bike, or you know, play some touch football…Those are things I used to be able to do, but my neuropathy has gotten worse. I didn’t think that something could still be done about it.”

Southern Nevada Social Determinants of Health

Under our second overarching theme, we identified three subthemes, all of which were known social determinants of health within the Southern Nevada context. These subthemes included: (1) access to health services, (2) housing stability and food security, and (3) education.

Access to Health Services

When our participants described the different ways they actively sought out information, care, and services related to their management of their HIV/AIDS, they also discussed important aspects related to their access to such information, care, and services. Although many participants were happy to acknowledge the variety of crucial sources of HIV/AIDS information, care, and services offered in our community, they were also quick to point out the issues related to accessing essential information, care, and services in the sprawling region of Southern Nevada, where public transportation was available but not as frequent or convenient as many hoped it would be. Originally coming from a city with fast and cost-effective means of public transportation, David (61 years old, gay, White man living with HIV/AIDS for over 30 years), noted the lack of consolidated community resources and the significant physical distances between clinics, community health centers, community-based not-for-profit agencies, and AIDS service organizations, “Barriers to access to health services I’ve noticed here are the limited public transportation options and not having everything under one roof. Where I'm originally from, they had the HIV doctor, pharmacy, psychologist, and case worker in one place."

Helen (61 years old, straight, Black woman living with HIV/AIDS for over 30 years) also expressed some frustration as she found it too challenging to successfully access resources, running into too much bureaucratic red tape and having to provide the same information and requirements repeatedly to different agencies:

> It's hard for clients here to get transportation. People got to jump through too many hoops just to get around…I did get a bus pass last month, but this month it's hard. Also, it would be good if all these clinics and agencies could have just one system where they can share our information so that we don't have to do the same paper work and provide the same documents over and over again.

Housing Stability and Food Security

For several participants, addressing their neurocognitive challenges could not be their priority as it was much more important for them to establish housing stability and food security. Often, they needed the support of Southern Nevada community-based not-for-profit agencies for housing assistance and the help of food banks. Like many middle-aged and older PLWH struggling to make ends meet, Kimberly (59 years old, straight, trans, Black woman living with HIV/AIDS for over 35 years) availed of multiple services and programs across the region, "During COVID, they closed down [an AIDS service organization] and it was where I would get help with my housing…and my food. I couldn't worry about memory problems, much less anything else but food and a roof over my head." Bianca (58 years old, straight, White woman living with HIV/AIDS for over 15 years) echoed Kimberly's sentiments, "I've experienced difficulty concentrating a lot of times. But that's something I can't worry about because my priority is to get supplies from the food banks."

According to Kimberly, she had been able to survive through her most difficult times with the help of the different food banks across the greater Las Vegas area and other charities in

Southern Nevada. Her housing situation had been a bit less stable up until recently when she was able to get into emergency and bridge housing programs. For all our participants with housing and food insecurity, neurocognitive challenges only made their struggles even more difficult.

Education

When it came to community-based education programs and other learning opportunities, participants reported that most of the programs and opportunities that became available to them in the community focused primarily on HIV/AIDS prevention, particularly on strategies and interventions to prevent HIV/AIDS spread and transmission. The information provided in these programs were predominantly presented by experts and representatives from pharmaceutical companies who discussed the latest therapeutic options for not only treatment, but also for post-exposure and pre-exposure prophylaxis. Their presentations often came in the form of seminars or lunch and learns, and in annual summits, which were principally geared towards supporting the continuing education requirements of HIV/AIDS sector providers and informing communities about their respective drug companies' latest medications. Although there were presentations about risks and other concerns they may have as older PLWH, these presentations were fewer and far between, so they needed to be more self-sufficient in terms of gaining more information. In the case of learning more about neurocognitive challenges related to HIV/AIDS, many participants shared the various ways they engaged with different sources of information on HIV/AIDS to try and educate themselves. Many participants explained how they did their own research to remain in the loop. Nick (62 years old, gay, White man living with HIV/AIDS for over 35 years) shared in his interview that he first learned about HAND from an online magazine for PLWH and gathered more information about it by researching further online:

> Basically, just by keeping up on the reading. I think it was an article in POZ magazine or some other online source. I just kind of followed it up with some

> research articles that I get through [an AIDS service organization], where we keep up with what's developing and what's being learned in clinical practice.

When it came to building their knowledge, most participants revealed that they did their own research online, and then made an effort to discuss what they learned on their own with a healthcare or service provider to corroborate and further understand the information they learned from their own research. By discussing the information they gathered on their own with an HIV/AIDS sector provider, they gained more details and felt more confident about their understanding of the information they personally retrieved. It was their way of educating themselves using the resources at their disposal. Mike (52 years old, gay, White man living with HIV/AIDS for over 20 years) elaborated:

> Usually, I find out that my understanding of what I have read is either correct or at least somewhat on the mark. Not all of my understanding of the information is 100% accurate all the time. So, it's good to have a professional validate the information I researched or explain it to me further, you know.

Mike described how busy healthcare and service providers are, and how he finds it important to be able to fill in the gaps with his own research, especially when appointments are not long enough to get all the details he wants to know. Mike continued:

> Providers don't usually have the time to go into great lengths with explanations about new information. Although, my provider makes an effort to educate me and elaborate a lot on something I've researched, I usually have to take the initiative to bring with me some basic information for us to discuss.

A handful of our participants revealed that they only began to do some of their own research on HAND when they first heard about it during the recruitment stage of our study. As a qualitative CBPR study, an important goal we had in addition to our primary research aims was to concurrently raise awareness of HAND among relevant stakeholders in our region, and promote relevant knowledge and ongoing education. It was gratifying to find out that we actually stimulated interest on HAND among middle-aged and older PLWH in Southern Nevada. Helen shared that many PLWH in the community are actively participating in studies and becoming more knowledgeable through their engagement with research, “Yes, I learned about HAND when I did the survey about it last time. I’ve actually done a lot of studies and I enjoy learning new stuff each time.”

Discussion

Over half of our participants reported in their interviews that they were specifically aware of HAND as a condition that could affect the brain health of PLWH. This was because many of our participants also happened to be HIV/AIDS sector providers in Southern Nevada who had already learned about the term HAND in prior professional development presentations they have attended in the past. Also, knowing the focus of our study beforehand, several of our other participants purposely looked up and researched about HAND online in preparation for their participation in our interviews. For those who had not heard of HAND prior to their participation in our interviews, many appreciated learning from the study that milder forms of neurocognitive challenges can develop from living long-term with HIV/AIDS and that there are ways to address these challenges that would mitigate the challenges’ adverse impacts on their quality of life. Based on these findings, it would be prudent to surmise that there is still considerable room for improvement in the levels of awareness and knowledge of HAND among our participants, and potentially, the rest of the HIV/AIDS sector community in Southern Nevada.

Most, if not all, of our participants have not only been living with HIV/AIDS for over a decade, but many of them have also been long-term residents of Southern Nevada and actively availing of the region’s HIV/AIDS sector services for many years. When asked about their experiences with neurocognitive challenges over the years, many of them were quick to reply that they found it difficult to address these challenges as they needed to prioritize navigating certain aspects of their life first in order to survive. These aspects included their access to health services, housing stability and food security, and education on HIV/AIDS, all of which are known social determinants of health as described by the World Health Organization (WHO, n.d.).

Social determinants of health are non-medical factors in society that influence health outcomes, and are the conditions in which people are born, grow, work, live, and age, as well as the wider set of forces and systems shaping the conditions of daily life (WHO, n.d.). In the Southern Nevada context in which our participants live and age, the major implication of this second set of important findings is that, in order for our participants (and likely other middle-aged and older PLWH inhabiting our region) to have greater capacity to prioritize and address their potential risks or actual experiences of neurocognitive challenges, they must first procure access to health services, housing stability and food security, and education on HIV/AIDS.

In particular, education on HIV/AIDS has a key role to play in reducing HIV/AIDS-related vulnerabilities and risks (such as developing HAND), and in mitigating the impact of HIV/AIDS on affected individuals and communities (Aggleton et al., 2011). For healthcare and service providers in the HIV/AIDS sector, community-based education programs usually come in the form of professional development and continuing education activities such as lunch and learns, seminars, and conferences (Agate et al., 2003; Feng et al., 2020; Sowell et al., 2013), which are often less structured for PLWH and service users, especially for older adults. Research has shown that there is a paucity of available education materials and comprehensive education programs targeting PLWH 50 years of age and older, despite the fact that adults of this age range have been documented not only to be sexually active, but also lacking in knowledge about HIV/AIDS, in need of more HIV/AIDS education, and willing to participate in education programs tailored to their needs (Atschuler et al., 2004; Small, 2009). As our participants pointed out, most of the community-based education programs earmarked for their age bracket predominantly focus on promoting strategies to prevent HIV/AIDS spread and transmission, a finding that has also been previously documented by other research (Milaszewski et al., 2012). This implies that there is also room for improvement in terms of infusing a greater diversity of topics and concerns in community-based education programs targeting PLWH aged 50 and older so that they could gain more knowledge in addition to HIV/AIDS prevention information.

Aggleton et al. (2011) suggested that education on HIV/AIDS should include in its priorities analyzing more carefully different forms of HIV/AIDS-related education and considering how these different forms could be useful to specific audiences. Research has shown that there might also be a need for alternate approaches to delivering HIV/AIDS-related education to older adults living with HIV/AIDS (Small, 2009), and that different theoretical frameworks could be used to develop a typology of prospective approaches (Miedema et al., 2011). Based on the findings of our study, we provide recommendations below that could potentially be useful to enhancing community-based education programs specifically for middle-aged and older PLWH that could raise their awareness and improve their knowledge of HIV/AIDS-related neurocognitive challenges, among other topics and concerns that are relevant to them.

Recommendations for Community-Based Education Programs for Older PLWH

One of the first recommendations that comes to mind is the provision of information relevant to middle-aged and older PLWH through already existing channels and avenues that routinely reach them. For example, many clinics, community health centers, community-based not-for-profit agencies, and AIDS service organizations that have been providing care and services to middle-aged and older PLWH for years already have their patients, clients, and service users included in their email listservs, group chat apps, and social media networks, which are often used for making announcements and promoting events. Similarly, many of these health units and agencies have various types of support groups (e.g., counselling, therapy, spiritual, wellness, recovery) that middle-aged and older PLWH belong to and regularly attend. By taking advantage of these email listservs, group chat apps, social media networks, and support groups to provide new information relevant to middle-aged and older PLWH, such existing channels and avenues can be utilized more directly instead of just being used to make announcements and promote events. These channels and avenues could provide one-page

PDFs on information about HAND, such as what it is, how to recognize it, how to get support to address it, and different hyperlinks people could click on to gain more valuable details.

Another recommendation that could be potentially useful is for clinics, community health centers, community-based not-for-profit agencies, and AIDS service organizations to encourage more open dialogue with their middle-aged and older patients, clients, and service users. Rather than wait for them to bring up topics and concerns they have researched online during their medical consults and follow ups or service visits, health units and agencies could provide middle-aged and older PLWH separate opportunities to ask questions and bring up concerns through options such as a dedicated email address that can function as a community "suggestion box", or a monthly open forum where patients, clients, and service users can meet and learn from experts not only on the latest drug treatments or prophylactic options but also on topics such as their neurocognitive health. The open forum can be moderated by providers who work as peer navigators or advocates, or by middle-aged and older PLWH who have no health unit or agency affiliation. Stakeholders in these open forums could decide together the monthly topics they will cover ahead of time, which can include not only clinical or medical topics but also practical aspects such as new housing assistance options or other services that may influence and improve relevant stakeholders' social determinants of health.

A third but equally important recommendation is, no matter what channels, avenues, or opportunities are utilized to create improvements in current or future community-based education programs, it would be critical to remember to install in these improvements different ways to showcase the inherent knowledge and skills that middle-aged and older PLWH have accumulated over the years from their lived experiences. This recommendation could come in the form of ensuring leadership and other capacity-building opportunities for middle-aged and older PLWH in these improvements, not only to stimulate greater stakeholder engagement but also to sustain their meaningful involvement in the community-based education programs.

Conclusion

Based on the data we gathered from our study interviews, most of the community-based education programs our participants have encountered focused primarily on promoting strategies and means to prevent HIV/AIDS spread and transmission, especially those related to pre-exposure and post-exposure prophylactic antiretroviral medications. In order to raise awareness and increase knowledge of HAND among middle-aged and older PLWH, community-based education programs must adapt to include more diverse topics and concerns relevant to this target subpopulation. Case in point, our participants would welcome more topics that focused on the promotion of brain health of PLWH, as well as strategies and accessible resources that would help them anticipate and address neurocognitive challenges.

Additionally, several participants reported that they learned about HAND by doing personal research online or by taking the initiative and asking their healthcare and service providers about the possibility of developing neurocognitive challenges. This means that education programs must also consider utilizing different approaches that could maximize existing channels and avenues (i.e., social media, listservs, support groups) that middle-aged and older PLWH are already immersed in to initiate and sustain conversations and information-sharing on HIV-associated neurocognitive challenges, and highlighting the inherent knowledge and skills PLWH have gained from their lived experiences. Future research could prospectively examine the recommendations we provided in this article in terms of their appropriateness, acceptability, and feasibility based on the input of relevant stakeholders from other communities.

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Chapter 3: From PLWH to HIV Sector Providers

In the first paper, where we focused on the input of middle-aged and older PLWH, we found that while our participants had some awareness of HAND, there was still considerable room for improvement regarding their knowledge of the neurocognitive impacts of living with HIV/AIDS and how to address these impacts. We also found that issues related to social determinants of health, such as access to health services, housing, food security, and education, were critical challenges that PLWH had to prioritize in order to get their basic needs met before they can begin to focus on the neurolocognitive risks associated with living with HIV/AIDS. Based on these findings, we included recommendations on how to take advantage of existing systems to increase knowledge and awareness of HAND among PLWH. There are plenty of opportunities where PLWH interact in listservs and different forms of social media utilized by HIV-focused community-based organizations, as well as opportunities that could be maximized during direct interactions between PLWH and these organizations, particularly with their healthcare and service providers who work closely with PLWH to manage their chronic health conditions and other concerns. These opportunities provide a prime avenue for promoting knowledge and awareness of HAND to PLWH and their HIV sector providers. In the study discussed in the following paper, we chose to continue our qualitative CBPR by focusing on the input of HIV sector healthcare and service providers in Southern Nevada to assess their knowledge, perspectives, and work experience related to HAND. By switching focus to healthcare and service providers, we aimed to expand the scope of our research on HAND awareness to other relevant stakeholders. It stood to reason that providers (with their likely greater access to current information) would be more knowledgeable about HAND, and would be in auspicious positions to share their knowledge during their frequent interactions with PLWH in their work.

Chapter 4:

A Focus on Aging, HIV/AIDS, and Neurocognitive Challenges: Examining Southern Nevada HIV Sector Providers' Awareness and Prospective Roles

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Abstract

Although abundant research has been done to investigate the underlying mechanisms that may cause neurocognitive challenges among middle-age and older people living with HIV/AIDS (PLWH), monitor the prevalence rates of HIV-related neurocognitive deficits, and identify factors related to the improvement of diagnostic screening tools, classification and nosology, and clinical and rehabilitative treatment of HIV-Associated Neurocognitive Disorder (HAND); to date, there have been only few studies that have explored and examined the awareness and work experiences HIV sector healthcare and service providers have related to HAND. To address this research gap, we conducted a qualitative, community-based participatory research study and interviewed 12 HIV sector providers in Southern Nevada, USA, from January to April 2022. After performing a thematic analysis of our interviews, we were able to identify two major themes and several sub-themes. Under our first major theme, provider awareness and knowledge, we identified four sub-themes: (1) prior knowledge and current awareness; (2) lived experiences of patients and clients with neurocognitive challenges; (3) lack of knowledge as a barrier to providing needed care; and (4) continuing education and professional development. Under our second major theme, prospective provider roles, we identified three sub-themes: (1) early detection; (2) direct and practical support; and (3) appropriate and timely referrals. In this article, we discuss our findings and lessons learned from our study, as well as their implications for the future work of researchers and providers in the HIV sector related to improving care and support for people aging with HIV/AIDS experiencing neurocognitive challenges.

