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

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AWARENESS AND KNOWLEDGE ON AGING AND HIV-ASSOCIATED NEUROCOGNITIVE DISORDER: SERVICE USER AND PROVIDER PERSPECTIVES IN SOUTHERN NEVADA

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Abstract

HIV-Associated Neurocognitive Disorder (HAND) is a condition that can affect up to 50% of people living with HIV/AIDS (PLWH) and present as a cluster of neurocognitive difficulties in domains such as attention, memory, concentration, language, information processing, decision-making, problem-solving, and even motor skills. The current study intended to identify awareness and knowledge of HAND among middle-aged and older PLWH and their healthcare or service providers in Southern Nevada. Using a Community-Based Participatory Research approach, participants from the community were recruited to complete a survey that assessed awareness and knowledge of HAND. The survey also assessed the personal experiences of PLWH related to neurocognitive difficulties, as well as the work experiences of healthcare and service providers related to their patients' or clients' neurocognitive issues. In this thesis, the findings, descriptive statistics, and discourse reveal the current levels of awareness of HAND in Southern Nevada, as well as examine the demographic variables that are associated with knowledge of HAND in the community. The lessons learned discussed in this thesis underscore the need to raise awareness and knowledge of HAND among relevant community stakeholders so that individuals, programs, and services can be better prepared to identify and address HAND as the need arises.

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Introduction

The HIV-positive population in the United States is growing older and people aging with HIV/AIDS are displaying increased challenges related to living with the virus for such a long time (CDC, 2018). Since the introduction of combination antiretroviral therapy in the 1990s, the life expectancies of HIV-positive individuals have steadily increased, and the darkest days of the HIV/AIDS epidemic felt comfortably in the past (Cooper, 2008). However, more struggles have been documented as people aging with HIV/AIDS now have to deal with not only the anticipated decline in abilities that come with aging, but also the strains of having to manage other health issues related to aging with HIV/AIDS. These struggles related to natural aging and aging with HIV/AIDS have been found to have particularly strong interactions that affect the neurocognitive abilities of older HIV-positive adults. For example, prospective memory that is responsible for delayed intentions and is essential for everyday functioning, has been found to have additive, stable impairment in this population (Kordovski et al., 2020). Furthermore, research has shown that HIV-positive gay men over 40 are more likely to experience mental health issues compared to their HIV-negative peers, which speaks to the mental health strains of living with HIV/AIDS (Lyons et al., 2012).

In the realm of neurocognitive functioning, aging and HIV can have a particularly nefarious interaction. The combined effects of aging and living with HIV/AIDS increases dispersion, or intraindividual variability, on a variety of neuropsychological tests (Morgan et al., 2011). Intraindividual ability is indicated by large variations in performance of one person on multiple cognitive tests. For example, Morgan and colleagues (2011) have used 12 neurocognitive measures, and if a participant's z-scores on all measures were similar, they would have low dispersion. However, a person with high dispersion would have drastically different

performance outcomes across the tests. Neither HIV-positive young individuals nor HIV-negative older individuals fared as poorly in their neuropsychological tests as individuals who were both older and HIV-positive, indicating that it is the specific interaction of aging and living with HIV/AIDS that impairs some forms of neurological functioning. Essentially, people who were both HIV-positive and older were the most likely to have high variability in their performance outcomes across different cognitive domains. Another study found that on digit span and initial recall tasks, HIV-positive adults aged 50 to 65 performed more similarly to that of HIV-negative adults over 65 than they did to HIV-negative adults of their same age range (Sheppard et al., 2017). This effect could be conceptualized as something akin to accelerated neurological aging in people living with HIV/AIDS (PLWH).

The effects of HIV on the brain are not particularly new. However, due to the aforementioned increasing age of the HIV-positive population, and the effectiveness of medications at improving the longevity of PLWH, it has become increasingly notable that this group of older adults seem to be at greater risk for experiencing neurocognitive challenges compared to their HIV-negative counterparts.

The neurocognitive challenges, signs, and symptoms associated with HIV/AIDS have been found to be related to attention, learning, verbal language skills, memory, executive functioning, sensory functioning, psychomotor ability, and motor skills (Grant, 2008). This clustered symptomatology has been attributed to a spectrum condition known as HIV-Associated Neurocognitive Disorder (HAND) which has, as noted by Grant (2008), been documented to affect up to 50% of PLWH, at some point in their lives. More specifically, HAND is a spectrum of impairment in cognitive function ranging from Asymptomatic Neurocognitive Impairment at its mildest to HIV-Associated Dementia at its most severe (Antinori et al., 2007). Considering

the widespread effects of HAND on PLWH, it is imperative that this population at risk learns not only of its existence, but also of its signs and symptoms, prognosis, impacts, and management.

The proposed study intended to identify the awareness of HAND among middle-aged and older PLWH in Southern Nevada. The first task was to understand the levels of awareness and knowledge people in the community at risk of developing HAND (i.e., service users) have in order to determine the future efforts that should be made to build awareness and increase vigilance. Additionally, considering the significant role they play in the continuum of care of HIV-positive people, the study also assessed the awareness and knowledge of healthcare/service providers in Southern Nevada HIV/AIDS prevention and intervention services on HAND. These service providers include people in health and social services working to support PLWH in different capacities (e.g., clinicians, nurses, social workers, case workers, or disability support workers). The treatment of HIV/AIDS requires constant surveillance and testing, and as such, both HIV/AIDS service users and providers should be aware of the signs and symptoms that may signal the progression of neurocognitive impairments.

To this end, a Community-Based Participatory Research (CBPR) approach has been selected as the ideal strategy to conduct these assessments. The subtle nuances of urban health problems make them difficult to study through many traditional means, and CBPR will allow us to approach the issue with the mindset of community-wide involvement and change, and a cultural sensitivity uniquely suited to the Southern Nevada population (Minkler, 2005). By establishing collaborative partnerships with relevant Southern Nevada community-based organizations, and meaningfully involving them in every step of the research process possible, we can increase the overall impact of our findings while simultaneously ensuring that the test materials and everyday processes of the study would be both sensitive and relevant to the actual

concerns of the community. Additionally, with the rapport we establish within the community, we will be able to readily disseminate our study findings and promote real-world impacts.

HIV/AIDS

To best understand HAND, it would be helpful to first have a greater understanding of HIV/AIDS. The Center for Disease Control and Prevention [CDC] (2020b) describes human immunodeficiency virus, or HIV, as "a virus that attacks the body's immune system." HIV infection is defined in three unique stages. Stage 1, acute HIV infection, can sometimes be accompanied with flu-like symptoms as the body tries to fight off the large amount of HIV in the blood. At stage 2, the infection is asymptomatic, but still active and transmissible. This makes it particularly dangerous as someone may not know they are HIV-positive for years after the initial infection. At stage 3, the condition has evolved into what is considered Acquired Immunodeficiency Syndrome, or AIDS, and it is at this point that the individual's immune system has been so overwhelmed that people with the virus become susceptible to opportunistic infections or other illnesses, and without treatment, become at increased risk of dying from complications.

The way HIV is often measured is through what is called a viral load, which is the concentration of the virus itself in the blood, or through a "CD4 count", which is the level of CD4 helper T-cells found in the blood that fight off infection (Morgan et al., 2011). The lower the viral load or the higher the CD4 count, the better the health status of the person with HIV/AIDS. Importantly, there is no cure for HIV/AIDS, but it can be treated with medications. When a person with HIV/AIDS takes their medications as prescribed, they can reach a point where their viral load is so low that it cannot be detected by most tests. This "undetectable" status is the goal of HIV treatment, and at this well-managed point, the person while still

technically HIV-positive, cannot transmit the disease to others due to having such a low viral load (CDC, 2020a).

Defining HIV-Associated Neurocognitive Disorder

Beyond the typical vulnerabilities of the immune system found in HIV, there is also a set of neuropsychological difficulties that many PLWH experience. As mentioned previously, Grant (2008) found that the affected domains of neurological functioning include attention, learning, verbal language skills, memory, executive functioning, sensory ability, psychomotor ability, and motor skills. This cluster of impairments have been titled HIV-Associated Neurocognitive Disorder (HAND).

In the realm of attention, HIV-positive participants have been found to perform similarly to HIV-negative controls in a controlled attention task, but then perform more poorly in a more complex divided attention task (Sorenson et al., 1994). Similar attentional issues have been found in a study that used fMRI to evaluate the brain activity of HIV-positive patients with demographically matched controls, which documented that HIV-positive participants required additional activation of the frontal lobes to perform more complex tasks (Chang et al., 2001). These results seem to point out that attentional difficulties may be exclusive to complex tasks while simpler tasks may be unimpaired. Additionally, using the Game of Dice Task to measure risky decision-making, Gomez and colleagues (2017) discovered that individuals with HIV/AIDS were unimpaired compared to HIV-negative controls with one exception: the participants diagnosed with HAND did in fact suffer from impaired decision-making. Considering the importance of continued daily medication in managing HIV/AIDS, the combined effects on both attention and decision-making skills in this population is concerning.

Socially, PLWH, and more specifically HAND, can encounter difficulties in recognizing and processing emotions. Characterized by frontostriatal dysfunction that leads to facial emotion recognition deficits, HIV-status was shown to increase reporting of psychosocial impairments, which was associated with emotion recognition difficulties, particularly for fear and anger (Clark et al., 2010). HAND was also associated with difficulties in the speed of recognition of negative emotional expressions like fear, sadness, and anger (Lane et al., 2010). These findings also included milder forms of emotional processing dysfunction in clinically stable HIV-positive individuals, and no correlations between nadir (i.e., lowest point) CD4 or current CD4 counts and emotion processing. While emotion recognition deficits are not typically considered a symptom of HAND, this could be a symptom of the reduced processing speed that is characteristic of HAND.

To further complicate the issue, the typical medications used to treat HIV infection seem to be ineffective at preventing the development of HAND. Even with antiretroviral therapies that successfully manage HIV, PLWH still show neurocognitive impairment (Robertson et al., 2007). However, restoring immunocompetence seems to slow down the progression of neurocognitive impairments and increase the likelihood of neurocognitive recovery. Furthermore, a low nadir CD4 count is associated with neuropsychological impairment. In a study by Ellis and colleagues (2011), participants whose nadir CD4 count was never allowed to fall exceptionally low due to starting antiretroviral therapies sooner, were found to be better protected. This finding further emphasizes the importance of early detection since beginning treatment as early as possible may be effective in preventing the worst of HAND.

Additional difficulties may also arise with the possible side effects of antiretroviral therapies used to treat HIV. For example, efavirenz, a commonly prescribed antiretroviral drug in

combination with other HIV medications, is known to have neurological side effects including confusion, forgetfulness, and mood changes (MedlinePlus, 2020). In addition to efavirenz, other antiretroviral medications prescribed for HIV/AIDS can, over prolonged periods of use, build up in the body and cause drug toxicity that could be a factor in the neurocognitive declines often seen in older PLWH (Haughey et al., 2012). However, a study by Rakhmanina & Anker (2010) identified the rate of side effects as up to 55% but often clearing up within 2-4 weeks of continued use. Unfortunately, they also corroborate the increased risk of effects on the central nervous system due to long term suppression of HIV through the use of efavirenz. The exact cause of neurocognitive symptoms when multiple factors like HAND, medication side effects, and aging are at play make identification, treatment, and prevention particularly difficult.

The exact prevalence rate of HAND found in previous literature tends to vary but is consistently found in a concerningly high percentage of PLWH, particularly HIV-positive older adults. A study by Fernandes Filho & de Melo (2012) found a prevalence rate of 36.5% in a Brazilian population, while a separate study by Simioni and colleagues (2010) found rates as high as 84% among people with cognitive complaints, and 65% among those without cognitive complaints. A 2009 meta-analysis found rates of 30% in people with asymptomatic HIV infection, and 50% in those whose status developed to AIDS (Woods et al., 2009). However, among patients in Northern Nigeria a rate of 21.5% was found, while an analysis of the Multicenter AIDS Cohort Study assessed a frequency of 25% to 33%, depending on the year that was analyzed (Yusuf et al., 2017; Sacktor et al., 2016). Although these rates appear to vary, even at the lowest estimate of 21.5%, the prevalence of HAND is gravely concerning.

Diagnosing HIV-Associated Neurocognitive Disorder

The official criteria to identify HAND that is endorsed by the American Academy of Neurology requires assessment in at least five of seven possibly affected cognitive areas: attention/working memory, abstraction/executive memory, processing speed, sensory perception, motor skills, and verbal/language skills (Antinori et al., 2007). Additionally, the performance on these tests along with severity of symptoms can garner one of three specific diagnoses that all fall under the umbrella or spectrum of HAND. HIV-associated Asymptomatic Neurocognitive Impairment (ANI) requires performance in two of the tested domains to be at least 1 standard deviation below demographically appropriate norms with no interference of everyday functioning. HIV-1-associated Mild Neurocognitive Disorder follows as a second diagnosis in the spectrum, in that it requires the same testing results of at least 1 standard deviation below the mean but with the additional criteria of mild interference in daily functioning. Lastly, and most severely, is HIV-1-Associated Dementia (HAD), which requires testing in at least two domains to result in scores two standard deviations below the norm with significant interference in day-to-day life.

While the grouping of these three conditions is logically sound, it poses an issue with screening. Since the difference in severity between ANI and HAD is so drastic, it can be difficult to identify a tool that is not too difficult for someone suffering from HAD but is not so easy that it fails to capture someone at the level of ANI (Barber et al., 2014). Interestingly, the most severe form may be the easiest to identify and diagnose, as there must be clearly problematic symptoms present to receive this diagnosis. For example, the International HIV Dementia Scale can be administered in two to three minutes and has even been cross-culturally validated (Sacktor et al., 2005).

However, for the mild and asymptomatic diagnoses, identification may be slightly more nuanced. While a clinical rating would be ideal to determine the presence of minor impairment, it may not be a realistic choice considering the personnel and time required to not only administer but also score such tests (Carey et al., 2004). An alternative option that has been suggested is to use global deficit scores, which is an automated approach that simulates clinician ratings and normalizes the patient's performance data to a deficit score that indicates severity of impairment. This approach was found to be highly accurate in identifying neuropsychological impairment in an HIV-positive sample. Furthermore, high interrater reliability was found when six neuropsychologists were asked to independently rate the presence and severity of impairment. A large point of contention was whether the impairment was due to HIV/AIDS or another issue (Woods et al., 2004).

Identifying neuropsychological impairment does not appear to be particularly difficult, but the attribution of it to HIV/AIDS, and the expectation of neuropsychological symptoms in HIV-positive patients may be. In a sample of South African healthcare providers, 80% had heard of HAND, only 2% had actually received any kind of training on it, 11% would screen for it, and 45% were unaware of what screening tool to use (Gouse et al., 2020). Providers could recognize the relevance of screening for HAND, as 77% found it important. However, almost all providers currently lacked, yet desired, training with 94% of them wanting to be trained on the topic. Qualitative research has also corroborated this finding as Liboro and colleagues (2018) found Canadian healthcare providers openly discussing their lack of awareness and limited knowledge of HAND in open-ended interviews. Those that were made aware of HAND through conferences or community reports had also admitted that they felt their level of understanding of HAND was not as great as they felt it should be for their role. This further

elucidates the importance of continued research on the topic of healthcare/service provider awareness of HAND.

Demographics

The connection between neuropsychological symptoms of HIV/AIDS and aging have been well documented. Going hand-in-hand, age and the duration of HIV infection are both significantly associated with HAND (Mcombe et al., 2013; McCutchan et al., 2012). It logically follows that as the duration of HIV infection increases, so would one's age. However, even while factoring in the duration of HIV infection, the association of HAND with older age is well-researched and the link is undeniable (Sheppard et al., 2017; Morgan et al., 2011; Joska et al., 2010).

In addition to age, other demographic states seem to affect neurocognitive declines and HAND symptoms. Halkitis and colleagues (2016) have administered a battery of neurocognitive tests to older HIV-positive people and found that while neurocognitive declines vary by domain of functioning it was the non-White, non-gay, HIV-positive people with lower levels of education that were most at risk in their sample. Similar studies have corroborated these findings, with one such study focusing on HIV-positive people identifying as Latinx (Mindt et al., 2014). While the groups of participants in this study (defined in the study as non-Hispanic White and Latina/o) did not differ in educational attainment, there were differences found in neurocognitive ability based on ethnicity and age. The results indicated a difference in older Latinx individuals compared to older non-Hispanic Whites on a variety of neurocognitive tests. However, there was no difference in younger Latinx individuals compared with younger non-Hispanic Whites. This suggests that perhaps the interaction of age and race/ethnicity may play a role in HAND presence and severity.

While the study by Mindt and colleagues (2014) was unable to assess level of education as a factor, other research has shown that education may play a role in protecting against the development of HAND. As education can be protective against standard dementia and Parkinson's disease, it reasonably follows that this effect could extend to HAND (Glatt et al, 1996). Even when not reaching the severity of a diagnosable cognitive impairment, cognitive reserve, which is a combination of factors such as educational attainment and premorbid intelligence, helps to lessen the cognitive decline associated with aging (Foley et al., 2012; Lenehan et al., 2015). Indeed, HIV-related dementia, as well as HAND overall, have been found to be more prevalent in people with lower educational attainment (Joska et al., 2011; Joska et al., 2010).

Effects on Daily Functioning

Depending on the severity, deficits in cognitive functioning can have tremendous impacts on daily life. In a group of HIV-positive participants, those with neuropsychological impairment experienced difficulties in shopping, cooking, financial management, medication management, and vocational abilities (Heaton et al., 2004). These effects can then ripple outward, and lead to difficulty establishing and maintaining employment, or heavily impair one's sense of independence. Additionally, reductions in attentional ability have implications for heightened risk of driving accidents making it even harder for HIV-positive people with neuropsychological impairment to live what most would consider a normal, independent life (Marcotte et al., 2006).

A person's mood can also suffer, not only as a symptom of HAND, but also as a byproduct of the aforementioned loss of independence and everyday impairment. Apathy and depression appear more often in HIV-positive people, with depression significantly affecting quality of life (Tate et al., 2003). Considering that gay, bisexual, and transgender men who have

sex with men are the most impacted by HIV/AIDS in the US while already being at heightened risk for mental health issues, depression resulting from HAND could create a dangerous, and sometimes even deadly, combination (CDC, 2018; Lyons et al., 2012; Budge et al., 2013). There is also significant stigma associated with being HIV-positive that could lead to a sense of isolation or depression (Wohl et al., 2013). It would not be unreasonable to anticipate how these factors could interact to leave HIV-positive individuals feeling like they have lost their independence, and potentially, to feelings of isolation and depression.

One of the most important aspects of HIV/AIDS treatment is daily medication adherence. Unfortunately, the cognitive deficits found in HAND could impair an HIV-positive individual's ability to consistently adhere to their medications, especially among older people (Barclay et al., 2007). The combined effects of aging with neuropsychological impairment can be rather detrimental to functional task performance, leading to medication management difficulties (Thames et al., 2011). While the occasional missed dose may not severely subvert HIV treatment, the effects of HAND combined with aging could prospectively lead to a level of inconsistency in medication adherence that would ultimately worsen HIV/AIDS symptoms. Considering that typical antiretroviral therapies appear to not fully protect against HAND, it is imperative that there be both a firm understanding and vigilance of HAND's problematic symptoms (Heaton et al., 2011).

Considering the domains of cognition that are impaired in HAND, there are plenty of instrumental activities of daily living that are impeded by this condition (Heaton et al., 2004). As already mentioned, the memory deficits can affect daily medication adherence. Additionally, difficulties with motor skills can make household chores and using technology like cellphones,

tablets, or computers particularly challenging. Quality of life, which can already be a challenge while managing HIV, is undermined by the neurocognitive symptoms of HAND.

Community-Based Participatory Research (CBPR)

CBPR is more than just a research methodology, it is an approach to building knowledge that focuses on learning with the community and establishing a long-term commitment to change (Wallerstein & Duran, 2006). By establishing a mutually beneficial relationship with the community and participants, researchers using a CBPR approach are able to further their research goals while also collaborating with stakeholders and providing opportunities for all to learn and grow together. More specifically, when it comes to public health research, CBPR focuses on inequity and takes advantage of the "active involvement of community members, organizational representatives, and researchers in all aspects of the research process" (Israel et al., 1998). This collaborative approach attempts to create a stronger bridge between the research itself, and the community that the research is intended to aid, by intentionally involving the community and disseminating information along the way.

Research on health practices and policies tends to show little real-world application and this is being met with frustration from communities and funding sources (Green & Mercer, 2001). To this end, CBPR shows promise in ensuring meaningful community involvement, focusing the research on questions important to the community, and developing research focused on real-world solutions. This approach can help bridge the gap between the researcher and the target community to speed up the normally long and arduous process of disseminating findings to those who are intended to benefit from them.