Keywords: aging; healthcare and service providers; HIV/AIDS; HIV-Associated Neurocognitive Disorder; neurocognitive challenges; older people living with HIV/AIDS

Introduction

As healthcare and service providers in the HIV sector across the globe have strived to improve the care and support they provide for people living with HIV/AIDS (PLWH) (Gandhi et al., 2023; Mutchler et al., 2011), great strides have been made in the treatment of HIV/AIDS since the beginning of the pandemic in the 1980s (Gandhi et al., 2023; WebMD Editorial Contributors). The introduction of combination antiretroviral therapy (cART) during the mid-1990s has had a profound effect on the advancement of different treatment options. Novel and effective viral suppression strategies using cART have been developed in recent decades, which have dramatically reduced the risk of PLWH developing AIDS-related conditions, decreased their HIV-associated mortality, improved their survival rates, and greatly increased their life expectancy (Alford et al., 2021; Buckley et al., 2021; Liboro et al., 2019; Liboro et al., 2018; Wei et al., 2020). Despite such treatment advancements with the use of cART, PLWH have markedly continued to experience neurocognitive challenges as they age (Wei et al., 2020; Robertson et al., 2007). In particular, HIV-Associated Neurocognitive Disorder (HAND) among PLWH, especially among middle-aged and older adults, has persisted as a public health concern in both developed and developing countries (Alford et al., 2021; Liboro et al., 2019; Liboro et al., 2018; Wei et al., 2020; Gouse et al., 2021).

HAND refers to a spectrum of neurocognitive challenges that may be experienced by PLWH in the realms of attention, executive functioning, language, learning, memory, motor skills, and sensory perception (Clifford & Ances, 2013; Grant, 2008; Vastag et al., 2022). Even with the effectiveness of current HIV treatments, the prevalence of HAND has remained high with rates that range from 45% to 64%, based on different studies investigating distinct settings (Buckley et al., 2021; Wei et al., 2020; Grant, 2008; Simioni et al., 2010). Neurocognitive challenges could be present even among PLWH with well-controlled viremia (Gouse et al., 2021), as milder forms of HAND have become even more prevalent in recent years (Vastag et al., 2022; Rosenthal & Tyor, 2019). Mild to moderate forms of neurocognitive challenges have been reported to significantly impact the adherence to medications, instrumental activities of daily living, and overall quality of life of PLWH (Alford et al., 2021; Wei et al., 2020; Heaton et al., 2004; Zenebe et al., 2022).

The exact mechanisms that lead to the development of HAND are still under research (Irollo et al., 2021). Since HAND is a heterogenous condition, PLWH experiencing a cluster of neurocognitive challenges may have very different disease processes as they age (Johnson & Nath, 2022). Research has suggested that the pathogenesis of HAND in the era of cART is multifactorial with possible contributions from central nervous system damage that occurs before the initiation of cART, chronic immune activation, cART neurotoxicity, neurodegenerative diseases, premature aging, and age-related comorbidities such cardiovascular and cerebrovascular diseases, diabetes, and hyperlipidemia (Rosenthal & Tyor, 2019). Complex interactions associated with aging, HIV/AIDS, and neurocognitive challenges have been investigated and it appears that PLWH develop age-related brain health issues sooner compared to their HIV-negative counterparts despite achieving effective viral suppression with cART (Buckley et al., 2021; Rosenthal & Tyor, 2019).

With life expectancy and estimated prevalence rates of neurocognitive challenges among PLWH remaining consistent in the 21st century (Buckley et al., 2021; Wei et al., 2020; Grant, 2008; Simioni et al., 2010), it would be reasonable to anticipate that PLWH will need to access healthcare, social services, and support programs from the HIV sector that will help them address the impacts and consequences of HAND on their day-to-day lives as they grow older (Liboro et al., 2018). The management of HAND will be increasingly important for PLWH and the healthcare and service providers who support them with meeting their needs and promoting their wellbeing (Gouse et al., 2021).

Current best clinical practices recommend that healthcare providers working with PLWH should include routine screening for HAND and appropriate referrals to diagnosticians and HIV specialists in their growing list of responsibilities (Gouse et al., 2021; Vastag et al., 2022). This recommendation has been based on the premise that early detection of HAND is important to facilitate the adequate treatment and management of HAND (Gouse et al., 2021). Earlier studies have documented that clinicians using global deficit scores have been able to accurately classify neurocognitive impairments among PLWH (Carey et al., 2004), and that there has been high interrater reliability among neuropsychologists independently rating the presence and severity of neuropsychological impairment of HIV-positive patients (Woods et al., 2004). More recent studies have reported that healthcare providers in occupational treatment settings have started to receive training and resources to conduct neurocognitive screening among PLWH, and in the not-so-distant future, could prospectively be able to perform this screening without prejudicing patients and clients in the workplace (Gouse et al., 2021). It remains to be seen if healthcare providers in settings other than occupational health, and service providers with little to no clinical background, would subsequently receive such training and resources to conduct neurocognitive screening. Related to this, it is not clear at this time how familiar or knowledgeable most healthcare and service providers are of HAND and the persistent public health concern that is associated with it (Liboro et al., 2019; Liboro et al., 2018; Gouse et al., 2021).

Although abundant research has been conducted to investigate the underlying mechanisms that lead to the neurocognitive challenges of PLWH (Buckley et al., 2021; Rosenthal & Tyor, 2019; Johnson & Nath, 2022; Cysique & Rourke, 2020); monitor the prevalence rates of HIV-related neurocognitive deficits (Vastag et al., 2022; Zenebe et al., 2022; Cysique & Rourke, 2020; Mastrorosa et al., 2023; Wang et al., 2020); and identify factors related to the improvement of diagnostic screening tools (Vastag et al., 2022; Rosenthal & Tyor, 2019; Cysique & Rourke, 2020; Rosca et al., 2019; Rosca et al., 2021), classification and nosology (Wei et al., 2020; Matchanova et al., 2020; Meyer, 2022), and clinical and rehabilitative treatment of HAND (Alford et al., 2021; Cysique & Rourke, 2020); to date, there have been only few studies that have explored and examined the awareness and work experiences healthcare and service providers working with PLWH have related to HAND (Liboro et al., 2019; Liboro et al., 2018; Gouse et al., 2021). For instance, a recent study that was conducted by Gouse and colleagues revealed that 80% of HIV sector providers in South Africa have heard of HAND before participating in their study, but only 11% have screened for it in their work, and only 2% have received appropriate training to address it (Gouse et al., 2021). The study reported that lack of expertise on HAND was the largest obstacle providers experienced to confidently address it, and that 77% of providers thought it would be important to screen for HAND, which suggested that they found value in gaining knowledge about HAND but have not had the opportunity to learn more about it (Gouse et al., 2021). In a qualitative study that was conducted in Southwestern and Central Ontario, Canada, research findings revealed that service providers in the HIV sector faced numerous personal and professional barriers (e.g., limited knowledge about HAND), service access barriers (e.g., limited access to needed services with adequate expertise and experience working with PLWH), and systemic barriers (e.g., lack of funding in the HIV sector) while addressing HAND in their work (Liboro et al., 2018). These barriers prompted service providers to develop and employ intrapersonal strategies (e.g., staying informed about HAND using online sources), interpersonal strategies (e.g., providing practical assistance for the memory-impaired), and organizational strategies (e.g., creating dedicated support groups) to help their clients who experienced neurocognitive impairment (Liboro et al., 2019). Further research on this focus still needs to be done to learn more about the awareness and the potential roles healthcare and service providers could assume to support PLWH experiencing neurocognitive challenges that could be attributable to HAND.

While it might be plausible to assume that primary care providers (i.e., doctors, nurse practitioners, physician assistants) with a clinical practice focused on HIV/AIDS, psychiatrists, healthcare providers in occupational treatment settings, neuropsychologists, and HIV specialists and researchers would have a strong grasp of the underpinnings of HAND as a relevant condition that may significantly impact the lives of aging PLWH, it would be imprudent to surmise the awareness and work experiences other healthcare and service providers working with PLWH (specifically those in community-based settings) might have related to HAND without conducting systematic, empirical research.

Based on this premise, we conducted a qualitative study in 2022 within the context of Las Vegas, Nevada, USA, in order to gain a greater understanding of the awareness of community-based HIV sector providers on HIV-related neurocognitive challenges in our local setting. It is important to note that in 2020, there were 10,459 PLWH in Las Vegas, and that our city had an HIV prevalence rate of 655 per 100,000 people (AIDSVu, 2022). In the same year, the number of new HIV diagnoses in Las Vegas was 312, and 83% of all people diagnosed with HIV were documented to have linkage to care, which meant that they had visited an HIV healthcare provider within one month of being diagnosed with HIV (AIDSVu, 2022).

The primary research aims of our qualitative study described in this article were to (1) examine HIV sector community-based healthcare and service providers' awareness of HAND, and (2) explore what providers are or may be able to do in their work to support PLWH experiencing neurocognitive challenges, particularly in the context of the HIV sector in Las Vegas and the surrounding region of Southern Nevada, USA.

Materials and Methods

Partnerships and Collaborations

In close collaboration with our primary community partner, The LGBTQIA+ Community Center of Southern Nevada (The Center), we conducted the present qualitative study as part of a larger sequential mixed-methods (Creswell et al., 2018) project utilizing a community-based participatory research (CBPR) approach (Coughlin et al., 2016; Rhodes et al., 2010; Wallerstein & Duran, 2006) that principally sought to examine awareness of HAND among relevant stakeholders (i.e., PLWH and community-based healthcare and service providers) from

Southern Nevada, and explore their perspectives and lived or work experiences related to addressing neurocognitive challenges. For our focus on healthcare and service providers dedicated to serving PLWH, the Center was instrumental in linking us with a wide network of clinics, community health centers, community-based not-for-profit agencies, AIDS service organizations, and other relevant stakeholder groups from Southern Nevada, which were all dedicated to providing health and social services specifically to aging PLWH in our region. Our community partners actively participated in many phases of our project. They collaborated with us in determining our research focus, choosing our research method, recruiting our study participants, assessing and interpreting our findings from our data analysis, and disseminating our study findings and lessons learned with the rest of the Southern Nevada community. For this article, we discuss only our study findings and lessons learned based on the perspectives and work experiences of HIV sector providers from Southern Nevada. Our study findings and lessons learned based on the perspectives and lived experiences of middle-aged and older PLWH from Southern Nevada are beyond the scope of this article, and has been discussed elsewhere in another research article.

Participants

Before we began conducting our study, we sought and received ethics approval for our research protocol from the Institutional Review Board (IRB) of the University of Nevada, Las Vegas. In order to recruit participants, we utilized printed flyers that we posted on the premises of our community partner organizations, agencies, and clinics, and recruitment messages that we made available through our community partners' different email websites and listservs. We actively participated in numerous community events that our community partners organized and sponsored, which allowed us to directly hand out recruitment pamphlets and flyers to prospective participants during these events. Together with our community collaborators, we implemented a purposive sampling technique (Palys, 2008) to recruit our participants. Interested stakeholders were able to participate in our interviews if they met our inclusion criteria, which required them to be (1) 18 years of age or older at the time of the study, and (2) working as a community-based healthcare or service provider in the HIV sector of Southern Nevada for at least 6 months. We purposively selected providers interested in participating in our interviews who were not primary care providers (i.e., doctors, nurse practitioners, physician assistants) with a clinical practice focused on HIV/AIDS, psychiatrists, healthcare providers in occupational treatment settings, neuropsychologists, and HIV specialists and researchers since these providers were much more likely to stay current on academic literature on HAND as a consequence of the expectations of their professions or jobs. We continued to recruit and interview participants until data saturation for key themes was achieved (i.e., no new information relevant to the key themes emerged as additional interviews were conducted).

All of the 12 providers who participated in our interviews had direct and regular contact with middle-aged and older PLWH who have experienced neurocognitive challenges at some point in their lifetime since their HIV diagnosis. Our participants were counselors, community health workers, outreach workers, patient advocates, linkage to care coordinators, and case managers in the HIV sector of Southern Nevada. Their ages ranged from 33 to 64 years old, with a mean age of 47 and a standard deviation of 10.19. Half of our participants (n = 6) identified as female, and the other half (n = 6) identified as male. Half of our participants (n = 6) identified as straight, and the other half (n = 6) identified as gay. All of our participants identified as cisgender, and none of our participants identified as lesbian, bisexual, queer, transgender, or nonbinary in our sociodemographic questionnaire, which also provided them space and an opportunity to self-identify in the way they were most comfortable with or preferred. In terms of race, our participants identified as Black (50%, n = 6), White (40%, n = 5), and Asian-Pacific Islander (10%, n = 1). In terms of ethnicity, three of our participants (25%) identified as Hispanic, while the rest identified as non-Hispanic. At the start of their interview, we assigned each participant a pseudonym, and subsequently used their respective pseudonym to identify them in this article. Each participant received a $50 gift card at the end of their interview as compensation for their efforts and the time they spent on the study.

Procedures and Material

We conducted our confidential semi-structured interviews with our 12 participants virtually over Zoom between January and April 2022, with each interview taking approximately one hour to complete. We developed and set our interview questions so that they would be open-ended to allow participants to elaborate more freely with their responses. Our interview guide questions were focused on topics that we identified as important based on the survey findings of the recent quantitative study we conducted in Southern Nevada as part of our larger mixed-methods CBPR project that examined HIV sector providers' awareness of HAND (Creswell et al., 2018; Ranuschio et al., 2022). These questions were ratified by our community partners, and included topics such as work encounters with patients and clients, providers' awareness of HAND, barriers to gaining knowledge on HAND or providing care to PLWH, and community resources to help address issues related to neurocognitive challenges experienced by PLWH (Creswell et al., 2018; Ranuschio et al., 2022). Our interview guide included general questions to encourage interview participants to open up about their day-to-day work experiences such as, "Could you please tell me about your practice/work as a healthcare or service provider in the HIV sector of Southern Nevada?". It also included more probing questions that helped us learn more about their awareness of HAND (e.g., "How long has it been since you have been aware of the existence of HAND as a condition that affects PLWH?"), or any strategies or community resources that they were familiar with that may help support PLWH experiencing neurocognitive challenges (e.g., "What kind of strategies do you use, if any, to support your patients/clients living with HIV experiencing neurocognitive challenges?"). (Please see Table 1 for Interview Guide Questions)

In order to obtain constructive input from our community partners, we shared our survey results with them prior to creating a community report for distribution to the larger Southern

Nevada community, and then we asked for their input. Not only did our community partners find our survey results noteworthy, but they also deemed it imperative for our research partnership to further explore the possible foundations and implications of our quantitative findings through one-on-one interviews with our survey participants who expressed interest in joining the qualitative stage of our CBPR project. Our research team's research project coordinator conducted and digitally recorded our virtual interviews after receiving each of our participant's express consent. We anticipated and addressed possible interview bias by having our interview guide questions reviewed and ratified by our community partners from the HIV sector prior to the conduct of our interviews. The interviews were then de-identified and transcribed by our research project coordinator and three other members of our research team using a structured transcription protocol. Transcriptions of the interviews that were transcribed by other members of our research team were meticulously cross-checked by our research project coordinator for accuracy prior to analysis.

Table 4.1: Interview Guide Questions

Could you please tell me about your practice/work as a healthcare or service provider in the HIV sector of Southern Nevada?
Have you ever encountered any clients/patients living with HIV/AIDS in your work who may be experiencing changes in their neurocognitive functions or having brain health issues that may be related to HAND? Please elaborate.
Why do you think some of your clients/patients have been experiencing these challenges or brain health issues?
How long has it been since you have been aware of the existence of HAND as a condition that affects PLWH?
Do you believe there are effective ways you and other providers could help address brain health issues related to HIV/AIDS or HAND? Please elaborate.
How have you discussed brain health challenges related to HIV/AIDS with your clients/patients?
What kind of strategies do you use, if any, to support your patients/clients living with HIV experiencing neurocognitive challenges?
Could you please tell me about your practice/work as a healthcare or service provider in the HIV sector of Southern Nevada?

Analysis of Data

We analyzed our de-identified transcripts using the thematic analysis phases that have been established and recommended by Braun and Clarke (Braun & Clarke, 2006). Due to its inherent flexibility, we chose Braun and Clarke’s thematic analysis as our guiding framework to analyze our interview data. We deemed it as the best approach to fulfill our study’s goals because its epistemological and theoretical freedom allowed for a flexible examination of the different perspectives we derived from our participants (Braun & Clarke, 2006). Braun and Clarke's thematic analysis method is an iterative process that consists of six phases: (1) becoming familiar with the data, (2) generating codes, (3) generating themes, (4) reviewing themes, (5) defining and naming themes, and (6) locating exemplars for writing up (Braun & Clarke, 2006). To execute the first phase of our analysis, we used the first half of our data set of 12 interviews to establish an initial thematic codebook. Reviewing the first six transcripts of our study’s data set provided the more seasoned coders of our research team a considerable opportunity to familiarize themselves with our interview data. After perusing the first six participant interviews twice to become intimately familiar with the raw data, our research project coordinator and two of this article’s senior authors held face-to-face meetings as preliminary coders to discuss and agree on the possible major themes and sub-themes to include in the initial codebook. Our preliminary coders discussed in length which among our initial themes stood out as major themes that could serve as central organizing concepts for our codebook, and which initial themes could be subsumed under these major themes as sub-themes with distinct elements that had a natural fit under one of the major theme’s central organizing concept. Upon reaching a consensus based on the review and initial coding of the first six interviews, our preliminary coders shared the contents of the initial codebook with the remaining members of our research team, who subsequently assisted in coding the remaining six interview transcripts to execute the second to fifth phases of our thematic analysis (Braun & Clarke, 2006). For the final phase of our analysis, members of our research team reviewed the remaining six interview transcripts as separate coders using the initial codebook as a guide, and then gathered together in regular, bi-weekly meetings to discuss their identified codes, and finalize the themes and sub-themes from the interviews. Our research team uncovered 42 codes from our analysis, and we used an average of five to seven codes that eventually led to the generation of each of our themes and sub-themes.

Results

We identified two major themes from our interview data. The two major themes we identified were: (1) provider awareness and knowledge, and (2) prospective provider roles. For each of these major themes, we were also able to identify a number of sub-themes, which we describe in detail below.

Provider Awareness and Knowledge

It was evident in our interviews that all our participants recognized the importance of being aware that their patients or clients living with HIV/AIDS could potentially be or already have been experiencing neurocognitive signs and symptoms due to HAND. As they discussed the importance of being aware of the existence of HAND as a condition that could considerably affect the day-to-day functioning and quality of life of the PLWH they were working with in their jobs, several sub-themes became apparent in our analysis of our interview data. Under the first major theme, provider awareness and knowledge, we identified four sub-themes: (1) prior knowledge and current awareness; (2) lived experiences of patients and clients with neurocognitive challenges; (3) lack of knowledge as a barrier to providing needed care; and (4) continuing education and professional development. In the next sub-sections, we discuss these sub-themes and provide representative quotes to help elucidate them.

Prior Knowledge and Current Awareness

Most of our participants had some prior working knowledge of brain health as it relates to HIV/AIDS. The vast majority of our participants had already heard of PLWH developing HIV-associated dementia (HAD), which was very common knowledge among providers who had been working in the HIV sector for several years. Since nearly all of our participants (save for two) had already been working as HIV sector providers for four years or more, most of them had also already encountered at least one patient or client of theirs who had suffered from HAD. This prior knowledge on the existence of HAD as a condition that could affect PLWH made them aware that it was possible for any of their aging patients or clients to have neurocognitive challenges related to HIV/AIDS. Marianne (a straight, White female who had been working in the HIV sector for over five years) explained that she had a working knowledge of HAD based on her work experiences:

> "Well, I know there's such a thing as HIV dementia. I've had a number of older clients who I know would fall into that category [based on what I've learned in the past from reading about it]. You know, most of them are without a diagnosis, so it's very difficult to say for sure. I have a number of clients who appear to have issues related to memory, and just cognition, in general."

Although having prior knowledge of HAD had made most of them aware of the possibility that some of their patients and clients could develop or already had neurocognitive challenges, it was evident based on our interviews that many of our participants were not particularly aware that dementia was only at the severe end of the spectrum of neurocognitive challenges older PLWH could experience, and that for the most part, the more common manifestations of HAND among PLWH were mild to moderate since the advent of cART. Interestingly, some participants revealed that they had subsequently made efforts to learn more about HIV-related neurocognitive challenges by building on the knowledge they had about dementia that developed among PLWH.

A few of our participants readily acknowledged that their participation in the survey we conducted for the quantitative stage of our larger mixed-method CBPR project improved their awareness and knowledge of HAND. Bob (a gay, Black male who had been working in the HIV sector for over 10 years) shared, “Ever since the [HIV/AIDS] epidemic began, there had always been discussion of ‘HIV-related dementia’, is what I believe they called it. However, the specific designation ‘HAND’…it’s the first time I am actually learning of it in this study.”

Lived Experiences of Patients and Clients with Neurocognitive Challenges

Aside from gaining more awareness of different HIV-related neurocognitive challenges from building on the prior knowledge they had learned related to HAD, a majority of our participants were able to recall specific times they encountered in their work PLWH who presented signs and symptoms that could have been attributable to HAND. While it takes more than one or two symptoms to even suspect that PLWH may have HAND, it was notable in the interviews that our participants were already attending to the neurocognitive decline of some of their patients and clients aging with HIV/AIDS. The lived experiences of their patients and clients experiencing neurocognitive challenges became an important catalyst for raising their awareness and knowledge of HAND. Franc (a gay, Asian-Pacific Islander male who had been working in the HIV sector for over one year) described the deterioration of some of his clients’ abilities to maintain their attention during their appointments:

> “I’ll literally be working with someone, and I had to help them understand that, yes, they got their HIV care, but I’m like, oh my goodness, they’re not even paying attention to their care provider anymore. Their brain and their focus were literally withering away. I was re-explaining to them, ‘You’re going to a doctor for your HIV care, but they’re not your neurologist or psychiatrist.’ They were having difficulty paying attention and understanding that they needed to see another healthcare provider for their brain health issues.”

Beyond observing attention deficits, our participants also noticed memory-related challenges among some of their patients and clients such as difficulties in making and keeping appointments or recalling recommended solutions to personal issues, in addition to their general forgetfulness. Marianne recalled a couple of her clients calling multiple times a day to repeatedly ask about the same concerns that they've already began to resolve:

> "I have two clients right now that called me five times already today. So, they have definite memory issues and are just struggling to put the pieces together. We have one client who has a problematic situation, and they're contacting different case managers across the city. I realize that they forget that they've already sought help and received it. What ends up happening, stuff gets complicated because they keep, you know, going in circles asking more and more people for help, and we don't know that they've already asked for help from other people. So, I give them advice to resolve their situation, not knowing somebody else is giving them a different piece of advice, and then they get confused and think that people are trying to trick them."

Having worked for a very long time supporting PLWH, Steve (a, gay, White male who had been working in the HIV sector for over 20 years) reported that he was able to note who among his long-term clients began to display obvious signs of forgetfulness, "Among my clients, I could see the differences between those who had been taking their medications regularly and who had not. Some who had not been able to adhere to their treatment regimen eventually showed signs of early memory loss."

Neurocognitive challenges can lead to significant difficulties navigating the HIV care continuum PLWH rely on a regular basis to manage their health issues and related options. Accessing a community organization's services often requires a load of paperwork, which can be complicated as is, and then can be exacerbated by a patient's or client's neurocognitive challenges. Patrice (a straight, Black female who had been working in the HIV sector for over 10 years) shared how she supported a client with overcoming their issues related to the neurocognitive challenges they experienced by helping them access important resources:

> “I had to basically walk them through in detail the paperwork and different steps needed so that they could access their social security benefits. I was able to experience that on a one-on-one basis, and I think they had like an education level of 3rd grade to begin with. Over time, I was able to see their cognitive function decline as they kept going on without getting medication.”

Lack of Knowledge as a Barrier to Providing Needed Care

The vast majority of the providers we interviewed expressed in some way that a lack of knowledge on HAND poses as a major barrier to accessing or providing care. This lack of knowledge can exist among both patients or clients and their providers. Both patients or clients and their providers need to have some awareness and knowledge of HAND in order to notice or look for the signs and symptoms of HAND. Gail (a straight, Black female who had been working in the HIV sector for over five years) commented, “The biggest barrier is our lack of knowledge. If you don’t know [HAND] exists…you don’t know who to refer them to for their problems, and it's hard to give them the help they need.” Gail continued to explain:

> “I think, the biggest thing is just getting the information out there. That this is a problem that PLWH are facing, and could later be facing. I think a lot of the clients that I meet [minimize it and] attribute their challenges to age, and have made flippant comments like, ‘Oh, at this age, I have to write everything down’… not knowing that it could be an effect of living with HIV for so long.”

According to the participants, the main challenge to raising awareness and spreading knowledge is having a consistent source of reliable information. Participants noted that if HAND is not brought up or discussed in meetings, trainings, or seminars, then providers and the PLWH they work with would not even learn of its existence. Gail pointed out that providers’ knowledge could easily translate into knowledge useful to their patients or clients because of their regular provider and patient or client interaction:

> "If they're not aware, not educated, and if it's not talked about, this can lead to their deteriorating health mentally and physically. It's basically a lot of lack of knowledge, and it's not discussed, you know. We need more provider education so that we could offer more education to clients."

Our participants believed that raising awareness and sustaining knowledge are the first steps to enhancing early detection of and improving care for neurocognitive challenges. Victor (a gay, Black male who had been working in the HIV sector for over three years) remarked that knowledge on the neurocognitive challenges that may develop or may already be present among people aging with HIV/AIDS should ideally be shared to frontline providers like them who are not necessarily specialists in HIV care but are responsible for supporting PLWH who may have substantial issues related to neurocognitive challenges. Based on Victor's remarks, although HIV specialists and researchers who are entrenched in academic literature are likely already well-aware of HAND, other providers who may engage with or provide services to middle-aged and older PLWH on a more regular basis should also be cognizant of the fact that their patients and clients could develop or already have HIV-related neurocognitive challenges. This is so that they could stay alert and keep an eye on the cognitive health of their patients and clients aging with HIV/AIDS. According to Victor:

> "[Even] a primary care doctor [who does not specialize in HIV/AIDS] may not even recognize that certain symptoms are related to their patient's HIV/AIDS because they haven't necessarily been educated [about HAND]. 'Cause I don't think there's a lot of people out there that know that part. So, it's the education of professionals and providers more than, you know, the people that are in the HIV community."

Continuing Education and Professional Development

In addition to bringing up the topic of their patients' and clients' brain health and neurocognitive challenges during meetings as necessary, and discussing them intermittently in once- or twice-a-year trainings or seminars, many participants believed that their need for current and updated information on HAND should be considered as an indication that they should have a more regular forum for continuing education and professional development activities on the relationships involving aging, HIV/AIDS, and neurocognitive challenges. In terms of information on HAND that is pertinent to providers, a few participants who had previous knowledge of it learned about it from routine continuing education opportunities. Marianne had some baseline knowledge of HAND, and explained that she first heard of it in seminars she attended on a regular basis:

> "Well, um, in the job that I do, I am constantly training. There's constant training and continuing education. So, I've attended hundreds of seminars, and that's often brought up this topic. I think all providers should have regular training so they are able to help their clients better."

Likewise, Patrice revealed that she gained her knowledge on HAND from taking part in regular training opportunities, "Over the years, I've attended trainings with the health department and Pacific AIDS Educations Training Center, where I learned about HIV-related neurocognitive challenges and HAND. I believe it's important for providers to stay current with all kinds of information." Even participants who had limited knowledge of HAND expressed their desire to attend future trainings and seminars that would cover the neurocognitive challenges related to HIV/AIDS. They recognized the importance of improving their understanding of HAND, and revealed that most of the information related to HIV/AIDS being taught in continuing education and professional development opportunities they were able to attend tended to focus on medications to manage the virus and updates on cART. Gail elaborated:

> "A lot of the ongoing information that we received is about, you know, new medications or new forms of treatment delivery, which we get from the actual drug companies themselves. They would send representatives to talk about their drugs. Getting some sort of resource on brain health would be really beneficial

> for us. Not only how to watch out for symptoms or perhaps even how to identify HAND, but also how to best address its impacts and what practical resources are out there for our clients to utilize."

Having an acute awareness of the signs and symptoms to watch out for in their patients and clients, knowledge on what is already definitely known and documented by researchers and scientists about HAND, and vital information on the kind of strategies and resources that their aging patients and clients experiencing neurocognitive challenges could utilize were some of the things that our participants wanted to gain more from attending continuing education and professional development opportunities.

Prospective Provider Roles

The second main theme that we identified from our interview data revolved around prospective provider roles that our participants and their colleagues could potentially play in the future, particularly in addressing the neurocognitive challenges of their patients and clients, as well as the adverse impacts of those challenges on their patients' and clients' medication adherence, activities of daily living, and overall quality of life. Based on their perspectives and work experiences, our participants had several ideas on how they could be very helpful in terms of supporting PLWH experiencing neurocognitive challenges, which we categorized into three sub-themes. Under this second major theme, prospective provider roles, we identified three sub-themes: (1) early detection; (2) direct and practical support; and (3) appropriate and timely referrals. In the next sub-sections, we discuss these sub-themes and provide representative quotes to help elucidate them.

Early Detection

Most participants readily pointed out the fact that although screening for and diagnosing HAND were not part of their job descriptions, list of responsibilities, and skills set, they believed they could still play crucial roles in addressing the neurocognitive challenges of their patients and clients. As many of them met with their patients and clients often and/or on a regular basis, our participants thought that they could potentially play an important role in the early detection of their patients' and clients' neurocognitive challenges. If they had enough awareness and knowledge from training and other professional development activities that would give them enough confidence to note or recognize any changes in the neurocognition of the aging PLWH they worked with, especially over time, then they would be able to initiate a plan that could possibly prevent their patients' and clients' challenges from getting worse, as well as address some of the impacts of the neurocognitive challenges on their patients' and clients' daily lives. Robyn (a straight, Black female who had been working in the HIV sector for over 10 years) remarked:

> "I'm not a medical doctor, so I always try to encourage clients to talk to their physicians or see a health specialist within our community, especially when I notice something odd or different with the clients. The challenge at times, is a client has to acknowledge that there's something going on. You know, some people, especially if they're estranged from their families or friends, and they're alone, it's challenging for them to admit that they may be losing their independence or may require [professional] help from someone. So sometimes, it's down to us to find creative ways to get them more help."

Marianne agreed with these sentiments, "I suspect that anybody having neurocognitive challenges may soon experience progressive deterioration. Since we see our clients on a regular basis, we could help with detecting subtle changes early on so that we could support them sooner rather than later."

Another idea that was expressed by our participants involved assuming the role of patient advocate in light of the importance of the early detection of neurocognitive challenges. Although many providers may not be able to physically accompany patients and clients to seek help as they are already overwhelmed with numerous responsibilities, there are some providers who have it in their job description to personally advocate for the needs of the most vulnerable

PLWH who seek their help. Janice (a straight, White female who had been working in the HIV sector for over one year) suggested:

> “For example, at a doctor’s appointment for someone [with neurocognitive challenges] newly diagnosed or maybe trying to get back in care, there could be a case manager, patient advocate, or some provider who can help with bringing the client to someone who screens for different cognitive disorders. That person could be there with them, at least until a care plan is set in place.”

Direct and Practical Support

In addition to the crucial role they could play in the early detection of their patients’ and clients’ neurocognitive challenges, our participants believed that they could be of great help in terms of supporting PLWH experiencing neurocognitive challenges by assisting them with managing the adverse impacts of the neurocognitive challenges on their patients’ and clients’ daily lives. Although they recognized that it is beyond their capacity to initiate therapies that would treat the actual neurocognitive challenges their patients and clients are experiencing, many of our participants were confident that they would be able to assist the PLWH they worked with through the programs and services that are offered by the clinics, community health centers, not-for-profit agencies, and AIDS service organizations they worked in Southern Nevada. Our providers acknowledged that they could share with their patients and clients access to a wide array of programs and services that would help address many of the adverse impacts of the neurocognitive challenges the PLWH were experiencing. The adverse impacts of the neurocognitive challenges that PLWH experience often involve creating more difficulties in accessing their most basic needs because the deficits PLWH do develop most often relate to attention, decision-making, language, learning, memory, and problem-solving. Our participants emphasized that these basic needs are critical to the survival of PLWH but are mostly covered by the programs and services of the agencies and organizations that they work for in the community. Gail recounted the different programs and services, which her agency had been able to offer to her clients:

> "A lot of it is food assistance, housing assistance, and emergency financial assistance for things like bills and utilities. Some are mental health programs or educational programs, things like lunch and learns, and group education events. With some patience and compassion from us, our programs and services could help our clients cope with concerns and problems they may have resulting from their brain health issues."