The key features of CBPR are collaboration between researchers and community members, valuing the use of various methods to discover and disseminate information, and

working towards the ultimate goal of social action with an emphasis on social change and social justice (Strand et al., 2003). What this looks like in practice is researchers reaching out to community organizations to collaborate on the establishment of the research questions and methods of a study. Then, when results are known, the researcher returns to the community organizations to share their findings. These findings can then be used to promote social change by informing policy decisions or establishing and improving social programs.

CBPR can drastically reduce the time required to move from reporting research findings to effective and meaningful implementation in the community, yet within psychology it is drastically underutilized. Espinosa and Verney (2020) searched databases for articles from 2004 to 2014 and found only 311 papers in the 10-year period that could be considered a psychology related CBPR article. Its efficacy in studying topics linked to inequity, such as HIV, is invaluable and should be brought into the mainstream. Taking a CBPR approach provides PLWH the opportunity to participate in research meaningful to them and can help them feel empowered as owners of the knowledge built (Liboro, 2019).

Goals of the Study

We were primarily guided by the intention to identify the current level of awareness of HAND in Southern Nevada. In doing so, we had a secondary goal of educating participants and spreading awareness, which speaks to the CBPR approach. Concretely, the main questions that guided our research were: (1) What does awareness look like in both PLWH who are at risk of developing HAND and the healthcare/service providers that are critical to HIV care? (2) Is there a difference in the levels of awareness based on any demographic characteristics? And (3) What are some current experiences that PLWH and their providers report encountering related to HAND?

Methods

This quantitative study gauged awareness and knowledge on HAND among middle-aged and older PLWH in Southern Nevada, and their local healthcare and service providers, using two separate surveys that explored their lived and work experiences (related to aging, HIV/AIDS, and neurocognitive issues), respectively. This was done utilizing a CBPR approach, in which partnerships were established with local Southern Nevada organizations, key opinion leaders, and other relevant stakeholders, and participants were recruited from the broader community. Primary community partnerships were established with the LGBTQ Center of Southern Nevada ("The Center"), and the Southern Nevada Health District, particularly their Ryan White care program, which provides HIV treatment and prevention services, as well as vital information on necessary resources to HIV-positive folks. Additionally, community collaborations were formed with other agencies such as the Aid for AIDS of Nevada, Golden Rainbow, and Community Counseling Center of Southern Nevada. The conduct of this study had been approved by the (Social/Behavioral) Institutional Review Board (IRB) of the University of Nevada, Las Vegas, (January 15, 2021) through an expedited review process.

Recruitment

A purposive (criterion) sampling strategy (Palys, 2008) was used to recruit participants from August 2021 to February 2022, with the help of community partners and collaborators. Recruitment flyers were posted on the physical premises, websites, and social media outlets of these organizations, as well as a scripted recruitment email messages sent out to any applicable newsletter mailing lists and email listservs the organizations were willing to share the messages. Additionally, we participated in some local community events to conduct recruitment outreach activities and spread the word about our ongoing surveys and recruit in-person when possible,

considering the safety precautions in place for COVID-19 during the height of the pandemic. The COVID-19 pandemic in 2021 created significant barriers to recruiting our already difficult-to-reach prospective participants, and we needed to adjust our recruitment strategies based on the input of our community partners and collaborators. Prospective participants responded to these flyers and recruitment posts by reaching out to our research team via email and were then screened and subsequently officially invited to participate with a survey link.

On a personal note, this study was my first true exposure to the CBPR approach and especially after dealing with the isolation experienced during the pandemic recruiting people from the community felt deeply meaningful. Even in the few outreach events we were able to join I recognized the importance of what we were doing, perhaps even more so as a Gay second-generation Hispanic. I have a great deal of compassion for the older generation of PLWH, many of whom recall times during the 80s when they lost many friends or were given mere months to live. They are a pillar of strength often overlooked and I enjoyed having the opportunity to give back.

Participants

Since those most at risk of developing HAND are older PLWH, the inclusion criteria for this set of participants required that they were: (1) 45 years of age or older, (2) current residents of Southern Nevada, and (3) living with HIV/AIDS for at least one year. Participants who have been living with HIV/AIDS for at least a year would have already had significant lived experiences that would be useful to the study. These requirements ensured that participants were middle-aged and older PLWH in Southern Nevada. Screening was done prior to granting participants access to the survey, and inclusion requisites were double-checked using demographic questions within the survey.

Community-based healthcare and service providers also had to meet inclusion criteria. Providers were required to be: (1) aged 18 or older, (2) currently working in programs or services that support PLWH in Southern Nevada, and (3) in their role/position for a minimum of six months. Similar to the participants living with HIV, providers were also be screened prior to gaining access to the survey so they could be confirmed to meet the criteria for eligibility. Qualifying roles for providers included anyone providing health or social support services to PLWH. Examples of such roles include, but are not limited to, clinicians, nurses, social workers, case workers, and disability support workers.

A power analysis using G*Power indicated that detecting a main effect among three groups with a moderate effect size would require 177 participants. This was ultimately increased to 250 PLWH and 30-40 healthcare or service providers, as the sample size would have to be greater to test for other variations and interactions, as well as to give enough statistical power to detect a smaller effect size.

The demographics of the sample were expected to be racially and ethnically diverse. Based on the most up to date data from Healthy Southern Nevada (2021), Clark County's population is 32.75% Hispanic or Latino. Furthermore, the breakdown of the three largest groups of racial identities in Clark County include Black/African American (12.51%), Asian (10.28%), and White (54.40%). The remaining 22.81% belong to "Some Other Race" (15.08%), 2+ Races (6.18%), American Indian/Alaskan Native (0.78%), and Native Hawaiian/Pacific Islander (0.76%). In comparison, the US Census Bureau reported that the 2019 US population demographics showed the Hispanic/Latino population to be 18.5%, Asian population to be at 5.9%, Black or African American alone at 13.4%, and the White population to be at 76.3%. Considering these percentages, it was clear that while Clark County has a slightly lower

percentage of Black or African American people, there was a considerably greater proportion of non-White people relative to the overall US population, and specifically a larger percentage of people identifying as Hispanic/Latino. This racial and ethnic diversity was seen in our sample. As further discussed in the results, we saw a rate of 61% non-white participants in the recruited PLWH, and 65% non-white participants in the recruited providers.

Another aspect of Southern Nevada to consider is that, based on the latest data from Healthy Southern Nevada, the rate of persons living with HIV increased from 374 per 100,000 population in 2011-2013, to 418 per 100,000 in 2014-2016, and people aged 45-54 showed the highest rates at the time of measurement. While there is data to inform us about the PLWH we can expect to find in Southern Nevada, there is little information about providers which adds to the importance of the current study.

Procedures

Participants reached out to the research team via email expressing their interest to participate in the study. The contact information for the research team was retrieved from the recruitment materials posted with the help of our community partners on their physical premises and virtual platforms, and some were recruited in-person during events specific for PLWH that were hosted by our community partners and collaborators. The participants were then screened by the research team with screening questions that vary slightly between the PLWH and the providers. In order to qualify, the interested parties need to meet the inclusion criteria described for PLWH or providers, which were determined through screening questions answered by prospective participants over email or in a screener survey for participant convenience.

After being screened, qualified participants were emailed a link to the Qualtrics survey, or directly linked to it if they completed the screener survey and met the criteria. The first page

of the survey contained all the consent information necessary for participants to make an informed decision on whether or not they wished to continue. Once consent was provided, participants proceeded to complete the 15–20-minute survey, which ended with demographic questions. Afterwards, the participants continued email correspondence with the research team to arrange delivery and activation of their $15 gift cards sent anonymously by mail. The $15 gift card that each participant received was compensation for their time and efforts.

Survey Items

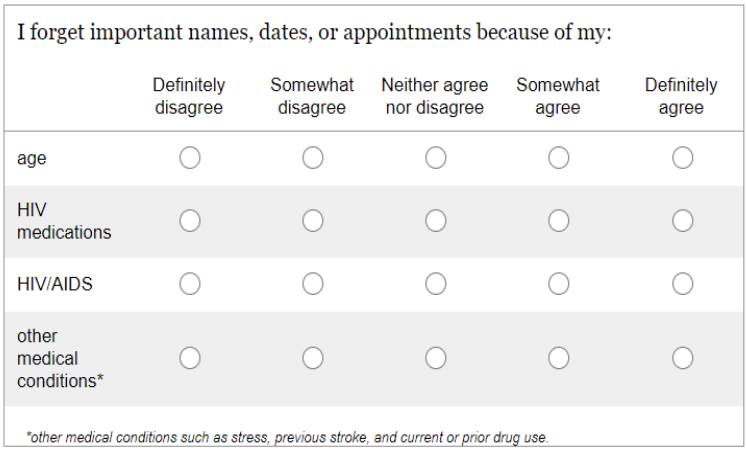
Survey items were generated to gain a greater understanding of how HAND affects participants (for PLWH), and the patients of participants (for providers). Additionally, it gauges familiarity and knowledge of HAND, as well as awareness of support resources related to neurocognitive challenges, among participants. Themes from recent prior research were considered, and ultimately, brought together to create a set of questions that would properly examine a broad sense of the level of awareness and knowledge of HAND in the samples with a focus on the qualitative research conducted by Liboro and colleagues in Toronto, Canada (Liboro et al., 2018; Liboro, Rourke, et al., 2019; Gallagher et al., 2013; Hopcroft et al., 2013).

The first section addresses personal experiences and contains two questions for each of the cognitive domains that are affected by HAND. The first question, for example, states, “I have trouble remembering important names, dates, or appointments” with the response options *always, frequently, sometimes, occasionally,* and *never*. Should the participant answer anything other than “never” they were given the follow-up question, “I forget important names, dates, or appointments because of my:” with a matrix containing possible causes of the symptom as shown in Figure 1. The format of this memory question is mirrored in the following questions to address personal experiences and perceived causes of problems with concentration/complex

attention, learning, language, decision making, problem solving, and motor skills. PLWH who took the survey answered these questions in terms of their own lived experiences, while healthcare and service providers received slightly modified questions to ensure they answer based on their own work experiences. Following these dyads were questions regarding real-world difficulties participants or the patients of participants may have experienced. Again, for these questions, PLWH answered based on their own experiences, and providers answered regarding their patients' reported experiences and own work experiences.