The variety of programs and services in their workplaces was perceived as something very positive by our participants, who shared their passion for their work in their interviews. For instance, our participants who were case managers revealed that they would take on not just their clients' HIV care, but also their various needs, aiding them by addressing other hardships that were linked to their neurocognitive challenges. Victor described the different hats that he wears at his job working through various workshops and housing programs, and providing education to clients:

> "I am in charge of health education, the risk reduction to our clients who are virally suppressed, as well as creating new and exciting workshops that combat negative emotions and provide psychosocial support. Through these different programs, we're able to help older folks with cognitive problems."

There was a notable joy and pride in the voices of our participants as they shared in their interviews how they believe their work made a difference to PLWH struggling with different neurocognitive challenges. Many of our participants revealed that they chose to work in their roles in healthcare and support services, specifically to help PLWH, because they find great value in the work they do. Patrice shared with us that her work in case management keeps the job active, fresh, and exciting, "That's why I love doing case management, and I stay in weekly meetings that list new resources. It includes housing, child care, clothing, jobs, social security, and more information from other case management providers."

Appropriate and Timely Referrals

Apart from potentially maximizing their role in providing direct and practical support for their patients and clients in the future, many of our participants also saw the crucial role they played and could continue to play in linking PLWH experiencing neurocognitive challenges to specific resources that their own clinics, organizations, and agencies may not offer, but are offered by partner clinics, organizations, and agencies in the community. Our participants reported that the HIV sector network of providers in Southern Nevada is strong, tightly knit, and well connected. So, another role they could play that would be critical to supporting PLWH experiencing neurocognitive challenges is helping assess patients' and clients' needs, and then providing them appropriate and timely referrals to other healthcare and service providers in their network. To support the varied needs of PLWH in Southern Nevada, providers reported that they have utilized their network of care that runs and relies heavily on referrals. Janice revealed that they have connected their clients to many healthcare practitioners across the region, "We have a long list of doctors we refer our clients to for all sorts of medical problems, including cognitive issues. We refer clients to family physicians, infectious disease specialists, neurologists, and psychiatrists." Our participants, several of whom are case managers and linkage to care coordinators whose jobs involve fostering connections between clients and community organizations or not-for-profit agencies, have recognized the breadth of support some older PLWH they have been working with need.

According to our participants, providers in Southern Nevada have established a referral network in which they can get their patients and clients connected to almost any program or service PLWH may need. Clinics, community health centers, community-based not-for-profit agencies, and AIDS service organizations have been interconnected in their network in such a way that each of their unique contributions to the Southern Nevada HIV continuum of care combine to create a nearly comprehensive whole. Victor explained that the organization he works for is explicitly a referral organization wherein they have established and maintained multiple options to refer clients to address any need that comes up, “We’re only a referral-based organization. We try to have a rolodex of as many providers and community partners as possible to help us. Perhaps the next step is to determine the hidden needs of PLWH with cognitive deficits.” These needs may involve aspects such as screening, patient intake, initiation of new cART treatments, and retention in care, in addition to the more practical supports that many providers offer in their places of work.

Discussion

As we examined HIV sector community-based healthcare and service providers’ awareness of HAND and explored what they are or may be able to do in their work to support PLWH experiencing neurocognitive challenges, we were able to obtain and analyze invaluable information based on our participants’ perspectives and work experiences. In terms of their awareness and knowledge of HIV-related neurocognitive challenges, providers seemed to mostly be aware of some of the brain health impacts of living with HIV/AIDS, but only few were actually very familiar with HAND. Their awareness was either based on their prior knowledge of the possibility that dementia could develop among PLWH with poor access and/or adherence to cART and poor viral suppression, or their work encounters with middle-aged and older patients and clients who exhibited neurocognitive deficits over time. Some participants revealed that they only became aware of HAND as an actual condition and public health concern when they participated in our study. Although there would likely be important differences in terms of cultural contexts and healthcare systems to consider, these findings are consistent with the results of previous research conducted by Gouse and colleagues that found healthcare providers in South Africa had already heard of HIV-related neurocognitive challenges or HAND, but lacked pertinent expertise in recognizing, addressing, and managing such challenges (Gouse et al., 2021).

In our study, many providers reported that they engaged in different forms of continuing education opportunities, such as seminars, lunch and learns, and trainings, but noted that these opportunities rarely, if ever, covered topics related to the brain health of people aging with HIV/AIDS, and instead focused more on HIV medications or the clinical impacts of living with HIV/AIDS. It is important to consider that our participants expressed strong interest in gaining more learning opportunities in the future, particularly about the neurocognitive challenges that PLWH may experience, and that there is a clear path to disseminating critical information about HAND through increased continuing education and professional development focused on the neurocognitive aspects of living with HIV/AIDS. On a related matter, it is vital to note that our collaborative team's decision to utilize a CBPR approach to not only investigate our research focus, but at the same time, engage and create opportunities to educate relevant stakeholders throughout our research process (e.g., by advertising our study to stimulate interest during our recruitment phase, discussing HAND in greater detail during our participant interviews, disseminating a community report on our findings and lessons learned to providers and at their places of work after our thematic analysis) was a significant step towards successfully raising awareness and knowledge of HAND in the Southern Nevada HIV sector. Our decision to utilize a CBPR approach for our study was based on the documented merits of using it in studies dedicated to addressing health disparities that impact marginalized communities and examining crucial issues related to the prevention, care, and treatment of middle-aged and older PLWH, such as organizational representation, partnership synergy, co-learning, community collaboration and empowerment, and checks on the dynamics of power and privilege (Coughlin et al., 2016; Rhodes et al., 2010; Wallerstein & Duran, 2006).

In their interviews, our participants recalled instances at work where they encountered patients and clients who exhibited HAND signs and symptoms. They described older PLWH they worked with who grew increasingly forgetful or progressively required more assistance handling paperwork due to their neurocognitive decline. These work experiences are consistent with findings of prior studies that have reported that PLWH experiencing neurocognitive challenges attributable to HAND struggle with their self-efficacy, become more dependent on others even with simple daily activities, and in particular, waver when navigating online and other health resources to meet their needs (Heaton et al., 2004; Morgan et al., 2019; Woods et al., 2016). Our participants emphasized that lack of awareness and knowledge of HAND was a considerable barrier to supporting patients and clients. These findings stressed the need to disseminate information on HAND to providers who can further spread this information to their patients and clients, while also increasing their preparedness to address neurocognitive signs and symptoms of PLWH. It was apparent that our participants were already attending to these concerns and needs without necessarily realizing that they were dealing with issues that developed from their patients' and clients' HIV-related neurocognitive challenges.

Based on our data, we were able to confirm that provider awareness is important for early detection of neurocognitive challenges that would allow PLWH to adopt valuable coping strategies and access relevant resources, as well as providers to improve their HIV care with memory and other cognition-related services (Bougea et al., 2019; Alford et al., 2019). Several studies have already documented the inherent value of the early detection of neurocognitive challenges of PLWH, which could then lead to the initiation or modification of patients' or clients' cART, and potentially, the prevention of their functional decline and preservation or optimization of their physical functions (Vastag et al., 2022; Belete et al., 2017; Ng et al., 2023; Tsegaw et al., 2017). For patients and clients experiencing neurocognitive challenges with lower levels of self-efficacy to advocate for themselves when interacting with providers (Morgan et al., 2019), or for those who struggle to navigate online and other health resources (Woods et al., 2016), provider awareness becomes a critical aspect of HIV care as it enhances providers' abilities to ask important questions or concerns that patients and clients aging with HIV/AIDS may not think of or remember to bring up. This is especially the case as we recognize that neurocognitive signs and symptoms need to be documented by or reported to a provider first before they could be addressed accordingly and managed in a treatment plan (Justice et al., 2001).

Healthcare and service providers in Southern Nevada have been providing a wide variety of programs and services in addition to basic HIV care in order to meet their patients' and clients' needs. Whether through their own programs and services or through their referrals to community partners, providers have connected PLWH to healthcare, food and housing assistance, transportation options, and job opportunities, to name a few. This finding is important because it not only underscores the fact that PLWH have a wide variety of needs that are created or exacerbated by their neurocognitive challenges, but it also underscores the point that providers are critical to keeping their patients and clients engaged in the HIV care continuum, as well as connecting them to programs and services that help ensure their food, housing, and transportation security, which have been documented as critical social determinants of health that influence health disparities (Ng et al., 2023; Centers for Disease Control and Prevention; World Health Organization). Our participants have been flexible and versatile with their job responsibilities and have remained highly aware of vital resources available in the local community so that they could go above and beyond their duties to support PLWH. Beyond facilitating access to diagnostic and treatment services, many of our participants from the HIV sector have provided indispensable resources to PLWH in the community. They have helped address the adverse impacts of the neurocognitive decline of PLWH on known social determinants of health such as food and housing security, which could not only present as obstacles in everyday life, but also jeopardize HIV treatment adherence (Muhammad et al., 2019; Logie et al., 2022; Surratt et al., 2015). They have also helped facilitate their patients' and clients' access to transportation options (e.g., through bus passes, complimentary ride shares), which are essential for aging PLWH to get to various health-related appointments and needed social services (Kiplagat et al., 2019; Schatz et al., 2021).

Providers are critical to sustaining the HIV care continuum. Their attitudes, connections with patients and clients, and established trust in communities engender effective engagement, treatment linkage, and retention (Dawson-Rose et al., 2016; Magnus et al., 2013; Tobias et al., 2007). Positive patient-provider relationships and the availability of case managers and linkage to care coordinators are essential to establishing comprehensive primary care for PLWH, further highlighting the importance of research examining provider perspectives and work experiences (O’Brien et al., 2018). Previous research has explored and addressed provider perspectives on HIV care (Edelman et al., 2014), but little work has been done to assess the awareness and knowledge of HAND among various providers in the 21st century (Liboro et al., 2019; Liboro et al., 2018; Gouse et al., 2021).

Our study findings demonstrated a few key points. Firstly, there is room for improvement in terms of increasing awareness and knowledge of HAND, and many providers are open and eager to gain opportunities to learn more. Second, providers do notice HAND signs and symptoms in their patients and clients living with HIV/AIDS, whether they feel confident about their knowledge of HAND or not. This is a finding that could be maximally utilized to its fullest potential through the promotion of appropriate HAND-focused continuing education and professional development opportunities. Third, providers take on more responsibilities than merely providing basic HIV care, often facilitating access for PLWH to resources in their place of work or through referrals to community partners. It is paramount to recognize the crucial roles providers could play in terms of the early detection of the neurocognitive challenges of PLWH and providing resources that could address the adverse impacts of these challenges on the lives of their patients and clients. Lastly, providers largely depend on a referral network that includes other providers, clinics, community health centers, agencies, and organizations to establish and sustain full and comprehensive care, programs, and services for people aging with HIV/AIDS experiencing neurocognitive challenges. Future research could investigate on new ways to bolster and enhance already established HIV sector networks and referral systems of care.

Strengths and Limitations of the Study

Our study adds novel findings and important lessons learned to the limited current body of knowledge and academic literature on HIV sector healthcare and service providers' awareness and knowledge of HAND, and additionally, contributes new insights on the prospective roles providers could play in the future to support aging PLWH experiencing neurocognitive challenges. However, it is important to acknowledge our study's limitations. Our use of a purposive sampling technique (Palys, 2008) to recruit specific HIV sector healthcare and service providers from the community has excluded the examination of the awareness and knowledge of HAND of other providers (i.e., primary care providers with a clinical practice focused on HIV/AIDS, psychiatrists, healthcare providers in occupational treatment settings, neuropsychologists, and HIV specialists and researchers), and consequently, restricted the findings and lessons learned we gained. Furthermore, a strong interest and eager willingness to participate in our research focused on HAND, perhaps to learn more about the neurocognitive challenges of PLWH, may have led or prompted keen providers from our community to join our study, which in turn, may have influenced the types of responses we obtained in our interviews. Researcher bias and subjectivity could also have affected our research team's qualitative thematic analysis. We utilized consensus coding among eight researchers to minimize this concern, but the perspectives of our research team are still those of university-based psychology scholars. Greater diversity among coders could prove useful in future related studies to avoid the possibility of overlooking themes that are typically not captured by the coding practices and mindset of many academic researchers.

Conclusion

In pursuit of its primary research aims, this CBPR study examined the awareness and knowledge of HAND among healthcare and service providers in the HIV sector of Southern Nevada, and additionally, explored their prospective roles in supporting aging people with HIV/AIDS experiencing neurocognitive challenges in the future. Our findings revealed that while providers demonstrated a general awareness of brain health impacts related to HIV/AIDS, specific knowledge of HAND could still be improved, and many providers are open and willing to learn more. Lack of awareness and knowledge of HAND was a key barrier to supporting PLWH with neurocognitive deficits. Our findings also revealed that continuing education opportunities to learn about HAND would improve providers' abilities to identify and meet the needs of PLWH exhibiting neurocognitive challenges attributable to HAND. Furthermore, our study highlighted the critical roles providers already play in connecting PLWH to the wide range of services beyond basic HIV care, such as housing assistance, access to nutritious food, transportation options, and job opportunities, which are necessary to providing the full range of care for PLWH experiencing neurocognitive challenges. Future studies on this research focus could potentially explore different ways providers could sustain reliable opportunities to increase their awareness and knowledge of HAND, as well as investigate other crucial roles providers could play to support PLWH experiencing neurocognitive challenges.

Overall, our study contributes important and valuable insights that fill specific knowledge gaps in current literature, and could help improve the capacity and skills set of HIV sector healthcare and service providers in Southern Nevada. Our findings call for continued efforts from researchers, scholars, and relevant communities to improve awareness and knowledge of HAND, promulgate the critical roles providers could play in supporting PLWH with neurocognitive challenges, and augment access to relevant resources for PLWH and their providers. By heeding this call, HIV sector healthcare and service providers could facilitate the early detection of neurocognitive challenges among people aging with HIV/AIDS; provide much needed programs, services, and appropriate referrals; and institute comprehensive care and support for their patients and clients experiencing neurocognitive challenges.

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Chapter 5: Shifting to a Strengths-Based Approach

In the second paper, we discussed the awareness of HIV sector providers related to HAND and their roles in providing crucial access to needed resources. In terms of their awareness, most providers had some knowledge regarding HIV-associated neurocognitive challenges, but it was evident that there was still room to improve their knowledge. Many providers discussed their efforts to pursue continuing education through personal research, trainings, and seminars. However, HAND seemed to be infrequently discussed as most learning opportunities they encountered mostly focused on other clinical impacts of HIV/AIDS or on the latest HIV medications. Overall, providers felt that with more knowledge on HAND, they would be better equipped to tackle the neurocognitive challenges of their patients and clients. We also discussed in the second paper the use of available programs and services in Southern Nevada, and noted that providers have been referring patients and clients to a wide range of services. This finding, combined with the findings in the first paper, where PLWH discussed their challenges obtaining transportation to and from the plethora of services they need, highlighted the necessity for consolidated services to help PLWH access their various needs in one place.

A strong commonality in manuscripts one and two is that they described more deficits-based research findings with shortcomings and challenges clearly in the spotlight. While it is important to explore the risks associated with living with HIV/AIDS, it is also critical to examine and discuss the inherent strengths of PLWH, especially when working with the ethno-racially diverse population of Southern Nevada. The third and final paper once again describes a study with a qualitative CBPR approach. But this time, the study examines the facilitators and challenges to building PLWH's inherent HIV/AIDS resilience to highlight a more strengths-based approach. We continue to use a social determinants of health perspective in this third paper as we recognize that we would be remiss to ignore the influential ecological context of our participants.

Chapter 6:

Promoting Resilience Among Middle-Aged and Older Men Who Have Sex with Men Living With HIV/AIDS in Southern Nevada: An Examination of Facilitators and Challenges from a Social Determinants of Health Perspective

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Abstract

Most prior research on resilience to HIV/AIDS among middle-aged and older men who have sex with men (MSM) has utilized quantitative methods that employ surveys and scales to measure constructs researchers have used to approximate the concept of resilience to HIV/AIDS. Only few studies have purposively made efforts to incorporate input of relevant stakeholders to guide their research on HIV/AIDS resilience and examine the perspectives and lived experiences of middle-aged and older MSM. To address this research gap, we conducted a community-based participatory research qualitative study to examine the perspectives and lived experiences of HIV-positive, middle-aged and older MSM from Southern Nevada in order to identify factors that promote such resilience. We conducted 16 semi-structured interviews with middle-aged and older MSM living with HIV/AIDS from January to April 2022. From our thematic analysis of our interviews, we identified factors that served as facilitators or challenges to the promotion of our participants' HIV/AIDS resilience. We discuss in this article both the facilitators and challenges to our participants' resilience-building as the key themes from our interviews. We recognized that the impacts of these factors were mediated by their strong influence on social determinants of health that were explicitly relevant to our participants. We offer important insights based on our findings, which could be especially useful to future research on resilience to HIV/AIDS.

Keywords: resilience to HIV/AIDS; middle-aged and older; men who have sex with men; social determinants of health; facilitators and challenges

Introduction

Resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands (American Psychological Association Psychology Topics, n.d.). It has been described in academic literature as a multi-system process between the self, others, and the surrounding community (Liu et al., 2017), and has been reported not only to be of great value to bolstering mental health, but also protective against the effects of trauma and stigma, often acting as a buffer against various types of stressors (Halkitis et al., 2017; Krause & Halkitis, 2022; Reyes et al., 2018). Resilience has been defined as a positive adaptation within the context of significant adversity (Luthar et al., 2000), and has been commonly referred to as the ability to recover from, withstand, or overcome significant stress or illness (Colpitts & Gahagan, 2016), including chronic forms of illness such as cancer, autoimmune diseases, and HIV/AIDS (Al & Aqudah, 2023; Cal & Santiago, 2013; Dulin et al., 2018; Harrison et al., 2019; Molina et al., 2014; Seiler & Jenewein, 2019).

In research exploring the value of resilience to HIV/AIDS, scholars have examined the essential role of resilience in meeting ongoing and evolving global HIV goals, drawing attention to personal conceptualizations of resilience among people living with HIV/AIDS (PLWH) and the delineation of factors that PLWH identify as critical to promoting their ability to cope with HIV-related challenges (Harrison et al., 2019). The scientific study of resilience among HIV/AIDS populations has continued to grow in the 21st century (Harrison et al., 2019; Fang et al., 2015; Lyons et al., 2012). Researchers focused on strengths-based approaches for developing interventions to address various issues related to HIV/AIDS have increasingly recognized the important role of resilience in the focus of their scholarly work (Green & Wheeler, 2019; Liboro, Yates, Fehr et al.).

Among the different groups affected by HIV/AIDS, ethno-racially diverse, middle-aged and older men who have sex with men (MSM) living with HIV/AIDS have been the specific subpopulation that has been impacted by HIV/AIDS the longest (Centers for Disease Control and Prevention, 2018; Liboro, Ranuschio et al., 2021), and likely the group that has exhibited resilience to HIV/AIDS the most since the beginning of the pandemic (Liboro, Yates, Bell et al., 2021). Evidence of resilience to HIV/AIDS among middle-aged and older MSM has been documented and discussed in research articles (Emlet et al., 2010; Emlet et al., 2017; Herrick et al., 2014), and consequently, resilience to HIV/AIDS has been reported to be key to the successful aging of MSM living with HIV/AIDS (Samuel, 2020). In their quantitative, descriptive, comparative, and cross-sectional study, Batista and Pereira reported HIV-positive older gay, bisexual, and other MSM to have higher than expected levels of resilience (Batista & Pereira, 2020). This is potentially because, along with other older PLWH, middle-aged and older MSM have been reported to be able to build their levels of resilience by positively adapting to different types of adversity (Xu et al., 2018). When utilizing a strengths-based approach in research involving older MSM living with HIV/AIDS and other PLWH, an emphasis on resilience not only helps ensure that the research process does not primarily focus on pathology, weaknesses, and risks, but also encourages research efforts to empower individuals by focusing their attention on controllable aspects of life (Orsulic-Jeras et al., 2003).

Recent studies have explored and discussed a variety of factors that have either prospectively served as facilitators to the promotion of resilience to HIV/AIDS among MSM living with HIV/AIDS, or as barriers and challenges to such resilience-building (Liboro, Yates, Bell et al., 2021; Barry et al., 2018; Harper et al., 2014; Liboro, Bell et al., 2021; Liboro, Despres et al., 2021). Examples of facilitators that have been explored include individual characteristics such as perseverance (Liboro, Bell et al., 2021; Liboro, Despres et al., 2021); external protective factors such as social support from family and friends, religion and spirituality, and education (Green & Wheeler, 2019; Liboro, Yates, Bell et al., 2021; Xu et al., 2018); and community-level resources such as lesbian, gay, bisexual, trans, queer, intersex, and asexual (LGBTQIA+) not-for-profit agencies and AIDS services organizations (Liboro, Yates, Fehr et al.; Flicker et al., 2009; Kwait et al., 2001; Paterson et al., 2014). Examples of challenges that have been examined in research include HIV stigma and discrimination (i.e., negative attitudes toward HIV/AIDS and negative treatment of PLWH that have been found to exacerbate social isolation and other co-occurring psychosocial health problems) (Liboro, Yates, Fehr et al.; Liboro, Yates, Bell et al., 2021; Samuel, 2020; Liboro, Bell et al., 2021; Liboro, Despres et al., 2021; Dean & Fenton, 2010); cultural and language barriers; and racism (Liboro, Bell et al., 2021). Other studies have discussed factors that may have served as facilitators or challenges to promoting resilience to HIV/AIDS among middle-aged and older MSM living with HIV/AIDS and other PLWH, and described how these factors may have exerted their influence through their impacts on various social determinants of health (Centers for Disease Control and Prevention, 2022; World Health Organization, n.d.).

A Social Determinants of Health Perspective

Social determinants of health are the non-medical factors in society that influence health outcomes, and are the conditions in which people are born, grow, work, live, and age, as well as the wider set of forces and systems shaping the conditions of daily life (Centers for Disease Control and Prevention, 2022; World Health Organization, n.d.). They have an important influence on health inequities, which are avoidable inequalities in health between groups of people within countries and between countries. Socioeconomic conditions and their impacts on people’s lives determine their risk of illness and the actions taken to prevent them from becoming ill or treat their illness when it occurs (Centers for Disease Control and Prevention, 2022). The World Health Organization (WHO, n.d.) enumerates and describes a list of social determinants of health, which can influence health equity in positive and negative ways. This list includes, but is not limited to: (1) education; (2) income and employment; (3) access to quality health services, (4) food security, (5) housing stability, and (6) social inclusion and non-discrimination. Social determinants of health present as an important framework and perspective scholars could consider when examining health disparities that affect the wellbeing of underserved populations and people at the margins, including middle-aged and older MSM living with HIV/AIDS. In this article, we examine the findings of our study through a social determinants of health perspective, particularly from the specific framework described by the WHO (World Health Organization, n.d.).

Research on Resilience to HIV/AIDS among Middle-Aged and Older MSM and Our Study

It is very important to note that most prior research that has been conducted to explicitly focus on and examine resilience to HIV/AIDS, specifically among middle-aged and older MSM, has utilized quantitative and statistical methods that employ surveys and scales to measure constructs that researchers themselves have identified, chosen, and used to approximate the concept of resilience to HIV/AIDS (Halkitis et al., 2017; Emlet et al., 2017; Batista & Pereira, 2020; Brown et al., 2022). To the best of our knowledge, in the past decade, only few scholars have purposively made efforts to not only include the direct input of relevant community stakeholders to define the concept of resilience to HIV/AIDS and guide their research, but also examine the perspectives and lived experiences of middle-aged and older MSM, so as to gain a more in-depth understanding of factors that impact their resilience to HIV/AIDS (Liboro, Yates, Fehr et al., 2021). Based on our literature search for studies that have both deliberately involved the input of relevant community stakeholders to explicitly define and describe their resilience to HIV/AIDS, as well as examined the perspectives and lived experiences of middle-aged and older MSM living with HIV/AIDS through in-depth, confidential interviews, we were only able to identify a few pertinent studies, all of which were conducted, and at this time, regionally defined within the context of the Greater Toronto Area, and Central and Southwestern regions of Ontario, Canada (Liboro, Yates, Bell et al., 2021; Liboro, Bell et al., 2021; Liboro, Despres et al., 2021). Most importantly, none of these studies have examined factors that promote resilience to HIV/AIDS from a social determinants of health perspective. To address these different research gaps, our community-based participatory research (CBPR) qualitative study, described in this article, examined factors that have impacted the promotion of resilience to HIV/AIDS among middle-aged and older MSM living with HIV/AIDS in Southern Nevada from a social determinants of health perspective (Centers for Disease Control and Prevention, 2022; World Health Organization, n.d.).

We conducted our CBPR qualitative study in Las Vegas and the greater area of Southern Nevada, which is a sprawling region that has many features and characteristics distinct from other large urban cities of North America (City of Las Vegas, n.d.; Howarth & McGillivray, n.d.; Lankevich, n.d.; O'Connor et al., n.d.; Dassopoulos et al., 2012; Ionescu, 2022; Stout, n.d.; Stout, 2021). For the purposes of our study, we operationalized the definition of resilience to HIV/AIDS in close consultation and collaboration with our community partners as the capacity of middle-aged and older MSM living with HIV/AIDS to: (1) survive the clinical and social impacts of living with HIV/AIDS, (2) live full lives despite having a chronic illness, (3) thrive despite challenges brought about by HIV-related discrimination, and/or (4) purposefully contribute to the goal of ending the HIV/AIDS pandemic.

Materials and Methods

Partnerships and Collaborations

We conducted the qualitative study discussed in this article as part of a larger, mixed-methods, CBPR project, in collaboration with our primary community partner, The LGBTQIA+ Community Center of Southern Nevada (The Center). The Center was instrumental in connecting us with a larger network of community-based agencies, AIDS service organizations, clinics and community health centers, and other relevant stakeholder groups from Southern Nevada, which were all dedicated to providing health and social services specifically to PLWH in our region, including middle-aged and older MSM living with HIV/AIDS. The Center also played an important role in creating a Community Advisory Board (CAB) composed of healthcare and service providers from other relevant Southern Nevada agencies such as the Golden Rainbow, Southern Nevada Health District, and Community Counseling Center of Southern Nevada who were involved in our project from the very beginning, collaborating with our research team on several research process stages such as finalizing our research focus, designing our research method, recruiting our study participants, evaluating and ratifying our findings from our data analysis, and disseminating our study findings and lessons learned to the rest of the Southern Nevada community. Our CAB members provided us with timely and valuable input and feedback during the research process, which helped our research team respond and adjust accordingly to both anticipated and unexpected issues such as matters related to participant recruitment and occasional miscommunication.

Participants

Prior to conducting our study, we obtained ethics approval for our research protocol from the Institutional Review Board (IRB) of the University of Nevada, Las Vegas (IRB protocol # 1657449-2). During our participant recruitment process, we utilized IRB-approved printed flyers that we posted on the premises of our community partner agencies and organizations, and recruitment messages that we made accessible through our community partners' various email listservs and websites. We became actively involved in several community events that our community partners sponsored and organized, which allowed us to personally and directly hand out IRB-approved recruitment flyers and pamphlets to prospective participants during these events. Working with numerous community partners, we recruited participants from Southern Nevada, all of whom participated in our semi-structured interviews. We continued to recruit and interview participants until data saturation for key themes was achieved (i.e., no new information relevant to the key themes emerged as additional interviews were conducted). In order to qualify, participants needed to (1) be 40 years of age or older, (2) have lived with HIV/AIDS for at least 1 year, (3) currently reside in Southern Nevada, and (4) be someone who self-identified as gay, bisexual, queer, or a man who has sex with men. Our inclusion criteria ensured that our participants (n =16) were middle-aged and older MSM living with HIV/AIDS from Southern Nevada, and had enough lived experience with HIV/AIDS to develop and form their own perspectives and insights. Our participants' ages ranged from 41 to 68 years old, with a mean age of 54. All 16 participants self-identified as gay and were regularly taking prescribed antiretroviral therapy medications at the time of their study participation. In terms of race, our participants identified as White (50%, n = 8), Black (37.5%, n = 6), Asian-Pacific Islander (6.25%, n = 1), and Middle Eastern (6.25%, n = 1). We assigned each of our participants a pseudonym when they joined our study, and we subsequently used their respective pseudonyms to identify them in this article (see Table 1 for all participant demographics). Each participant provided express written consent to join our study, and received a $50 gift card at the end of their participation as compensation for their time and efforts.

Table 6.1. Participant Demographics (n = 16)

Pseudonyms	Age	Identified as	Race	Years HIV+
Roy	41	Gay	White	7
Jay	41	Gay	Black	12
Gar	61	Gay	White	34
Peter	50	Gay	Middle Eastern	29
Kris	45	Gay	White	23
Robbie	68	Gay	Black	11
Hugh	56	Gay	Black	22
Mark	58	Gay	White	23
Joseph	61	Gay	White	38
Charles	52	Gay	Black	32
Burt	56	Gay	Black	20
David	61	Gay	White	28
Jack	46	Gay	Asian	23
Jimmy	64	Gay	White	42
Bart	54	Gay	White	26
Tim	50	Gay	Black	27

Procedures and Materials

Adhering to our IRB-approved research protocol, we conducted our confidential, one-on-one, semi-structured interviews remotely over Zoom between January and April of 2022, and on average, our interviews lasted from 40 to 60 minutes. Our interviews addressed questions that were deemed important both by the findings of the recent quantitative study we conducted as part of the larger, mixed-methods CBPR project we based in Southern Nevada (Bell et al., 2022), and by our community partners. Based on the preliminary results of the quantitative study we conducted in Southern Nevada, we were able to document that (1) knowledge on HIV/AIDS and (2) family support were significant predictors of resilience to HIV/AIDS (Bell et al., 2022). Our previous study analyzed online survey responses that assessed for individuals' level of resilience to HIV/AIDS, previous knowledge on HIV/AIDS, and family support. Our preliminary results demonstrated a negative correlation between knowledge on HIV/AIDS and resilience to HIV/AIDS, in which higher scores from correctly answering questions regarding HIV/AIDS (e.g., Can one become HIV infected by donating blood?) were related to lower levels of resilience to HIV/AIDS ($r(33) = -.36$, $p = .034$). Contrastingly, we found a positive correlation between family support and resilience to HIV/AIDS, in which higher levels of support received from family were related to higher levels of resilience to HIV/AIDS ($r(33) = .37$, $p = .026$). In order to obtain valuable input from our community partners, we shared these results with them prior to creating a community report for dissemination to the larger community, and solicited their feedback. Not only did our community partners find our survey results interesting, but they also deemed it important for our research partnership to further explore the possible rationales and implications of our quantitative findings through one-on-one interviews with our participants who expressed interest in joining the qualitative stage of our CBPR project during the time they participated in our survey.

Together, we customized our interview guide questions so that we could explore how and where our participants gained their knowledge on HIV/AIDS, and why an increase in their knowledge on HIV/AIDS could be related to lower resilience to HIV/AIDS, as well as better understand what family support actually meant to them, and how family support was able to help them build their resilience. We tailored our interview guide questions so that they would be able to address our operational definition of resilience to HIV/AIDS. We included questions in our interview guide that would help us explore our participants' perspectives and lived experiences, and more specifically, understand factors they believed helped them survive the clinical and social impacts of living with HIV/AIDS, live full lives despite having a chronic illness, thrive despite the challenges they encountered as middle-aged and older MSM living with HIV/AIDS in Southern Nevada, and purposefully contribute to the goal of ending the HIV/AIDS pandemic. For instance, we asked our participants open-ended questions in order to encourage them to spontaneously elaborate on their own experiences. These included general questions such as, "How do you think you were able to persevere in the face of health and social challenges brought about by HIV/AIDS?", as well as more pointed prompt questions such as, "What do you think has helped lower your health risks in relation to HIV/AIDS over the years?", and "What kind of resources are available to you that you believe help you access essential HIV-related care and services?". We recorded our interviews with each participant's consent, and later, de-identified and transcribed them verbatim for our analysis.