Figure 1

Matrix containing possible causes of a symptom



Four questions from the PROMIS (Patient-Reported Outcomes Measurement Information System) cognitive function scale addressing every-day cognitive function were also included to create the opportunity to compare our questions generated from the previous qualitative study in Toronto with a validated measure (Saffer et al., 2015). The PROMIS scale

item bank assesses patient-perceived cognitive deficits on aspects such as concentration, mental acuity, verbal and nonverbal memory, verbal fluency, and perceived changes in cognitive functions.

Next, both groups of participants completed a short quiz wherein they answered questions about HIV/AIDS, cognitive functioning, and HAND. These questions were in a true/false format that were presented across a scale of confidence. The response options included, “Yes, I am certain this is true”, “Yes, I am mostly certain this is true”, “I’m not sure”, “No, I am mostly certain this is false”, and “No, I am certain this is false”. These options reveal the level of knowledge the participants have on the topics presented. Lastly, participants answered a handful of questions addressing the accessibility of relevant resources and support.

Lastly, participants completed a demographics questionnaire. Both PLWH and providers supplied their age, gender/gender identity, race/ethnicity, sexual orientation, and highest level of education completed. PLWH were additionally asked for their geographical area of residence, length of time living with HIV, length of time (if any) of consistent HIV medication adherence, and other social determinants of health they may have experienced (e.g., housing insecurity, food insecurity, ability to afford medication, etc.). Providers were additionally asked to supply their current geographical area of work, how long they had been working to support PLWH, and their current role or position at work.

For copies of the full surveys see Appendix A and B.

Analysis Plan Adjustments and Recruitment Challenges

Conducting research during the height of the COVID-19 pandemic presented many challenges related to our participant recruitment. Traditionally, in CBPR one would be involved in multiple outreach events with community partners, and recruit on the premises of community

organizations. However, due to the safety restrictions that were in place early on during the COVID-19 pandemic, we were unable to recruit in these traditional physical manners outright. All of the premises, services, and programs of the organizations where we would have potentially been able to reach many prospective participants were closed down or converted to virtual options for most of the year of 2021. Working around this, we increased our recruitment efforts through email listservs, flyers, social media posts, and snowball sampling by encouraging participants to spread the word and refer potentially qualified participants to our surveys.

Originally, we had intended to make use of analysis of variance (ANOVA) statistical procedures to identify differences in knowledge based on sociodemographic variations. For example, previous research has identified that HIV prevention knowledge is lowest among older, non-Hispanic, non-White gay, bisexual, and other men who have sex with men (Akshay et al., 2018). While it would have been ideal to compare each possible demographic group identity separately, we found that with our recruitment difficulties, this would be implausible and unwise as some identities had very low rates of participation. Instead, for many analyses, we had to switch to independent-samples T-Tests and group some characteristics together, such as comparing responses of people who identified as White with the responses of those who did not identify as White, rather than having a group for each racial identity identified in our surveys (e.g., Black, Asian, Indigenous).

Results

We concurrently conducted both surveys for PLWH and for their healthcare/service providers from August 2021 to March 2022. Including those with incomplete data, we successfully recruited 75 participants in total: 34 PLWH and 50 healthcare/service providers. Nine participants completed both surveys, as they satisfied all inclusion criteria involved. Due to

the difficulties we encountered in recruiting our already hard-to-reach populations during the COVID-19 pandemic, we decided to allow participants to complete both surveys. We also believed it was necessary to include participants with partial data, even though we were thus unable to verify that they met the inclusion criteria. Previously, our data analysis plan included the use of ANOVA to identify differences in knowledge on HAND based on sociodemographic variables. However, as detailed in the specific analyses below, this was restricted due to the small sample size we were able to obtain. Instead, we used t-tests after combining groups with low participant identification.

People Living with HIV

Thirty-six PLWH were recruited. Two participants were removed because they were under the required age of 45 years old, and 1 participant had incomplete data (47% completion), leaving 33 PLWH with full data for analysis. The participant with incomplete data was included in analyses only where there was sufficient data to do so.

Demographics

Table 1 shows the demographic variables collected from the sample: age, time living with HIV, gender/gender identity, race/ethnicity, and sexual orientation. Participants were able to select more than one option (if applicable) when answering demographic questions. Ages ranged from 45 to 68 (mean = 56.5), and time spent living with HIV ranged from 1.3 years to 36.4 years (mean = 19.4). Participants were racially and ethnically diverse, with only 39% of respondents identifying as white. A small majority of participants identified as gay men (55%). Additionally, 100% of participants reported currently being on medication to treat their HIV.

Table 1

Participant Demographics (People Living with HIV)

	N	%	Mean	SD
Age, yrs.	33	—	56.5	5.7
Time living with HIV, yrs.	33	—	19.4	10.7
Gender/Gender Identity				
Cisgender Man	19	58	—	—
Cisgender Woman	7	21	—	—
Non-Binary	2	6	—	—
Gender Non-Conforming	1	3	—	—
Prefer Not to Say	4	12	—	—
Race/Ethnicity*				
White	13	39	—	—
Black/African American	9	27	—	—
Asian/Pacific Islander	4	12	—	—
Hispanic/Latine	3	9	—	—
Native American	3	9	—	—
Middle Eastern	1	3	—	—
Self-Describe	1	3	—	—
Sexual Orientation*				
Gay	18	55	—	—
Straight	12	36	—	—
Pansexual	2	6	—	—
Bisexual	1	3	—	—
Self-Describe	1	3	—	—

Note: Categories with no participants (e.g. Transgender Woman, Asexual, etc.) are not shown

* Participants were able to select multiple options. Percentages do not sum to 100

Personal Experiences

Composite variables were created for self-reported cognitive impairment, functional impairment, and social difficulties. The cognitive impairment composite variable consisted of the

responses to questions 1, 3, 5, 7, 9, 11, and 13, which can be seen in Appendix A, and are additionally reported in Table 2. The functional impairment composite variable consisted of the first five questions presented in the matrix for question 15, while the social difficulties composite was the combination of the remaining three questions presented in question 15, which are also available in Appendix A, as well as Table 3. Reliability analyses were conducted to ensure these variables could be appropriately grouped, and all three composite variables had a Cronbach alpha level greater than 0.8, indicating acceptable levels of inter-question reliability.

Cognitive impairment self-report was rated on a Likert-type scale with options “Always”, “Frequently”, “Sometimes”, “Occasionally”, and “Never”, where the value 1 was assigned to Always, and 5 was assigned to Never (mean = 3.67). Both functional impairment and social difficulties were measured by participants responding to questions such as “Challenges related to memory, concentration, decision-making, and other cognitive functions make it difficult for me to shop, prepare meals, and/or do my household chores” on another Likert-type scale with options “Definitely Agree”, “Somewhat Agree”, “Neither Agree nor Disagree”, “Somewhat Disagree”, and “Definitely Disagree”. 1 was assigned to “Definitely Agree” and 5 was assigned to “Definitely Disagree” (mean Functional Impairment = 3.76, mean Social Difficulties = 3.28).

The composite variables were used to assess for any correlations or differences between demographic variables and the self-report ratings of impairment or difficulty. No correlation was found between age and any of the three composite variables (Cognitive Impairment, Functional Impairment, and Social Difficulties $p > .05$). Additionally, no correlation was found between time spent living with HIV and any of the composite variables (Cognitive Impairment, Functional Impairment, and Social Difficulties $p > .05$). Due to sample size restrictions and low response rates for some options, race was grouped as participants who identified as White

compared with those who did not. With these two groups established, an independent samples t-test was conducted on all three composite variables to identify if there were differences in the levels of impairment and difficulties based on race. No significant differences were found in any of the three composite variables (Cognitive Impairment, Functional Impairment, and Social Difficulties $p > .05$).

Table 2 shows participants' self-rated frequency of cognitive difficulties. The most commonly reported cognitive difficulty was having trouble remembering names, dates, and appointments, which 97% of participants reported experiencing to some degree. Table 3 shows participant responses to questions about how cognitive difficulties affect their daily life and social functioning. When looking at those who reported "Definitely Agree" or "Somewhat Agree", we see that 44% of participants report their cognitive issues making it difficult to actively participate in community events and activities, the most often reported issue with daily life.

Table 2

Frequencies of participant self-rated cognitive difficulties

	Always	Frequently	Sometimes	Occasionally	Never
Trouble remembering important names, dates, or appointments	1	9	10	13	1
Difficulties following stories, conversations, or directions	1	4	9	8	12
Challenges learning how to do new things on a computer	3	7	6	9	9
Coming up with the right words to communicate my thoughts or feelings	2	4	8	8	12
Prioritizing my tasks and errands for the week	1	3	5	10	15
Coming up with solutions for day-to-day problems	2	1	6	8	17
Challenges related to my balance and coordination	4	4	5	11	10

Table 3

Frequencies of participant responses to daily function difficulties

Challenges related to memory, concentration, decision-making, and other cognitive functions make it difficult for me to:	Definitely Agree	Somewhat Agree	Neither	Somewhat Disagree	Definitely Disagree
Shop, prepare meals, and/or do my household chores[1]	3	5	5	6	15
Use a cellphone, tablet, or computer[1]	2	6	4	8	14
Use public transportation and keep appointments[1]	3	6	5	6	14
Take my HIV and/or other medications correctly or on time[1]	2	5	4	8	15
Manage my finances[1]	1	4	6	12	11
Engage with others socially[2]	6	5	5	5	13
Actively participate in community events and activities[2]	7	8	4	4	11
Not feel isolated[2]	5	6	5	9	9

[1] functional impairment composite

[2] social difficulties composite

PROMIS Measure

The average PROMIS total raw score was 12.8. Using the provided scoring table this approximates to an average T-score of about 45.81, which indicates that our participants, on average, reported only slightly more difficulty with cognitive function abilities than the national average.

Quiz Scores

In order to keep quiz scoring simple and easily interpretable while simultaneously handling a lack of variance in answers due to the small sample size, answers were grouped such that if the correct answer were "true" then a participant who selected "Yes, I am certain this is true" or "Yes, I am somewhat certain this is true" would be considered correct, while the responses "I'm not sure", "No, I am somewhat certain this is false", and "No, I am certain this is false" would all be marked as incorrect. While measuring confidence in an answer can be useful for analysis of specific questions, grouping the answers in this way creates a more meaningful overall score. The quiz consisted of 12 questions.

PLWH had an average score of 6.1 (SD = 3.1) on the knowledge test. To assess if knowledge on HAND varied by race, we again grouped participants into categories of white and non-white. No significant difference was found between those who identified as white and those who identified as non-white on HAND knowledge ($p > .05$). To compare how varying levels of community resource awareness and community resource access affect HAND knowledge, two more composite variables were created. Resource awareness was the combined results from question 33, "If I have (or start experiencing) difficulties related to memory, concentration, learning, decision-making, and other cognitive functions, I know I can access different

community sources for: (1) reliable information, (2) medical/clinical care, & (3) social services/programs." Resources accessed was the sum of all resources a participant reported having accessed in the past ten years. A bivariate correlation was conducted on each of these two composite variables with quiz score and no significant relationship was found (Resource Awareness and Resources Accessed $p > .05$). Additionally, neither age nor education was found to be correlated with quiz score (age and education $p > .05$).

Due to low sample sizes in other gender identities, an independent samples t-test was used to compare the mean quiz scores of cisgender men ($n = 19$) and cisgender women ($n = 7$), and no significant difference was found ($p > .05$). Similarly, low sample sizes restricted the analysis of sexual orientations, but we proceeded with another independent samples t-test comparing the quiz scores of participants who identified as gay ($n = 18$) and those who identified as straight ($n = 12$). A significant difference was found ($p = .027$, M gay = 5.0, M straight = 7.5) indicating that participants who identified as straight/heterosexual had greater HAND knowledge than those who identified as gay. To further probe this finding, a chi-square test compared the frequencies of HAND discussions with providers to see if this was possibly the result of Straight folks having more discussions with providers. No significant difference was found in the frequency of discussions of HAND with providers between the two groups ($p > .05$).

Another key question asked was to what extent participants had discussed HAND with a healthcare/service provider. Twenty five of the 33 participants reported that their healthcare or service provider has "never or almost never" discussed HAND with them in the past. Due to so many participants responding "never or almost never", we were restricted in the type of analysis possible to compare quiz scores based on frequency of HAND discussion with providers. Consequently, we conducted a t-test to compare those who never or almost never discussed

HAND with a provider to those who report ever having discussed HAND with a provider. No significant difference was found ($p > .05$).

Resources Accessed

As for other resources accessed, the top 5 resources reported by PLWH were AIDS service organizations, food banks, HIV specialists, counseling services, and the Southern Nevada Health District. Table 4 contains detailed reporting rates for all resources.

Table 4
Resources Accessed by PLWH

	N	%
ASOs	26	79
Food banks	26	79
HIV specialists	26	79
Counseling services	22	67
SNHD	22	67
Case workers	20	61
Physicians	20	61
HIV education programs	17	52
Housing services	17	52
Health centers/clinics	16	48
Outreach workers	15	45
Social workers	13	39
Online sources	12	36
Psychiatrists	12	36
Nurse practitioners	10	30
LGBTQ agencies	9	27
Psychologists	9	27
Support workers	8	24
Harm reduction programs	6	18
Homeless shelters	3	9

Healthcare and Service Providers

Fifty-one healthcare and service providers participated in the survey. One participant was removed since they did not meet the inclusion criteria of working in Southern Nevada for at least 6 months. Of the remaining 50 participants, 13 had incomplete data ranging from 12% complete to 93% complete. These participants were still included in analyses where their data was sufficient to do so.

Demographics

Table 5 shows the demographic variables collected from the sample: age, time spent working to support PLWH, gender/gender identity, race/ethnicity, and sexual orientation. Ages ranged from 24 to 64 (mean = 44.4) and time spent working to support PLWH ranged from 0.58 years to 20 years (mean = 6.27). Participants were racially and ethnically diverse, with 68% of respondents identifying as non-white.

Table 5
Participant Demographics (Providers)

	N	%	Mean	SD
Age, yrs.	38	—	44.4	11.9
Time working, yrs.	38	—	6.3	5.5
Gender/Gender Identity				
Cisgender Man	20	53	—	—
Cisgender Woman	15	39	—	—
Non-Binary	1	3	—	—
Prefer Not to Say	2	5	—	—
Race/Ethnicity*				
White	12	32	—	—
Hispanic/Latine	10	26	—	—
Black/African American	9	24	—	—
Asian/Pacific Islander	5	13	—	—
Native American	1	3	—	—
Middle Eastern	1	3	—	—
Self-Describe	1	3	—	—
Prefer Not to Say	1	3	—	—
Sexual Orientation*				
Straight	18	47	—	—
Gay	17	45	—	—
Queer	4	11	—	—
Bisexual	2	5	—	—
Asexual	1	3	—	—
Pansexual	1	3	—	—
Prefer not to Say	1	3	—	—

Note: Categories with no participants (e.g. Transgender Woman, etc.) are not shown
* Participants were able to select multiple options. Percentages do not sum to 100

Patient Experiences

Three composite variables were made for patient experiences to match those created for personal experiences of PLWH. Again, reliability analyses showed that these groupings were

statistically sound as all Cronbach Alpha levels were above 0.85. Cognitive Impairment mean = 3.17, Functional Impairment mean = 2.32, and Social Difficulties mean = 2.44. No further demographic comparisons were done for healthcare and service providers' ratings of patient experiences as there is no reason to believe that any one demographic variable would affect how many patients a healthcare and service provider encounters dealing with neurocognitive difficulties. However, as with PLWH, tables 6 and 7 show more detailed provider responses to reported patient experiences.

Table 6

Frequencies of provider rating of cognitive difficulties in clients/patients

	Always	Frequently	Sometimes	Occasionally	Never
Trouble remembering important names, dates, or appointments	6	15	18	5	6
Difficulties following stories, conversations, or directions	4	12	14	9	9
Challenges learning how to do new things on a computer	4	9	18	7	10
Coming up with the right words to communicate my thoughts or feelings	2	13	14	13	6
Prioritizing my tasks and errands for the week	2	13	11	12	9
Coming up with solutions for day-to-day problems	3	16	10	7	11
Challenges related to my balance and coordination	0	6	12	17	11

Table 7

Frequencies of provider responses to daily function difficulties reported by clients/patients

Challenges related to memory, concentration, decision-making, and other cognitive functions make it difficult for my clients/patients to:	Definitely Agree	Somewhat Agree	Neither	Somewhat Disagree	Definitely Disagree
Shop, prepare meals, and/or do my household chores[1]	8	27	3	1	5
Use a cellphone, tablet, or computer[1]	7	23	4	7	3
Use public transportation and keep appointments[1]	9	22	4	6	3
Take my HIV and/or other medications correctly or on time[1]	7	26	6	3	2
Manage my finances[1]	8	26	4	2	4
Engage with others socially[2]	4	24	11	2	3
Actively participate in community events and activities[2]	2	25	12	3	2
Not feel isolated[2]	9	18	11	4	2

[1] functional impairment composite

[2] social difficulties composite

Quiz Scores

The quiz scores for healthcare and service providers were scored in the same way as PLWH, wherein we exclusively mark the 12 questions as correct or incorrect while disregarding the confidence in the answer. Healthcare and service providers had a mean score of 7.08, with scores ranging from 0 to 12.

Due to the strong, positive skew in years worked we were restricted in how to best compare participants newer to the field with those that have many years of experience. Since a simple correlation or regression would not be possible, an independent samples t-test was conducted wherein the two groups being compared are those below the median score of 4.5 years worked an those above. No significant difference was found between the lower work experience group ($M = 6.21$) and the higher work experience group ($M = 7.95$) ($p > .05$). Again, as with the PLWH, we did not have enough group identification in all race/ethnicity fields to do multiple comparisons, so another independent samples t-test was conducted revealing no significant differences between non-white ($M = 6.51$) and white ($M = 8.45$) service providers, indicating no effect of race on quiz scores ($p > .05$).

The final comparison conducted was based on the question "I have discussed HIV-Associated Neurocognitive Disorder (HAND) with my clients/patients living with HIV/AIDS in the past." Providers who selected "Never or Almost Never" were compared with those who selected any other option ("Rarely", "Sometimes", "Often", "Always or Almost Always"), indicating that they ever, regardless of frequency, discuss HAND with their clients and patients. This grouping was done due to low response rates for some of the response options. With another independent samples t-test, a significant difference was found between providers who ever discuss HAND with their clients and patients ($M = 8.53$), and those who never or almost

never discuss HAND with their clients and patients (M = 5.63; p = .010). Providers who discussed HAND with their clients and patients were more knowledgeable than those who did not. Levene's Test for Equality of Variances was significant (p = .005) so equal variances were not assumed.

Resources Referred

Healthcare and service providers report referring clients and patients mostly to AIDS service organizations, food banks, counseling services, LGBTQ agencies, and the Southern Nevada Health District. Table 8 contains more detailed reporting rates for all resources.

Table 8
Resources Referred by Providers

	N	%
ASOs	31	82
Food banks	30	79
Counseling services	26	68
LGBTQ agencies	26	68
SNHD	26	68
Health centers/clinics	24	63
Housing services	24	63
Case workers	23	61
HIV specialists	22	58
Physicians	22	58
Harm reduction programs	21	55
HIV education programs	21	55
Homeless shelters	21	55
Social workers	21	55
Online sources	20	53
Outreach workers	19	50
Support workers	16	42
Nurse practitioners	14	37
Psychiatrists	14	37
Psychologists	12	32

Exploratory Analyses

The following analyses are considered exploratory due to the comparisons not being fully between-subjects as 9 participants completed both surveys. We found no significant difference when comparing quiz scores across providers ($M = 7.08$) and PLWH ($M = 6.06$; $p > .05$), indicating that providers and PLWH, on average, scored similarly on the quiz.

After each cognitive difficulty question, both providers and PLWH were given the opportunity to rate how much they attribute the difficulty to age, HIV medications, HIV itself, or other medical conditions. Table 9 shows the mean scores for each of these attributions, where 1 indicates “Definitely Disagree” and 5 indicates “Definitely Agree”. Comparisons between the two groups must again be taken carefully, but there is a notable increase in attribution to “other medical conditions” for providers compared to PLWH.