Analysis of Data

We analyzed our de-identified transcripts using the thematic analysis phases previously described by Braun and Clarke (Braum & Clarke, 2006). Due to its inherent flexibility, we chose thematic analysis as our method to analyze our interview data. We deemed it as the best approach to fulfill our study's goals because its epistemological and theoretical freedom allowed for a flexible examination of the different perspectives we derived from our participants (Braum & Clarke, 2006). Braun and Clarke's (2006) thematic analysis method is an iterative process that consists of six phases: (1) becoming familiar with the data, (2) generating codes, (3) generating themes, (4) reviewing themes, (5) defining and naming themes, and (6) locating exemplars. To execute the first phase of our analysis, we used the first half of our data set of 16 interviews to develop our initial thematic codebook. Reviewing the first eight transcripts of our study's data set provided the more seasoned coders of our research team a considerable opportunity to familiarize themselves with our interview data. Our research project coordinator and two of this article's authors separately read and re-read our first eight transcripts to thoroughly familiarize themselves with the interview data, and then subsequently gathered together to discuss potential common codes and themes during bi-weekly meetings as initial coders. Upon reaching a consensus based on the review and coding of our first eight interviews, our initial coders finalized our codebook with key themes and sub-themes to execute the second to fifth phases of our thematic analysis (Braum & Clarke, 2006). Our initial coders then shared the codebook with three other members of our research team, who served as additional coders. All six coders proceeded with analyzing our remaining eight transcripts using the finalized codebook as a guide during the remainder of our analytic process. For the final phase of our analysis, all six coders continued with bi-weekly meetings throughout the analytic process until an agreement was reached on our interview data's key themes, sub-themes, and representative codes and quotes.

Results

After completing the thematic analysis of our 16 interviews, we identified two key themes and four sub-themes from our interview data, all within the specific context of Southern Nevada. The two key themes we identified represented: (1) facilitators to promoting resilience to HIV/AIDS, and (2) challenges to promoting resilience to HIV/AIDS. Under the key theme, facilitators to promoting resilience to HIV/AIDS, we identified two sub-themes: (1) a strong network of local HIV/AIDS prevention, treatment, and related social services, and (2) emotional and mental health support from family of origin or chosen family. Under the key theme, challenges to promoting resilience to HIV/AIDS, we also identified two sub-themes: (1) absence of a central hub for HIV/AIDS care and services, and (2) persistent HIV stigma. The qualitative findings from the analysis of our interview data that could potentially explain our quantitative results regarding the negative correlation between knowledge on HIV/AIDS and resilience to HIV/AIDS are beyond the scope of this article and will be discussed elsewhere in a future research article.

Facilitators to Promoting Resilience to HIV/AIDS

As our participants candidly discussed in their interviews their perspectives and insights on factors related to the promotion of their resilience to HIV/AIDS based on their lived experiences as middle-aged and older MSM living with HIV/AIDS, certain factors stood out as important facilitators to their resilience-building over the years. These facilitators were able to promote their resilience specifically by helping them address both their physical health needs, as well as their emotional and mental health needs.

A Strong Network of Local HIV/AIDS Prevention, Treatment, and Related Social Services

As residents of Southern Nevada, most of our participants described having a strong network of local HIV/AIDS prevention, treatment, and related social services in our region as a crucial facilitator to promoting their resilience to HIV/AIDS. This strong network of services our participants described is composed of over half a dozen clinics and community health centers that have provided specific health care to PLWH, as well as numerous interconnected, community-based, not-for-profit agencies and AIDS service organizations, which have not only linked our participants to critical health-related (e.g., sexual health, mental health, counseling) services, but just as importantly, introduced them to practical social support programs and services (e.g., food banks, housing subsidy and vouchers, insurance coverage and employment assistance) to help meet their most basic needs, all within their network. Many participants emphasized how important it was for them to receive such practical social support because it allowed them to focus their efforts on staying actively engaged in the HIV/AIDS care continuum without having to excessively worry about day-to-day concerns such as where they would get their next meal or having a roof over their heads. Roy (41 years old, White, HIV-positive for seven years) explained:

> Of course, with funding from [an AIDS service organization], not only do I get better access to care with providers who really know their stuff about LGBTQIA+ folks and HIV, but their program has also helped me out with dealing with my food insecurity, you know. So, there's some absolutely amazing resources here in Las Vegas to help us keep going.

Many participants reported that they needed to make use of food banks and other types of dietary aid, which they were able to access thanks to the referrals they obtained from the local community-based agencies within the strong network of services they described. Some participants even shared how much they appreciated the assistance they received from clinic or agency nutritionists who helped them establish better dietary goals and eating habits to stay healthy. Participants described how during their clinic consults with their healthcare providers, they would get referrals to local AIDS service organizations, which in turn connected them to other agencies with healthy dietary programs. Roy (41 years old, White, HIV-positive for seven years) described the eventual end result from the series of referrals he received within the strong network:

> One grant program, the one run by [a local agency], was able to connect me to an [LGBTQIA-affirming] nutritionist who has really helped me learn about better eating habits. Like I said, when I mentioned my food insecurity earlier, they were able to get grant money to buy me a box of groceries once a month for four months, while I was implementing my new nutrition regimen. The program was a lot of help!

Other participants expressed their gratitude for the admirable work ethic of those working or volunteering in the network’s local organizations, particularly those from organizations that helped them meet eligibility requirements for obtaining health insurance, housing support, and financial assistance. Many participants noted how most of their healthcare and service providers knew each other and worked well together within their local network, and consequently expressed how much they appreciated some providers for their passion and willingness to help by going above and beyond their work responsibilities. Peter (50 years old, Middle Eastern descent, HIV-positive for 29 years) described the providers he admired within their strong and growing local network:

> And they're really, really nice people. I mean, they really work hard. They work long hours to raise money and get us benefits. I believe they're in the same boat too, so that makes them want to [fundraise] well even more. Something happened to my insurance once, a long time ago. I went to them for help and they didn't even ask any questions. They just took care of it. So, there's more and more places that can help. You just have to get the right connections.

Our participants found dependable sources of emotional and mental health support from the community organizations of their region’s strong network of services. Hugh (56 years old, Black, HIV-positive for 22 years) underscored the personal importance of the support group meetings he attended, which were regularly held by some local organizations. He described the support group meetings with earnest:

> These support group meetings are very helpful because, maybe four or five years ago, I wouldn't have talked about this disease. I wouldn't do anything. I kept to myself because I thought that my HIV was nobody's business. But leaving all that stuff all bottled up inside, it just doesn't help you. It hurts you in the long run, and prevents you from being at peace with it. So, the group meetings really helped get me there.

Lastly, many participants reported that they regularly utilized the services and programs of multiple community-based organizations in the Southern Nevada network to meet their health and practical needs, highlighting the explicit value of the strong connections among the many healthcare facilities, agencies, and organizations that belonged to the strong network of HIV-related services in their community. Burt (56 years old, Black, HIV-positive for 20 years), who utilized the HIV programs and services of four different organizations, pointed out that in addition to the great camaraderie of the providers within their community's network of services, they have an official HIV awareness and health consortium in Southern Nevada composed of diverse providers from different clinics, community health centers, agencies, and organizations. According to Burt (56 years old, Black, HIV-positive for 20 years), the Southern Nevada HIV consortium has significantly supported the sense of community and multi-directional communication that has been engendered and enhanced by their community's strong network of services.

Emotional and Mental Health Support from Family of Origin or Chosen Family

A sense of community and the support group meetings held by the different community-based organizations were not the only dependable sources of emotional and mental health support that our participants brought up in their interviews. Participants discussed how vital it was for them to have the emotional and mental health support they received from their family of origin (i.e., parents, siblings, relatives, caregivers, and other people they grew up with) or their chosen family (i.e., peers, friends, partners, and other people they have purposefully chosen for mutual support and love) in order to promote their resilience. Our participants claimed that having staunch emotional and mental health support from their family of origin or chosen family helped them build their fortitude, which in turn, promoted their resilience to HIV/AIDS and its adverse clinical and social impacts.

Many participants expressed how their closeness to family members would help combat loneliness and give them a reason to keep fighting. Gar (61 years old, White, HIV-positive for 34 years) found his inner strength when he knew for certain that their family had their back. He narrated a story about a time when he leaned on their sister for help during a time of dire need:

> When I found out about my HIV status, I eventually moved in with my sister and lived with her for a year. So that helped. I started to take my HIV medications and bounced back. Now I got 540 T-cells versus just two. So, my family has been instrumental in keeping me going, definitely. It's almost as if, by just being there for me, they gave me a reason to live. When I was living alone, I was like, "Well, what am I doing this for?" I kind of gave up at a certain point, you know, like … the fight was getting to be too much.

Close family bonds brought greater meaning to the lives of many participants. Some participants expressed the importance of having in their corner family who supported them and cared for their well-being unconditionally. Robbie (68 years old, Black, HIV-positive for 11 years) shared his feelings of greater security and joy whenever his son visited him:

> My son brings the grandkids by. He has a new baby that's, like, one year old, and they come by, and they tear up the house. I'm glad when they leave, but I also love the fact that they've been here. It's just a blessing to know that family is there and you have people that care about you, have your back, and look out for your interests. That's always good to have.

Emotional and mental health support came from life partners as well. Some participants specifically described the benefits that came with having a partner who was also living with HIV/AIDS. Emotionally, being with someone who truly understood one's own life circumstances and experiences brought a sense of safety, which considerably contributed to their resilience. For more practical reasons, it was beneficial to have someone who not only cared, but could also recognize the importance of keeping doctor's appointments and taking HIV medications regularly. Charles (52 years old, Black, HIV-positive for 32 years) shared his own personal experiences:

> My partner makes sure that I still take my meds because he takes his meds too. He takes his, and I take mine, and we kind of keep an eye on each other that way. He also tries to help others by being encouraging to a group of people that we co-mingle with. Yeah, he tries to keep up with the group, and keep them uplifted. So, I try to keep him uplifted too.

In addition to partnerships, close friendships apparently served a similar role. Much like having a family of origin one can rely on for support, having the support of close friends who are part of one's chosen family was often described by participants as a compelling reason to keep persevering. The struggles associated with living with HIV/AIDS can be draining to a person both physically and mentally, but having the care, concern, and understanding of close friends were key to promoting our participants' resilience. According to Joseph (61 years old, White, HIV-positive for 38 years):

> There was a dark period when, I thought I would be, you know, done. So, I thought I should just get it over with, and I was ready to die. It was probably the limited close personal relationships that I did have that saved me. They made me think long and hard, and gave me hope.

It was evident that having the love and support of their chosen family or the family they grew up with was good reason for our participants to endure. Some participants explicitly mentioned their reasons for remaining or wanting to remain resilient, particularly to the clinical and social impacts of HIV/AIDS. For instance, Burt (56 years old, Black, HIV-positive for 20 years) elaborated on the hope he believed was inspired by his powerful familial connections, "I had regular motivating conversations with my friends, and there was always hope there. They encouraged me, and [because of that] I never thought I was going to die…I didn't feel like HIV was going to kill me."

Challenges to Promoting Resilience to HIV/AIDS

As our participants discussed factors that they believed facilitated the promotion of their resilience to HIV/AIDS, they also spoke about the challenges they experienced over the years that prevented them from promoting their resilience. Interestingly, each of these challenges were intrinsically related to the facilitators they described in their interviews.

Absence of a Central Hub for HIV/AIDS Care and Services

While our participants lauded the fact that our region had a strong network of local HIV/AIDS prevention, treatment, and related social services, they were quick to point out the challenges related to having these numerous services and programs at separate clinics or agencies, particularly how these services and programs were so spread out across the region and difficult to access without having a dependable means of transportation. Our participants articulated that these significant challenges could potentially be addressed if there was a central hub that combined all the services and programs available in the region in one place and organized under one electronic records system.

Some participants who moved to Southern Nevada from other states in the last decade could not help but note the struggles they experienced commuting from one community-based organization to another to access the services and programs they needed, which they did not experience at the places they were previously residing. Gar (61 years old, White, HIV-positive for 34 years) described his own experiences trying to manage the services and programs he needed:

> The only thing about Vegas is they don’t have one-stop shopping, so to speak. Like, I’m just used to it in Chicago, when you went to the doctor, and you could also see the therapist. You could get your labs done, see the doctor, and go to therapy, all in one visit. Those are all under one roof. Here, everything is so separate…and so far from each other. Sometimes, you even need to go to, like, five different places to get one thing done, so to speak. Now, I currently go to [a community health center]. Over there, they do the labs and social work as far as,

> um, case management is concerned. So that’s a good thing. That’s a plus. I hear they’re planning to set up a pharmacy there as well. It’s in the works. Things are getting a bit better. But when I first got here, it wasn’t as easy. It was like going to six places to get everything done.

This challenge was fundamentally linked to whether or not participants had a reliable means of getting around the region. Many participants relied on public transportation, and some did not always have the funds to cover the costs of public transportation. Jack (46 years old, Asian descent, HIV-positive for 23 years) explained how long one errand could possibly take to complete due to long bus routes, “It’s just really time consuming for those of us who don’t have a car and are taking the bus. To take the bus to do anything, it takes almost the entire day just to get one chore done.”

During certain times of the year, commuting around the region could be even more challenging. Robbie (68 years old, Black, HIV-positive for 11 years) shared one of his experiences traveling in the scorching heat of the desert in order to get to an HIV clinic, “In the summer months, it’s a little more difficult because, especially when you’re traveling by bus, it can be quite an ordeal just to be outside in the sun waiting all day for the bus to arrive.”

Our participants described other challenges they encountered in addition to the struggles of having to go through long journeys from one agency or clinic to another. The time commitment required to avail of certain services and programs, and the fact that some organizations were exceptionally busy, posed as additional challenges. For example, accessing grocery supplies from a very busy food bank may involve being placed on a long waiting list that could make a grocery trip become a whole day commitment. Peter (50 years old, Middle Eastern descent, HIV-positive for 29 years) described one of his experiences when he lined up for groceries:

> There's the food bank in [a city of Southern Nevada] where I used to go to and sit outside to get grocery supplies. We'd write down our name on a pad and go in the

> order we arrived. But you know, what I do is I go there at like three in the morning. And I just kind of like doze off in my car because I want to just get the supplies and leave. It's my day off and I don't want to spend my whole morning waiting in line. So, I go the extra mile to get my groceries.

Aside from describing the difficulty of having to travel to several different places to access the services and programs they needed and making personal sacrifices to avail of such services and programs, our participants reported that they encountered challenges related to having to repeatedly complete forms and provide the same information at the different agencies since the agencies' records were not necessarily always stored in one centralized system. Jay (41 years old, Black, HIV-positive for 12 years) expressed his frustration concerning this challenge:

> I don't know that it can necessarily be improved. I mean, Las Vegas offers a lot of resources, actually. The resources are amazing here! Sometimes, I guess the improvement would be maybe not to have to go through so many referrals and the same steps over and over from one place to another. There must be a way to make things [like meeting eligibility requirements] easier for everyone.

Despite the fact that having a strong network of local HIV/AIDS prevention, treatment, and related social services in our community meant that there was an abundance of resources to facilitate the promotion of our participants' resilience to HIV/AIDS, the absence of a central hub that could provide all these resources' services and programs under one roof apparently represented a substantial challenge that our participants still needed to overcome.

Persistent HIV Stigma

The other challenge that we identified from our participant interviews is one that has long been pervasive since the start of the HIV/AIDS pandemic, HIV stigma. Participants discussed in their interviews aspects such as lack of knowledge, ignorance, fear, and judgmental behavior, which have all been associated with HIV stigma, and linked to its obstinate persistence. Although many participants recognized that people from their family of origin or chosen family could be great sources of support, they recognized that family members could likewise potentially be culprits who help perpetuate the HIV stigma that poses as a huge challenge to their resilience-building. Many participants revealed that when they encountered HIV stigma, especially and often from close family members and friends, these experiences made them feel unsafe and reluctant about sharing their HIV status to others. Their feelings of uncertainty often added a complicated layer to their lives as they always felt that they constantly needed to carefully discern when and to whom they could disclose their HIV status. Despite having disclosed their status only to very few family members, Hugh (56 years old, Black, HIV-positive for 22 years) revealed that he still encountered stigma from those closest to him:

> My brother still thinks if he uses the restroom after me that he might catch it. So, he's afraid to use the same toilet that I do. It's that stigma…that stupid stigma. I don't want to deal with it. Only a certain amount of people in my family actually know that I'm HIV positive but it's still difficult.