Table 9

Mean attribution scores for both PLWH and providers

	PLWH				Providers			
	Age	**HIV meds**	**HIV**	**Other***	**Age**	**HIV meds**	**HIV**	**Other***
Trouble remembering important names, dates, or appointments	3.21	2.79	2.97	2.97	3.14	2.7	2.95	3.86
Difficulties following stories, conversations, or directions	3.09	3.09	3.36	3.14	3.28	2.67	3.21	4
Challenges learning how to do new things on a computer	3.12	2.56	2.56	3.12	4.13	2.55	2.82	3.84
Coming up with the right words to communicate my thoughts or feelings to friends and family	2.82	2.82	2.77	2.95	3.21	2.93	3.63	3.88
Prioritizing my tasks and errands for the week	3.16	2.89	3.26	3.05	3.16	2.82	3.26	4.05
Coming up with solutions for day-to-day problems	3.29	3.18	3.41	3.29	3.33	2.64	3.31	4
Challenges related to my balance and coordination	3.50	2.96	3.13	3.29	3.77	2.6	3.14	3.94

Note. The underlined scores represent the highest ranked attribution for each item on the left.

Another comparison noticed post-hoc was a difference in the levels of cognitive impairment, functional impairment, and social difficulties experienced by PLWH compared to what was reported by providers. Table 10 contains the T-Tests conducted which show that the mean scores for all three of these composite variables were significantly different, indicating that PLWH are personally reporting more impairment or difficulty than is being reported by providers.

Table 10
Comparisons of Impairment and Difficulties Reported by PLWH and Noticed by Providers

	Providers Mean	PLWH Mean	Sig.
Cognitive Impairment	3.17	3.67	.018
Functional Impairment	2.32	3.76	<.001
Social Difficulties	2.44	3.28	.002*

* Equal variances not assumed

Discussion

People Living with HIV

Personal Experiences

The null findings for correlations between cognitive impairment, functional impairment, and social difficulties with both age and time spent living with HIV were novel as one would expect difficulties to increase with the normal aging process and with progression of HIV. The results for age could be explained by the relatively small range of ages sampled. Our inclusion criteria required participants to be over the age of 45 as those are the folks most at risk of HAND, as well as the age range of people who have been (at the very least) alive long enough since the HIV/AIDS epidemic began, but in doing so we restricted our ability to compare ages beyond our small 23-year range. It is also worth noting that the correlation between age and functional impairment seems to be approaching significance ($p = .088$), and perhaps with a larger sample size, we would have found this relationship to be significant.

Previous research has shown that HAND can still affect PLWH even if they take their medications as prescribed, but that medication does help reduce the symptoms (Ances & Clifford, 2008). This may help explain why time spent living with HIV did not correlate with any levels of impairment or difficulty due to the fact that all participants had been on HIV medication to keep their viral load under control, many of whom had been on medication for many years. The finding that 44% of participants report their cognitive issues make it difficult to actively participate in community events does, however, show that while our participants are not reporting extremely high levels of cognitive impairment, they do still feel an impact on their day-to-day life. Another point to consider is that this study was conducted during the COVID-19 pandemic, and perhaps that could have impacted this specific finding as community events were rare and may have been looked at with extra precaution.

PROMIS measure

The PROMIS measure was included in the study to give a short, validated measure of functional cognitive impairment that we could use to compare with our questionnaire items. The average T-score of 45.81, just slightly below average, seems to line up with our average scores for the cognitive impairment composite (M = 3.67) and functional impairment (M = 3.76). Recall that cognitive impairment scoring ranges from 1 to 5 where 1 indicates “Always” experiencing cognitive difficulties and 5 indicates “Never” experiencing cognitive difficulties, while functional impairment scores range from 1 indicating “Definitely Agree” to having a functional difficulty, and 5 indicating “Definitely disagree”. With this scoring criteria in mind, the mean score for cognitive impairment falls somewhere between “Sometimes” and “Occasionally” experiencing cognitive difficulties, and the mean score for functional impairment falls between “Neither Agree nor Disagree” and “Somewhat Disagree”.

Quiz Scores

HIV research tends to focus on physical symptoms, transmission, and treatment, which is definitely valuable, particularly because of the related clinical and epidemiological implications involved. However, it appears that knowledge on the neurocognitive and mental toll associated with living with HIV is lacking overall. With a mean score of 6.1 out of 12, we can see that our sample of middle-aged and older PLWH, who are most at risk of developing HAND, are generally unaware of either its existence or the extent of its effects.

Since there is a lack of research on the awareness of HAND, we must turn to previous research on general HIV knowledge where mixed results have been found in demographic comparisons of HIV knowledge. For example, one study found gender to be a significant predictor of HIV knowledge in Malaysian University students, where males were more knowledgeable than females (Talwar & Rahman, 2015). However, another study from South Africa found that education level and gender predicted HIV knowledge, where females had greater knowledge than males (Haile, Chambers, & Garrison, 2007). In our sample, however, we found no significant difference in knowledge based on gender in either direction, perhaps indicating that general HIV knowledge does not necessarily lead to knowledge of HAND. This could be due to the focus of most research and awareness efforts being on recognition and treatment of the physical aspects of HIV, with little emphasis on the cognitive impacts.

The only demographic variable that was found to lead to a significant difference in quiz score was sexual orientation. Considering that gay men are most at risk of HIV, it is surprising that those who identify as heterosexual were more knowledgeable than gay-identifying men (CDC, 2018). Further research would be necessary to identify a potential reasoning behind this,

but one possible explanation could be the double/compounding stigma sexual minorities experience, which may make them more reluctant to inquire or learn more about their condition.

Another unsettling result is the vast number of participants who reported never or almost never having had a discussion about HAND with a healthcare or service provider before. HIV treatment often requires a continuum of care with multiple providers, and the fact that 76% of participants have not had a discussion with their doctors or other providers about the neurocognitive symptoms they may develop due to HIV points to a stark need for raising more awareness and knowledge about HAND. While this variable did not ultimately lead to a difference in HAND knowledge quiz scores, it is possible that the null finding was due to the small number of participants who reported ever having discussed HAND with a provider previously. In the future, studies with a specific focus on this research question and a more robust analysis, ideally with a larger sample size, may be necessary to better understand how providers can successfully disseminate knowledge on HAND to their clients and patients.

Resources Accessed

It was noteworthy that AIDS service organizations and HIV specialists were highly reported as resources regularly accessed in the past 10 years by participants. Another notable result in accessing resources was that 79% of participants reported having availed of a food bank. An important note on this point is that this survey was conducted during the height of the COVID-19 pandemic, which may have led to an increase in food insecurity among our participants, and thus, the need for food banks. This may also mean that many of our participants represented a highly underserved population in the community that already accessed food bank services even prior to the COVID-19 pandemic (Strott, 2020). Regardless, the high need for food banks was of concern, particularly in a vulnerable population such as PLWH.

Healthcare and Service Providers

Patient Experiences

We noticed a disconnect between the levels of cognitive impairment, functional impairment, and social difficulties reported by PLWH and noticed by providers. The differences in these mean scores could be due to the fact that the providers sampled come from various service positions. For example, a medical doctor or nurse may encounter patients presenting with these types of impairments and difficulties, but someone in charge of referring resources, such as a caseworker, may not have that hands-on, in-depth, or appropriate contextual interaction with clients to note or report encountering these challenges. Another possibility is that these more personal questions like if household chores are becoming more difficult are the kinds of questions that do not come up in regular health screenings meaning providers are less aware of their presence.

Quiz Scores

It may be reasonable to expect that a provider working in the HIV sector would gain knowledge about neurocognitive challenges related to HIV over years of work experience. However, our results showed no difference between newer providers and veteran workers. Perhaps, with the overall average score for providers being 7.08, this null finding is due to a lack of knowledge and awareness across the board. If HAND is infrequently brought up, discussed, or researched, then no amount of work experience will increase knowledge since that knowledge is simply out of reach. There may not be enough opportunities for continuing education or professional development on this subject matter for the providers who have been working in the Southern Nevada HIV sector in the last many years. Another reason for this null finding could be

the mentioned positive skew in providers' years worked that restricted the analysis to a median split.

The finding that providers who ever discussed HAND with their clients/patients were more knowledgeable about HAND than those who never or almost never did so was apparent. It stands to reason that a provider would have at least some knowledge about HAND to confidently discuss HAND with a client/patient. However, this underscores an important point that providers and their patients would greatly benefit from being able to access this specific knowledge. Efforts to increase the awareness of healthcare/service providers could then lead to an increase in discussions with clients/patients. Consequently, this would also increase the chances of those who are at risk of developing HAND more aware and vigilant of its possible development.

Resources Referred

Comparing Table 8, resources referred by providers, and Table 4, resources accessed by PLWH, we find some similar results. AIDS service organizations, food banks, counseling services, and the Southern Nevada Health District are four of the top 5 resources for both groups, indicating that the resources referred by providers line up with those that are being utilized by service users. This information is valuable because it demonstrates that either providers are receptive to the needs of PLWH, and/or that folks in need of these resources are listening to and benefiting from the suggestions and referrals of providers. It may also likely indicate that these resources are simply indispensable to the continuum of care of HIV positive individuals in Southern Nevada.

Directions for Future Research and Limitations

Although our comparisons between groups should be considered carefully due to the fact that we had some participants completing both surveys, our analyses are still valuable not only because they shed light on the levels of awareness and knowledge of our Southern Nevada community participants living with HIV and their providers on neurocognitive challenges related to HIV, but they also raise awareness and bring greater attention to HAND and its possible consequences in relevant communities, as well as provide new directions for future research. The finding that PLWH and healthcare/service providers scored similarly on the knowledge test points to a possible lack of knowledge, particularly for service providers. One would hope and expect that the healthcare/service providers who serve as experts for their clients/patients would be more knowledgeable about HAND than most, but that does not seem to be the case. However, this could also mean that PLWH are well-versed in their condition, and they show just as much knowledge on the brain health impacts of HIV as their healthcare and service providers. Furthermore, it is up for debate what constitutes a low score on the knowledge test as it is not a widely used, validated measure, and while one would hope healthcare and service providers would score closer to 100% correct, it is also possible that their mean score of 7.08 out of 12 is acceptable. Regardless, this average score does show that there is room to improve the level of awareness and familiarity on HAND among providers.

Another interesting contrast is demonstrated in table 9, where we see that healthcare/service providers appeared to be more likely to attribute cognitive difficulties to other medical conditions than are the PLWH experiencing those cognitive difficulties themselves. Once again, this may point to a lack of knowledge amongst providers of the neurocognitive conditions that can be associated with aging with HIV, or perhaps it is due to providers having greater awareness of other medical conditions such as depression, strokes, or other issues that

could potentially cause neurocognitive issues. Further qualitative research with healthcare/service providers may gain the insight required to make this distinction.

One major limitation to the study is the low statistical power due to a small sample size. Conducting research with hard-to-reach populations requires a tremendous effort, which we did with the help of many community organizations. However, this effort was not enough to reach our original recruitment goals. Being one of the first CBPR labs in UNLV, and likely Southern Nevada as a whole, we had to forge networks that had not yet been developed and attempt to do so during the COVID-19 pandemic, which brought even greater challenges. Previous research on HAND by Liboro and colleagues (2018; 2019) in Ontario, Canada, for example, was able to avail of a strong existing network that was accustomed to being meaningfully involved in CBPR. A major positive result of our efforts is that we are beginning to establish that kind of network here in Southern Nevada for future efforts at connecting with such difficult-to-reach stakeholders of the community.

This low statistical power resulted in necessary changes to the analysis plan which included the collapsing of some demographic characteristics. For example, for racial comparisons we were not able to conduct an ANOVA with each racial group separate as some groups had very low levels of identification. As such, we simply compared white and non-white which is problematic because it seems to assume that someone identifying as Black or African American has the same experience as someone identifying as Hispanic. While it is unfortunate that we were unable to see the full spread of unique lived experiences that these different demographic groups could share we chose to proceed with the collapsed group T-Tests as it was the best option available with the current data.

Another limitation to consider is our failure to distinguish participants who completed both the service provider and service user versions of our survey. In an effort to better protect the identities of our participants, we used anonymous distributions that did not allow us to connect the surveys, effectively weakening our ability to make substantial between-group comparisons. However, we felt it was important to allow participants to complete both surveys as any one person who fits the inclusion criteria for both surveys is an important service provider, and also a person living with HIV, who interacts with HIV resources in Southern Nevada. Future research could better separate these participants with further questions within the surveys that would allow the researchers to, for example, exclude PLWH who are also service providers from certain analyses.

Moving forward, our goals are clear. Firstly, we aim to produce a community report from the data we have collected to disseminate our generated knowledge back to the community. A primary goal of CBPR is to share our knowledge with the community that would benefit the most from our research. By creating a community report, we would be able to share the knowledge we have gained and begin making noticeable, impactful, real-world, grassroots changes in the Southern Nevada community. Next, we would like to proceed with a qualitative follow-up study to gain greater insight and understanding of the results we found in this initial quantitative study. By utilizing in-depth qualitative interviewing, we could, for example, parse the previously mentioned differences in attributions between PLWH and their service providers. Where quantitative methodologies give breadth, qualitative methodologies can give depth and context to the results. While awareness and knowledge of HAND was generally low, with our continued efforts we could utilize community-focused strategies in research to increase our understanding of HAND, while also sharing ownership of that knowledge with the community.

Appendix A: Survey Items for People Living with HIV/AIDS

HAND Questionnaire - PLWH

Start of Block: Consent

Thank you for choosing to participate in our study!
First we will show you some information about the study. Once you have reviewed it and provided us with your consent, we will proceed to the survey.

People typically take about 15 to 20 minutes to complete this survey.
As long as you come to this survey through the same device and browser, you will be able to pick up where you left off, should you need to stop at any time.

Page Break

INFORMED CONSENT FOR STUDY SURVEY – SERVICE USERS
Department of Psychology
TITLE OF STUDY: Awareness and Knowledge on Aging and HIV-Associated Neurocognitive Disorder: Service User and Provider Perspectives in Southern Nevada
INVESTIGATOR(S): Dr. Renato (Rainier) M. Liboro

For questions or concerns about the study, you may contact Dr. Liboro at unlvhandstudy@gmail.com or 702-895-4654.

For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted, contact the UNLV Office of Research Integrity – Human Subjects at 702-895-2794, toll free at 888-581-2794 or via email at IRB@unlv.edu.

Purpose of the Study
You are invited to participate in this research study. The aim of the study is to identify and explore the perspectives and lived experiences of racially and ethnically diverse, middle-aged and older people living with HIV/AIDS on the relationships and interactions between HIV/AIDS, aging, memory, concentration, complex attention, and other cognitive functions. More specifically, the study aims to learn about the awareness and knowledge of people living with HIV/AIDS in Southern Nevada on the possible impact of a condition known as HIV-Associated Neurocognitive Disorder, or HAND, on their lives as they age.

Participants
You are being asked to participate in the study because you fit this criteria: You reside and can provide a mailing address within Southern Nevada, are 45 years of age or older, and have been living with HIV/AIDS for a year or more.

Procedures If you volunteer to participate in this study, you will be asked to do the following: Once you have read and understood this informed consent form, and agreed to participate in the survey, you will be asked to complete a 15 to 20-minute survey. Then, you will be asked to complete a brief demographic information sheet that will ask you about your age range, race/ethnicity, gender/gender identity, sexual orientation, number of years and/or months living with HIV/AIDS, and the geographical area where you currently reside. Before you start answering the survey questions and demographic information sheet, we encourage you to print and keep a copy of this consent form once you have decided to agree to participate in it.
Benefits of Participation
There may not be direct benefits to you as a participant in this study. However, we hope to learn about the levels of awareness and knowledge of people living with HIV/AIDS in Southern Nevada on HAND. The results of this study will help inform, influence, and improve current and future HIV/AIDS services, programs, and policies that are dedicated to supporting racially and ethnically diverse, older people living with HIV/AIDS at risk of, or already experiencing, signs

and symptoms of HAND.

Risks of Participation

Participation in this study includes only minimal risks. Some of these minimal risks may include fatigue, frustration, and/or momentary embarrassment that could occur while answering survey questions. These feelings are temporary and will quickly pass. In case you will need it, we can provide you information on where to get support for these feelings, if they persist. We can also provide you resources on how to get information about HAND, in case you are interested to learn more about it.

Cost /Compensation

There is no financial cost to you to participate in this study. The online survey will take 15 to 20 minutes of your time. You will be compensated for your time and efforts with a $15 Visa gift card upon completion of the survey. The gift card will be mailed to the mailing address you will provide to the research team over email (unlvhandstudy@gmail.com) after you complete the survey. With the exception of your name and mailing address on the envelope, and the gift card in the envelope mailed to you, there will be no other information on, or items in the envelope that may link you to this study. Once you receive the gift card in the mail, you will need to email the research team again to confirm receipt of the card so that the research team can activate and add the $15 amount to your card according to the secure and UNLV-approved Forte Payments System protocol.

Confidentiality

Information gathered from you during this study are or may be identifiable information (i.e., your name, email address, mailing address) or private information (e.g., age range, HIV status, etc.). We do not intend to share or disclose any of these identifiable and private information to anyone, and we will be employing several measures and strategies to maintain the privacy and confidentiality of these information. Only our Principal Investigator and two other members of our research team will have access to your identifiable information found in the team's email correspondences with you, which will be kept separate from your anonymized survey data. All information gathered in this study will be kept confidential. No references will be made in written or audio/video materials that could link you to this study. Findings from the study will be de-identified, aggregated, and reported in a way that will not identify any of the study participants. All physical copies of your study documents will be stored in a locked cabinet at UNLV for 5 years after completion of the study. All recordings and digital copies of your study documents will be encrypted, password-protected, and stored separately in the research team's lab computers. After the storage time, the information will be destroyed by our research team.

Voluntary Participation

Your participation in this study is voluntary. You may refuse to participate in this study, or refuse to answer any question you are not comfortable answering should you decide to participate in the survey. You may withdraw from the study at any time without prejudice to your relations with UNLV or any opportunity to participate in future studies. You are encouraged to ask questions about this study at the beginning, or any time during the study. You are encouraged to let the

researchers know if you have any concerns regarding the study at any time.

Future Use of Research Data
Identifiers might be removed from identifiable private information and, after such removal, the information in this research study could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you.

Participant Consent:
By participating in this the survey, I indicate that I am at least 45 years of age, I have read and understood the information provided, and agree to participate in the study.

Below is a link to a pdf of the consent form you just reviewed. The form will open in a new tab on your internet browser where you can then choose to download and/or print the form for your own records.

Survey Consent Form

After reviewing the above consent form, do you consent to participate in this survey?

- ○ I agree
- ○ I disagree

Skip To: End of Survey If After reviewing the above consent form, do you consent to participate in this survey? = I disagree

End of Block: Consent

Start of Block: Personal Experience

This first set of questions will ask you about some personal experiences you may have had regarding memory, attention, learning, language, decision-making, problem-solving, and motor skills.

Remember your answers are completely anonymous and you can skip any question that you are uncomfortable answering.

Page Break

I have trouble remembering important names, dates, or appointments.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have trouble remembering important names, dates, or appointments. = Always

Or I have trouble remembering important names, dates, or appointments. = Frequently

Or I have trouble remembering important names, dates, or appointments. = Sometimes

Or I have trouble remembering important names, dates, or appointments. = Occasionally

JS

I forget important names, dates, or appointments because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I have difficulties following stories, conversations, or directions.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have difficulties following stories, conversations, or directions. = Always

Or I have difficulties following stories, conversations, or directions. = Frequently

Or I have difficulties following stories, conversations, or directions. = Sometimes

Or I have difficulties following stories, conversations, or directions. = Occasionally

JS

I have difficulties following stories, conversations, or directions because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I experience challenges learning how to do new things on a computer.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I experience challenges learning how to do new things on a computer. = Always

Or I experience challenges learning how to do new things on a computer. = Frequently

Or I experience challenges learning how to do new things on a computer. = Sometimes

Or I experience challenges learning how to do new things on a computer. = Occasionally

JS

I experience challenges learning how to do new things on a computer because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I have difficulties coming up with the right words to communicate my thoughts or feelings to friends and family.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have difficulties coming up with the right words to communicate my thoughts or feelings to frie... = Always

Or I have difficulties coming up with the right words to communicate my thoughts or feelings to frie... = Frequently

Or I have difficulties coming up with the right words to communicate my thoughts or feelings to frie... = Sometimes

Or I have difficulties coming up with the right words to communicate my thoughts or feelings to frie... = Occasionally

JS

I have difficulties coming up with the right words to communicate my thoughts or feelings to friends and family because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I have trouble prioritizing my tasks and errands for the week.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have trouble prioritizing my tasks and errands for the week. = Always

Or I have trouble prioritizing my tasks and errands for the week. = Frequently

Or I have trouble prioritizing my tasks and errands for the week. = Sometimes

Or I have trouble prioritizing my tasks and errands for the week. = Occasionally

JS

I have trouble prioritizing tasks and errands for the week because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I have difficulties coming up with solutions for day-to-day problems.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have difficulties coming up with solutions for day-to-day problems. = Always

Or I have difficulties coming up with solutions for day-to-day problems. = Frequently

Or I have difficulties coming up with solutions for day-to-day problems. = Sometimes

Or I have difficulties coming up with solutions for day-to-day problems. = Occasionally

JS

I have difficulties coming up with solutions for day-to-day problems because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I have challenges related to my balance and coordination.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I have challenges related to my balance and coordination. = Always

Or I have challenges related to my balance and coordination. = Frequently

Or I have challenges related to my balance and coordination. = Sometimes

Or I have challenges related to my balance and coordination. = Occasionally

JS

I have challenges related to balance and coordination because of my:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

Challenges related to memory, concentration, decision-making, and other cognitive functions make it difficult for me to:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Shop, prepare meals, and/or do my household chores	○	○	○	○	○
Use a cellphone, tablet, or computer	○	○	○	○	○
Use public transportation and keep appointments	○	○	○	○	○
Take my HIV and/or other medications correctly or on time	○	○	○	○	○
Manage my finances	○	○	○	○	○
Engage with others socially	○	○	○	○	○
Actively participate in community events and activities	○	○	○	○	○
Not feel isolated	○	○	○	○	○

Difficulties related to memory, concentration, decision-making, and other cognitive functions **are difficult for me to adjust to because of their episodic and sporadic (on-and-off) nature**.