Some participants shared how this history of prejudice, mistreatment, or even discrimination, continued to affect them even though in recent times the social landscape has seemingly been changing. Although a lot of people may have become more knowledgeable and accepting of HIV/AIDS, many of our participants who have been aging with HIV/AIDS for over the last five to 20 years have spent the greater part of their lives hiding their HIV statuses to feel safe and have found it challenging to break this pattern of selective disclosure even to their loved ones. Tim (50 years old, Black, HIV-positive for 27 years) explained his continued reluctance to disclose his HIV status:

> Um, socially, gosh, socially it's been terrible. At first, there was no possibility of dating, no possibility of any intimacy. People are scared of you. Even at home, I was at my mom and dad's house. And my dad was like, "Yeah you should get an electric razor for shaving because of all the little cuts. We don't want blood on the towels if you cut yourself." It definitely affected me for a while. And even though

> now, there's a lot more of the U=U mentality…as long as you're undetectable, you're untransmissible, …people still find it a little hard mentally to wrap their heads around U=U. With such a long history of hiding, I'm still not one to share to others so readily.

The fear of being treated poorly extends beyond the boundaries of personal or familial relationships. Participants reported that many middle-aged and older MSM living with HIV/AIDS they knew feared being mistreated even in healthcare and larger social settings. Joseph (61 years old, White, HIV-positive for 38 years) knew someone living with HIV/AIDS who chose to access his care in a different city from where he lived and scheduled his clinic appointments very carefully out of fear of his HIV status being found out. Joseph recalled, "There was this one guy in one of my groups. He worked in entertainment. He was regularly driving from Las Vegas to [another city] to see his doctor because he didn't want to be seen in a local doctor's office!" According to our participants, the impacts of HIV stigma have continued to persist in the 21st century, and adversely affect them in their daily lives.

Discussion

Over recent decades, middle-aged and older MSM living with HIV/AIDS in Southern Nevada have encountered a variety of factors to promoting their resilience to HIV/AIDS, most of which appear to have existed in the context of their unique, sprawling urban landscape. As the largest urban area in Southern Nevada, Las Vegas is prospectively an important setting for CBPR on resilience to HIV/AIDS that is conspicuously distinct from other large urban areas in North America. Compared to other major cities (i.e., New York, Boston, Toronto) where quantitative research on resilience to HIV/AIDS has been previously conducted, Las Vegas is at least 100 years younger (City of Las Vegas, n.d.; Howarth & McGillivray, n.d.; Lankevich, n.d.; O'Connor et al., n.d.), and today, is still a fast growing, rapidly urbanizing city with surging property development and population growth that has resulted in unparalleled lateral expansion to adjacent suburban and rural areas in the last two decades (Dassopoulos et al., 2012; Ionescu, 2022). Las Vegas' ongoing lateral expansion has led to significant urban sprawl, which in turn, has led to higher dependency on automobiles, longer commutes, greater greenhouse emissions, and much more remaining land for rededication to new construction and open space for infill development (Stout, n.d.; Stout, 2021).

According to our participants, having a strong network of local HIV/AIDS prevention, treatment, and related social services in our community, as well as support from their family of origin or chosen family, have been crucial factors that served as facilitators to promoting their resilience. Our participants also revealed that the absence of a central hub for HIV/AIDS care and services in our community, as well as the persistence of HIV stigma in their daily lives, have been principal factors that proved to be challenges to their resilience-building. As we examined the positive and negative impacts of these different factors on the resilience-building of our participants, we began to recognize that these impacts have been mediated by the factors' significant influence on different social determinants of health. From a social determinants of health perspective (Centers for Disease Control and Prevention, 2022; World Health Organization, n.d.), factors that have a significant influence on critical determinants such as access to quality health services, food security, housing stability, and social inclusion, could be more important than people's individual health care or lifestyle choices in terms of influencing their health (World Health Organization, n.d.).

Based on their interview narratives, the strong network of local HIV/AIDS prevention, treatment, and related social services that we have in our community had a significant positive influence on the social determinants of health that are relevant to our participants. These determinants include their ready access to quality health services, food security, and housing stability. In terms of their ready access to quality health services, the strong network of local HIV/AIDS prevention, treatment, and related social services in Southern Nevada significantly improved our participants' access to HIV/AIDS care and services that not only have LGBTQIA-affirming healthcare and service providers, but also providers who specifically have notable competency in caring for LGBTQIA+ patients and clients. Research has documented that having LGBTQIA-affirming providers, as well as providers who are highly competent in delivering care to LGBTQIA+ patients and clients, are essential to providing quality care and services to MSM living with HIV/AIDS and other LGBTQIA+ PLWH (Adams & Tax, 2017; Marshall & Cahill, 2022; McKay et al., 2022). In terms of their food security, the strong network of services that we have in Southern Nevada has helped provide our participants better access to food banks, affordable or free groceries, and supermarket vouchers and coupons. By addressing issues related to our participants' food security, our community's strong network of services has helped prevent problems associated with food insecurity, such as the exacerbation of hunger and medication side effects from the intake of HIV antiretroviral therapy (Nagata et al., 2012; Young et al., 2014), poor diet quality (Muhammad et al., 2019), non-adherence to HIV antiretroviral therapy regimen (Nagata et al., 2012), and risky sexual practices among MSM living with HIV/AIDS (Whittle et al., 2015). In terms of their housing stability, our community's strong network of services has helped our participants gain better access to affordable housing opportunities, subsidized housing, supportive housing programs, and emergency shelters and transitional housing options. Studies have reported that unstable housing and homelessness are strikingly associated with poorer antiretroviral therapy and HIV program adherence among older MSM living with HIV/AIDS (Logie et al., 2022; Weinstein et al., 2023). Thus, it has been critical and particularly helpful to our participants that they had been receiving invaluable housing support from our community's strong network of local HIV/AIDS prevention, treatment, and related social services. Whether directly or indirectly, the significant positive influence of the strong network of local HIV/AIDS prevention, treatment, and related social services on the social determinants of health relevant to our participants has not only helped our participants improve their physical and mental health and overall wellbeing, but also facilitated the promotion of their resilience to HIV/AIDS.

Similarly, our participants pointed out that the emotional and mental health support they have received from their family of origin or chosen family has had a significant positive influence on their feelings of social inclusion. When our participants felt that they belonged and that they mattered to their families, were cared for, and valued, they were able to find firm and sustainable reasons to overcome their challenges related to living with HIV/AIDS, and persevere. Our participants reported that the help they had received from family and friends was paramount to their appreciation for life and willingness to maintain their health. Support, particularly from family members, friends, and partners, has been a well-documented aid to promoting resilience (Liboro, Yates, Bell et al., 2021; Catalan et al., 2017; Fredriksen-Goldsen et al., 2015). It has been recognized as a crucial facilitator of improved quality of life among older LGBTQIA+ adults and PLWH (Catalan et al., 2017; Fredriksen-Goldsen et al., 2015).

Conversely, it was apparent from our participant interviews that the absence of a central hub for HIV/AIDS care and services in Southern Nevada has had a significant negative influence on social determinants of health such as our participants' ready access to quality health services, food security, and housing stability. Having a strong network of interconnected HIV clinics, community health centers, and community-based organizations that have provided much needed health and social services has been incredibly valuable to middle-aged and older MSM living with HIV/AIDS in Southern Nevada, but our participants noted that these clinics, community health centers, and organizations must continue to make it a priority to be accessible so that their patients and clients could actually avail of their programs and assistance. While services like public transportation and rideshares with free passes from community-based agencies have been available in recent years, there still seems to have been a large burden placed on PLWH. This is because the multiple locations they need to access for their care and services are widespread all across the Southern Nevada region. The inability of patients and clients to move around a large urban city could inadvertently lead to health complications, and the lack of access to affordable and reliable transportation has been a known issue for older

PLWH for quite some time (Kiplagat et al., 2019; Pope et al., 2022; Schatz et al., 2021). Historically, this major issue has been exacerbated in a sprawling city like Las Vegas, where most of the health and social services for PLWH in the Southern Nevada region are located and spread out. These service locations make accessibility for PLWH difficult because they are not walkable distances and the temperatures are scorching in the peak of the summer, reaching as high as 120°F (Bartshe et al., 2018).

When patients and clients have numerous visits to make to multiple healthcare and service providers in order to receive their HIV/AIDS care and services, practical challenges to accessing their providers such as transportation issues have been reported to negatively impact their adherence to their prescribed medications and clinic appointments (Kiplagat et al., 2019). Such transportation issues among middle-aged and older PLWH have been associated with worse health perceptions, pain, social functioning, health distress, and health transitions (Pope et al., 2022). If transportation issues could be eliminated, or at the very least, significantly mitigated by establishing a central hub for all HIV/AIDS care and services in the community, middle-aged and older MSM living with HIV/AIDS and other PLWH would be able to not only access their HIV/AIDS care under one roof, but also avail of services that would help them achieve food security, housing stability, and even social inclusion. A central hub for all HIV/AIDS care and services would be able to help manage most, if not all, factors that influence social determinants of health, as well as ongoing engagement with patients and clients, which would be critical to devising novel interventions and strengthening existing programs aimed at improving outcomes across the HIV/AIDS care continuum (Ogunbajo et al., 2018).

Numerous research studies have suggested that social determinants of health such as access to quality health services, food security, housing stability, and social inclusion account for as much as 55% of health outcomes (World Health Organization, n.d.). Related estimates have identified that the contribution of various factors in sectors outside of health to population health outcomes actually exceeds the contribution of factors from within the health sector itself.

Addressing social determinants of health appropriately is fundamental to improving population health and reducing longstanding inequities in health (World Health Organization, n.d.), including health disparities impacting MSM living with HIV/AIDS (Centers for Disease Control and Prevention, 2018). In the specific context of our participants residing and obtaining HIV-related healthcare and social services in Las Vegas and Southern Nevada, interventions that could be utilized to address relevant social determinants of health could potentially benefit from considering policies and programs that would reverse decades of ongoing sprawl. For example, smart, land-efficient policies, zoning regulations, and public infrastructure investments, which favor high density and mixed-use infill land development that prioritizes affordable housing and other essential services, accessible and well-designed public transit options, the reduction of automobile dependence, and the promotion of walkable communities, could prospectively help address the social determinants of health that are relevant to our participants (Ionescu, 2022; Stout, n.d.; Stout, 2021).

Finally, our participants shared that the persistence of HIV stigma in their lives has likewise had a significant negative influence on their feelings of social inclusion and non-discrimination. Previous research has frequently discussed the ongoing detrimental effects of stigma, and the higher rates at which PLWH encounter it (Meyer, 2003; Correro & Nielson, 2020). Despite the fact that we only required a minimum of one year experience of living with HIV/AIDS in our inclusion criteria, all of our participants reported that they had lived with HIV/AIDS for more than 10 years, save for one participant who had been living with HIV/AIDS for seven years at the time of their interview. Over 80% of our participants had been living with HIV/AIDS for more than 20 years at the time they participated in our study, and there were no significant details that stood out in the interview responses of the three participants who had been HIV-positive for less than two decades in terms of their perspectives and lived experiences related to living with HIV/AIDS and their resilience-building. Among our 16 participants, only one reported that they were diagnosed with HIV/AIDS a couple of years before the advent of clinically approved therapy for the condition. This meant that the particular focus of the findings of our study was explicitly based on the responses of middle-aged and older MSM who not only have substantial experiences living with HIV/AIDS based on the number of years they had been HIV-positive, but who also have considerable experiences related to the availability of and continuous updates in HIV/AIDS treatments, and just as importantly, the changes associated with HIV stigma during their life course.

Meyer has discussed common experiences of people affected by stigma such as expectations of rejection, hiding and concealing their identities, and reluctance to self-disclose to significant others (Meyer, 2003); experiences that were described by many of our participants. Although some of our participants shared that their encounters with HIV stigma have not been as often as they were in earlier decades, they recognized that they still automatically resorted to old habits to protect themselves in certain circumstances or situations when they could reasonably expect the possibility of encountering discrimination and social exclusion from stigma. This recurring hypervigilance for stigma, in turn, has made it harder for them to freely connect with others and has remained an insidious challenge to their resilience-building. Present in both social and institutional settings, the effects of stigma can often feel inescapable, particularly for older adults living with HIV/AIDS who have experienced these effects for most of their life (Emlet, 2006). The documented detrimental effects of stigma on PLWH have included higher rates of depression, lower rates of social support, and poorer quality of life (Chan et al., 2022; Earnshaw et al., 2020; Rueda et al., 2016).

The findings of our study add important knowledge to the growing body of academic literature focused on examining factors that promote the resilience of middle-aged and older MSM living with HIV/AIDS. Based on the input and feedback of our participants, our study identified critical factors that have a strong influence on known social determinants of health, which are crucial to mediating the identified factors' impacts on our participants' efforts to promote their resilience to HIV/AIDS, especially in the context of residing in Southern Nevada.

Limitations of the Study

As we recognize the contributions of our study to extant literature, it is important for us to acknowledge the limitations of our study. One limitation of our study is related to its participant recruitment strategy. Since our participants were primarily recruited with the help of our Southern Nevada partner clinics, community health centers, and community-based organizations, it stands to reason that many of our participants would be active service users of these clinics, health centers, and organizations, and would likely have a healthy appreciation for the care and services they provide. It was unlikely that we were able to access much of the perspectives and lived experiences of middle-aged and older MSM living with HIV/AIDS from Southern Nevada who did not avail of the services of our community partners.

Another limitation of our study is the limited diversity of our participants. At the beginning of our study, it was our intention to recruit participants with a wide range of experiences living with HIV/AIDS in terms of the number of years they had been HIV-positive. As it turned out, over 80% of the participants we recruited were long-term survivors who had been living with HIV/AIDS for over 20 years. Thus, we were unable to examine the experiences of middle-aged and older MSM who had been recently diagnosed and living with HIV/AIDS for less than five years. We suspect that this outcome may be due to the possibility that most MSM living with HIV/AIDS from our community who were eligible and willing to participate in our study were also those who have more experiences and confidence in joining research studies over the last two decades. Nonetheless, this meant that our study was unable to draw the range of participant experiences we hoped we would gather. Related to this, although we received substantial support from our community partners to recruit a diverse range of participants from Southern Nevada in terms of ethno-racial background and how they identified in terms of their sexual identity (e.g., gay, bisexual, queer, MSM), only 50% of the participants we were able to recruit identified as ethno-racial minorities, and they all identified as gay. We acknowledge the significant importance of other critical factors to the resilience-building of middle-aged and older

MSM living with HIV/AIDS, which we were unable to discuss in this article as they were factors cognate to but outside of the WHO social determinants of health perspective, and not within the scope of our study. Despite this, we recognize that critical factors such as race, ethnicity, and other sociodemographic factors are crucial influences to the promotion of resilience of middle-aged and older MSM to HIV/AIDS based on the findings of prior related research (Liboro, Bell et al., 2021; Liboro, Despres et al., 2021). Future research would likely be able to gain even more diverse perspectives and lived experiences, and consequently more knowledge, if they are able to include participants through a wider range of recruitment strategies, as well as involve more participants who identify as ethno-racial minorities, as well as bisexual, queer, or simply as MSM.

Lastly, it is important to emphasize that the findings of our study are restricted to the context of the Southern Nevada region, and potentially applicable only to other relatively younger, fast-growing, and sprawling urban regions of North America that have an increasing number of HIV/AIDS services spread across the widening extent of their landscape. Despite the limitations we have enumerated, our study was able to address several research gaps by not only meaningfully engaging relevant community stakeholders from our region in order to identify and describe our stakeholders own definition of their resilience to HIV/AIDS and the factors that they believe promote it, but also examining our qualitative findings based on the rich perspectives and lived experiences of middle-aged and older MSM living with HIV/AIDS in Southern Nevada from a distinct social determinants of health perspective (World Health Organization, n.d.).

Conclusion

The results of our study corroborate the findings of previous research while presenting discoveries and lessons specific to the experiences of middle-aged and older MSM living with HIV/AIDS in Southern Nevada, which may prove useful for future research in urban locations with sprawling and other similar characteristics. Our study identified the importance of critical factors such as a strong network of local HIV/AIDS prevention, treatment, and related social services; emotional and mental health support from family of origin or chosen family; a central hub for all HIV/AIDS care and services in the community; the elimination of HIV stigma; and the mediating power of relevant social determinants of health (i.e., access to quality health services, food security, housing stability, and social inclusion) to promote the resilience of middle-aged and older MSM living with HIV/AIDS. To date, as far as we can determine, only a few empirical studies have taken advantage of the social determinants of health perspective in the conduct of their research to examine the resilience of MSM living with HIV/AIDS and other PLWH (Dean & Fenton, 2010; Cunha et al., 2015; Santos et al., 2018). Future studies focused on the promotion of resilience to HIV/AIDS could benefit from conducting research utilizing a social determinants of health perspective, particularly to identify other facilitators, challenges, and factors related to the resilience-building of middle-aged and older MSM living and aging with HIV/AIDS in the 21st century.

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Chapter 7: Manuscript 3 Summary

In our interviews regarding resilience-building among middle-aged and older MSMLWH, we identified a few key facilitators and challenges to building resilience. The first facilitator we found was the well-established network of local social services, which included those focused on HIV treatment/prevention as well as other services like dietary nutrition, financial assistance, and group meetings. The second facilitator was the social support of family. Importantly, this family varied in definition since there were some participants who expressed the importance of their blood-related family, while others found more support from their chosen families. Regardless, these close familial bonds were vital to the resilience-building of our participants. As for challenges, the lack of a central hub for HIV care and other related services presented as a barrier to resilience-building. Navigating transportation in Southern Nevada is challenging without a great public transportation system, so having services spread out wide makes it challenging for PLWH to access all the services they need. Lastly, HIV stigma persists as another challenge to this day. While HIV stigma has lessened in the last 30 years, it continues to be pervasive in the 21st century, and some participants expressed their difficulties facing the prejudice and bias that still comes with their HIV status. In order to promote the resilience of middle-aged and older MSMLWH, research needs to continue to find ways to address their challenges, and just as importantly, promote factors that have been documented to support their resilience-building.

Chapter 8: Discussion and Implications

The research presented in this dissertation sought to qualitatively assess the awareness and knowledge of HAND among relevant stakeholders in Southern Nevada, as well as factors that promote the resilience of middle-aged and older MSMLWH from the region, by utilizing a consistent CBPR approach and a social determinants of health perspective. In paper 1, we examined the awareness and personal experiences of middle-aged and older PLWH related to HAND. Then, in paper 2, we expanded this assessment to examine the awareness and knowledge of HAND among the healthcare and service providers who have frequent contact with PLWH in Southern Nevada. Lastly, in paper 3, we balanced out the deficits-based focus of papers 1 and 2 with a strengths-based focus by examining factors that build the resilience of ethno-racially divesre, middle-aged and older MSMLWH.

Our findings from the first manuscript indicated that there is room for improvement on HAND knowledge among PLWH, and that social determinants of health present as priorities for PLWH so that they may be able to focus their attention on addressing their concerns related to HAND. Following this, our findings from the second paper revealed that there is also some room for improving HAND-specific knowledge among HIV sector providers in Southern Nevada, and in line with the findings from the first manuscript, we found that providers frequently referred patients and clients to services to help meet their needs. These findings further support the critical importance of addressing issues related to social determinants of health among PLWH. In manuscript 3, we found that these issues related to social determinants of health presented as barriers to building the HIV/AIDS resilience of our participants, but alleviating factors like accessible local social services and family support served to bolster their resilience-building.

The full picture of this three-paper dissertation is one that underscores the value of accessible local health and social services in Southern Nevada, including the programs delivered by community-based agencies and the the support of dedicated and hardworking HIV sector healthcare and service providers. The need to improve the awareness and knowledge of HAND among all relevant stakeholders could potentially be met by the valuable services, useful programs, and dedicated providers that are already in place. These services, programs, and providers could be crucial to successfully disseminating knowledge on the neurological impacts of living with HIV/AIDS and the different strategies and interventions available to address them. Our findings highlight that the most key lesson to remember is that significant efforts should be consistently made to ensure that these services, programs, and providers remain accessible to middle-aged and older PLWH, particularly in the context of the sprawling region of the greater Las Vegas area and the surrounding Southern Nevada expanse.

A benefit to conducting research from a CBPR approach is the real-time opportunity to witness the real-world impacts of one’s work firsthand and much sooner than is typical for most other research approaches. While conducting our research, each interaction with a participant was not only an opportunity for us to gather data, but also a chance to directly share with a relevant stakeholder answers to questions they may have related to the risks that aging PLWH may have of developing neurocognitive challenges and the ways to anticipate and address these challenges. For example, within our interview guides for papers 1 and 2, which focused on HAND, we shared with our participants a concise description of HAND, a brief statistic of its frequency, and possible resources participants may want to avail of to improve their knowledge of HAND. During these interviews, I took the time to answer any questions they may have regarding HAND and explained to them how our research could personally impact them.

In addition to the opportunities to spread important information during the interview process and outreach efforts we exerted as a research lab team, we also had the unique opportunity to share our findings with local community-based organizations after the conduct of our studies through community reports and event presentations. The meaningful involvement of these local community-based organizations in our research process afforded us existing relationships that allowed us to disseminate our findings during the recruitment, interview, debriefing, and knowledge mobilization phases of our projects. One notable effect of sharing our findings with the LGBTQIA+ Community Center of Southern Nevada, our primary community partner, was their deliberate and purposeful response to the finding that a central hub that consolidated as many of the programs and services PLWH frequently used to survive and thrive was sorely needed. The LGBTQIA+ Community Center of Southern Nevada made an outstanding effort to incorporate as many programs and services their HIV-positive clients and patients needed to their recently built, in-house, Arlene Cooper Community Health Center. These included care and support delivered by primary care providers, case workers, knowledge brokers, program coordinators, and HIV advocates, as well as counselling services and a state-of-the-art pharmacy, effectively beginning the work to make a one-stop-shop location to mitigate the risks, meet the needs, and build the resilience of PLWH in Southern Nevada, especially ethno-racially diverse and middle-aged and older PLWH.

Future research that may stem from these findings could expand outside of the context of Southern Nevada. What would similar research find in a more urban, dense city with more accessible public transportation like Seattle or Chicago? New barriers to gaining knowledge and factors to building HIV/AIDS resilience could be further identified and explored. We did not ask questions regarding socioeconomic status, but this would be a vital aspect worth looking into due to the complex relationship between socioeconomic status and social determinants of health. Future research could also continue the important work of examining awareness and knowledge of HAND, as well as factors that build HIV/AIDS resilience, among specific subpopulations (i.e., Black heterosexual women, trans youth and adolescents) that were outside the scope of our recent research.

Chapter 9: Conclusion

The presented dissertation sought to assess awareness and knowledge of neurological challenges faced by PLWH as they age among two key stakeholders: middle-aged and older PLWH and their HIV sector healthcare and service providers. Additionally, it identified facilitators and barriers to building resilience to the clinical and social impacts of living with HIV/AIDS. With all three papers utilizing a CBPR approach, this dissertation also made valuable connections with the local Southern Nevada community throughout the research process. Importantly, the presented program of research not only investigated these topics to present empirical peer-reviewed research to interdisciplinary scholars, but also to deliver and communicate the results to the local community. While there is always more work to be done, the dissertation findings presented actionable insight and recommendations that empowered people and community-based organizations in Southern Nevada to begin progress toward solving some of the challenges elucidated by our collaborative research.

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Curriculum Vitae

Brandon Ranuschio

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Las Vegas, NV 89154
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Education

PhD, Psychological and Brain Sciences *expected Spring 2024*

University of Nevada, Las Vegas

B.A., Psychology *received 2018*

University of Nevada, Las Vegas

Peer-Reviewed Journal Publications

Ranuschio, B., Bell, S., Flatt, J., Barnes, L., Puno, T., Navarro, A., Ribeiro, A., Sheik-Yosef, N., Villalobos, E., Wackens, J., & Liboro, R. M. (In Press) Awareness and Knowledge of HIV-Associated Neurocognitive Disorder Among Middle-Aged and Older People Living with HIV/AIDS in Southern Nevada: Implications for HIV/AIDS Sector Community-Based Education Programs. *AIDS Education and Prevention*.

Ranuschio, B., Bell, S., Flatt, J. D., Barnes, L., Puno, T., Ribeiro, A., Sheik-Yosef, N., Villalobos, E., Wackens, J., & Liboro, R. M. (2023). A Focus on Aging, HIV/AIDS, and Neurocognitive Challenges: Examining Southern Nevada HIV Sector Providers' Awareness and Prospective Roles. *International Journal of Environmental Research and Public Health*, 20(19), 6876.

Ranuschio, B., Bell, S., Waldron, J. M., Barnes, L., Sheik-Yosef, N., Villalobos, E., Wackens, J., & Liboro, R. M. (2023, October). Promoting Resilience among Middle-Aged and Older Men Who Have Sex with Men Living with HIV/AIDS in Southern Nevada: An Examination of Facilitators and Challenges from a Social Determinants of Health Perspective. *Healthcare* 11(20), 2730.

Liboro, R., Despres, J., **Ranuschio, B.**, Bell, S., & Barnes, L. (2021). Forging resilience to HIV/AIDS: Personal strengths of middle-aged and older gay, bisexual, and other men who have sex with men living with HIV/AIDS. *American Journal of Men's Health*, *15*(5), 15579883211049016.

Liboro, R. M., Yates, T. C., Bell, S., **Ranuschio, B.**, Da Silva, G., Fehr, C., Ibañez-Carrasco, F., Shuper, P. A. (2021). Protective factors that foster resilience to HIV/AIDS: Insights and lived experiences of older gay, bisexual, and other men who have sex with men. *International Journal of Environmental Research and Public Health*, *18*(16), 8548.

Liboro, R. M., Bell, S., **Ranuschio, B.**, Barnes, L., Despres, J., Sedere, A., Puno, T., Shuper, P. A. (2021). Barriers and facilitators to promoting resilience to HIV/AIDS: A qualitative study on the lived experiences of HIV-positive, racial and ethnic minority, middle-aged and older men who have sex with men from Ontario, Canada. *International Journal of Environmental Research and Public Health*, *18*(15), 8084.

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Other Publications

Ranuschio, B., Waldron, J., Barnes, L., Bell, S., Puno, T., Despres, J., Sedere, A., Sheik Yosef, N., Villalobos, E., Wackens, J., & Liboro, R. (2022). Awareness and Knowledge of Aging and HIV-Associated Neurocognitive Disorder: Service User and Provider Perspectives in Southern Nevada. University of Nevada, Las Vegas. http://dx.doi.org/10.34917/29486317

Bell, S., Waldron, J., Barnes, L., **Ranuschio, B.**, Despres, J., Puno, T., Sedere, A., Sheik Yosef, N., Villalobos, E., Wackens, J., & Liboro, R. (2022). The resilience of middle-aged and older men who have sex with men to HIV/AIDS: Southern Nevada stakeholder perspectives in the 21st century. University of Nevada, Las Vegas. http://dx.doi.org/10.34917/29488636

Liboro, R., Bell, S., **Fraga, B.**, Despres, J., Puno, T., Sedere, A., & Barnes, L. (2020). Resilience to the clinical and social impacts of HIV/AIDS: Perspectives of middle-aged and older men who have sex with men – a community report. University of Nevada, Las Vegas: Las Vegas, Nevada, USA.

https://issuu.com/championmhlab/docs/mao_msm_r2ha_-_community_re port_-_unlv

Poster Presentations

Bell, S., **Ranuschio, B.**, & Liboro, R. (2022, August 5-7). *The resilience of middle-aged and older men who have sex with men to HIV/AID during COVID-19.* Poster presented at the American Psychological Association, Minneapolis, MN, USA (hybrid)

Bell, S., **Ranuschio, B.**, & Liboro, R. (2021, June 22-26). *Perspectives of racial and ethnic minority older men who have sex with men on barriers and facilitators that foster resilience to HIV/AIDS in the 21st Century*. Poster session presented at the 18th Biennial Conference on Community Research and Action: Uprooting White Supremacy, Society of Community Research and Action (SCRA – APA Division 27, American Psychological Association) (virtual)

Despres, J., Puno, T., Sedere, A., **Ranuschio, B**., Bell, S., & Liboro R. (2021, May 3-7). Awareness and knowledge on aging and HIV-Associated Neurocognitive *Disorder: Service user and provider perspectives in Southern Nevada*. Poster session presented at the UNLV Office of Undergraduate 2021 Research Symposium, Las Vegas, Nevada, USA (virtual)

Ranuschio, B., Bell, S. & Liboro, R. (2021, April 29-May 2), *Coping styles and specific coping strategies for promoting resilience to HIV/AIDS: A qualitative study on the lived experiences of older gay and bisexual men*. Poster session presented at the Western Psychological Association 101st Convention: The Big Issues (virtual)

Flood, S. M., Kuwabara, H., Hussey, J., **Fraga, B.**, Kinsora, T. F., Ross, S. R., & Allen, D. N. (2019, November). *Frequency of Sports-Related Concussion in Athletes with Neurodevelopment Conditions*. Poster session presented at the 39th Annual Conference of the National Academy of Neuropsychology, San Diego, CA.

Hussey, J., Witoslawski, D. E., **Fraga, B.**, Sheikh, R. M., Kinsora, T. F., Ross, S. R., & Allen, D. N. (2018, October). *Demographic factors and likelihood of sport concussion.* Poster session presented at the 38th Annual Conference of the National Academy of Neuropsychology, New Orleans, LA.

Kuwabara, H., Sheikh R., **Fraga, B.**, Ng, W., Kinsora, T. F., Ross, S. R., & Allen, D. N. (2018, October). *Demographic factors of invalid baselines on ImPACT.* Poster session presented at the 38th Annual Conference of the National Academy of Neuropsychology, New Orleans, LA.

Awards

Dean's Honor List

Spring 2016, Fall 2016, Spring 2017, Fall 2017, Spring 2018

Governor Guinn Millennium Scholarship

President's Award for Educational Excellence

Research Experience

Graduate Assistant *2020 - Current*

University of Nevada, Las Vegas - CHAMPION Mental Health Lab

Supervisor: Dr. Renato Liboro

The Community Health Advocacy for Minority Populations, Immigrants, and Other Newcomers, and their Mental Health (CHAMPION Mental Health) Lab uses a community-based participatory research approach to address mental health equity issues and health disparities affecting marginalized communities.

Current Study: Awareness and Knowledge on Aging and HIV-Associated Neurocognitive Disorder: Service User and Provider Perspectives in Southern Nevada

Working under the supervision of Dr. Liboro we are conducting this mixed-methods community-based study to assess awareness of HIV-Associated Neurocognitive Disorder (HAND) in Southern Nevada. The study consists of a quantitative survey aspect, distributed to middle-aged and older people living with HIV and their service providers in the area as well as a qualitative interview to be conducted with the same populations. In this project I manage recruitment, scheduling participants, conducting interviews, collecting data, aiding in both the qualitative and quantitative analyses, and developing reports and manuscripts from the data we collect.

Undergraduate Research Assistant *May 2018 - April 2020*

University of Nevada, Las Vegas - Development of Irritability, Mood, and Emotions Lab

Supervisor: Dr. Andrew Freeman

The DIME lab conducts research focused on the etiology, assessment, and treatment of mood disorders (Bipolar Disorder, Depression, & Disruptive Mood Dysregulation Disorder).

Study: Young Adults Attending to Emotions

I collaborated closely with Dr. Freeman and Breanna Garcia to help implement Breanna's dissertation study. I programmed tasks initially in Psychopy and then transferred them to OpenSesame. Some such tasks included a visual search, dot probe, asynchronous stimulus onset, free view, and attentional engagement & disengagement. I also developed scripts to process eyetracking from those tasks, ran participants through the study protocol, and trained new research assistants.

Study: Virtual Darkness for Young Adult Sleep Difficulties

I was trained to reliably administer the Mini International Neuropsychiatric Interview, neuropsychological measures including the balloon analog risk task (BART), the psychomotor vigilance task (PVT), as well as the multidimensional mood questionnaire (MDMQ), General Behavior Inventory (GBI), and the PennCNP. I also aided with data entry, management, and scoring.

Undergraduate Research Assistant *May 2018 - April 2020*

University of Nevada, Las Vegas - Neuropsychology Research Program *Supervisor: Dr. Daniel Allen*

The Neuropsychology Research Program investigates neuropsychological functioning in individuals with neuropsychiatric disorders, particularly schizophrenia, bipolar disorder, substance use disorders, and traumatic brain injury.

Study: Assessment of Sport Concussion in High School Athlete

I worked on a database of athletes from across the state of Nevada who completed baseline and post-concussion cognitive assessments using the ImPACT (Immediate Post-concussion Assessment and Cognitive Testing). This data was drawn from a naturalistic, longitudinal sample of 50,000 athletes between 2008-2016. We then used this data to investigate the psychometric properties of the assessment and address cross-cultural considerations. My duties included cleaning data using double-entry, checking data for abnormalities, searching for and gathering relevant previous research, conducting literature reviews, and creating poster presentations.