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree
- ○ Not applicable to me

Difficulties related to memory, concentration, decision-making, and other cognitive functions **leave me with feelings of uncertainty about the future**.

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree
- ○ Not applicable to me

Please respond to each statement by marking one box per row.

In the past 7 days...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
My mind has been as sharp as usual ...	○	○	○	○	○
My memory has been as good as usual ...	○	○	○	○	○
My thinking has been as fast as usual ...	○	○	○	○	○
I have been able to keep track of what I am doing, even if I am interrupted ...	○	○	○	○	○

End of Block: Personal Experience

Start of Block: Descriptive Text Block

The following questions will help us determine your familiarity with HIV/AIDS and cognitive functioning, and HIV-Associated Neurocognitive Disorder (HAND).

For each statement, please select from the options to inform us if you believe each statement to be true or false, along with how confident you are in your answer.

For these questions we are interested in the type of information participants can easily recall, so it is important that you answer to the best of your ability without any outside help. Also your honesty is very important, if you don't know an answer then just select "I'm not sure" instead of guessing true or not true. We will only look at averages, not your individual answers, and your responses will have no impact on your compensation for the study. We will also provide an opportunity to see the correct answers at the end of the study so please answer honestly.

End of Block: Descriptive Text Block

Start of Block: Quiz HIV/AIDS and Cognitive Functioning

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

HIV can still affect my memory, concentration, learning, decision-making, and other cognitive functions even if I don't develop dementia related to HIV.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making

and other cognitive functions are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

Taking my HIV medications exactly as my doctor prescribes will guarantee that I won't experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

Keeping my viral load undetectable and my CD4 (T-cell) count high will guarantee that I won't

experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

End of Block: Quiz HIV/AIDS and Cognitive Functioning

Start of Block: Quiz HIV-Associated Neurocognitive Disorder

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the memory, concentration, learning, decision-making, and other cognitive functions of people living with HIV/AIDS as they grow older.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

End of Block: Quiz HIV-Associated Neurocognitive Disorder

Start of Block: Continuity of Care, Resources, and Support

The questions below address resources and support you may or may not know about or have experience with.

My healthcare or service provider has discussed HIV-Associated Neurocognitive Disorder (HAND) with me in the past.

- ○ Always or Almost Always
- ○ Often
- ○ Sometimes
- ○ Rarely
- ○ Never or Almost Never

If I have (or start experiencing) difficulties related to memory, concentration, learning, decision-making, and other cognitive functions, I know I can access different community sources for:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
reliable information	○	○	○	○	○
medical/clinical care	○	○	○	○	○
social services/programs	○	○	○	○	○

I would feel more comfortable knowing that there are support groups in the community

composed of people who have successfully managed their own challenges related to HIV-Associated Neurocognitive Disorder (HAND).

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree

I believe it is important that more people living with HIV/AIDS be aware of or familiar with HIV-Associated Neurocognitive Disorder.

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree

I am interested in accessing more information about HIV-Associated Neurocognitive Disorder.

- ○ Yes
- ○ No
- ○ I'm not sure

End of Block: Continuity of Care, Resources, and Support

Start of Block: PLWH Demo

This final section will ask you a few demographic questions such as age and gender. When answering these remember that your answers are completely anonymous and your information will be kept secure.

*

Age (please answer with digits only, such as "45")

_____

Which of these best describes your current gender identity? (select all that apply)
Cisgender: My gender matches the gender I was assigned at birth.
Transgender: My gender differs from the gender I was assigned at birth.

- [ ] Cisgender woman
- [ ] Cisgender man
- [ ] Genderqueer/Gender Non-conforming or gender fluid
- [ ] Non-binary
- [ ] Transgender woman
- [ ] Transgender man
- [ ] Prefer to self-describe _____
- [ ] Prefer not to say

Race/Ethnicity (select all that apply)

- [ ] Asian or Pacific Islander
- [ ] Black or African American
- [ ] Hispanic or Latinx
- [ ] Middle Eastern
- [ ] Native American or American Indian
- [ ] White
- [ ] Prefer to self-describe _____
- [ ] Prefer not to say

What race or ethnicity do you feel you most identify with?

_____

Sexual Orientation (select all that apply)

- ☐ Asexual
- ☐ Bisexual
- ☐ Gay
- ☐ Straight (heterosexual)
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Questioning or unsure
- ☐ Prefer to self-describe _____
- ☐ Prefer not to say

Geographical area of residence

- ○ Boulder City
- ○ Enterprise
- ○ Henderson
- ○ Las Vegas
- ○ Mesquite
- ○ North Las Vegas
- ○ Paradise
- ○ Spring Valley
- ○ Winchester
- ○ Other _____

Highest level of education completed

- ○ Less than high school degree or equivalent
- ○ High school degree or equivalent (such as GED)
- ○ trade/technical/vocational training or certification
- ○ Some college but no degree
- ○ Associates Degree
- ○ Bachelor's Degree
- ○ Master's Degree
- ○ Doctorate Degree (includes professional degrees like JD, MD)

Which of the following, if any, have you experienced since being diagnosed with HIV/AIDS? (Select any/all that apply)

- [ ] Housing Insecurity
- [ ] Homelessness
- [ ] Substance Use
- [ ] Problematic Substance Abuse
- [ ] Depression
- [ ] Income Insecurity
- [ ] Food Insecurity
- [ ] Inability to Afford Medication
- [ ] Disability (please specify if you are comfortable doing so)

_____

In order to meet your needs related to HIV/AIDS, which of the following community-based resources have you accessed (if any) in the last ten years (select all that apply)

- [ ] AIDS service organizations (e.g., Aid for AIDS of Nevada)
- [ ] Community health centers/clinics
- [ ] Counseling services (e.g., Community Counseling Center of Southern Nevada)
- [ ] Food banks
- [ ] Harm reduction programs
- [ ] HIV education programs
- [ ] Homeless shelters
- [ ] Housing services (e.g., Golden Rainbow)
- [ ] LGBTQ agencies (e.g., The LGBTQ Center of Southern Nevada)
- [ ] Southern Nevada Health District (e.g., Ryan White program)
- [ ] Case workers
- [ ] HIV specialists
- [ ] Nurse practitioners
- [ ] Online sources
- [ ] Outreach workers
- [ ] Physicians

- [ ] Psychiatrists
- [ ] Psychologists (e.g., clinical psychologists, neuropsychologists)
- [ ] Social workers
- [ ] Support workers
- [ ] Others (Please specify) _____

How long have you been living with HIV? Please answer with your best estimate in years and months using digits only. For example if you would like to answer 2 and a half years you would enter "2" in years and "6" in months.

- ○ Years _____
- ○ Months _____

Are you currently taking any medications to treat HIV/AIDS?

- ○ Yes
- ○ No

Display This Question:

If Are you currently taking any medications to treat HIV/AIDS? = Yes

For how long (in years/months) have you been on your HIV medication?

- ○ Years _____
- ○ Months _____

Display This Question:

If Are you currently taking any medications to treat HIV/AIDS? = No

Have you ever in the past been on medication to treat HIV/AIDS?

- Yes
- No

Display This Question:

If Have you ever in the past been on medication to treat HIV/AIDS? = Yes

For how long (in years/months) were you on HIV medication?

- Years _____
- Months _____

Would you like to know which of the knowledge questions you answered correctly?

- Yes
- No

End of Block: PLWH Demo

Start of Block: Answers & Resources

Display This Question:

If Would you like to know which of the knowledge questions you answered correctly? = Yes

You got ${gr://SC_00dzjpnGsfRnEns/Score} answers correct out of 12.

Below are the correct answers to the knowledge questions you answered earlier.

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).
Correct Answer: Yes, this is true.

However, even if HIV-related dementia is rare nowadays due to the effectiveness of HIV medications, as much as 50% of people living with HIV/AIDS on prescribed HIV medications may still experience mild to moderate neurocognitive issues in their lifetime.
Your Answer: ${Q20/ChoiceGroup/SelectedChoices}

HIV can still affect my memory, concentration, learning, decision-making, and other cognitive functions even if I don't develop dementia related to HIV.
Correct Answer: Yes, this is true.
Your Answer: ${Q21/ChoiceGroup/SelectedChoices}

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making and other cognitive functions are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.
Correct Answer: Yes, this is true.
This is because in addition to HIV/AIDS itself, regular aging, accelerated aging associated with HIV/AIDS, certain HIV medications (i.e., Efavirenz) and long-term use of anti-retroviral drugs, other medical conditions such as stroke and Alzheimer's dementia, and problematic alcohol/substance use could all produce neurocognitive problems in people living with HIV/AIDS.
Your Answer: ${Q22/ChoiceGroup/SelectedChoices}

Taking my HIV medications exactly as my doctor prescribes will guarantee that I won't experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.

Correct Answer: No, this is not true.

However, taking your HIV medications as prescribed can significantly decrease the chances of these issues developing or progressing.
Your Answer: ${Q23/ChoiceGroup/SelectedChoices}

Keeping my viral load undetectable and my CD4 count high will guarantee that I won't experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.
Correct Answer: No, this is not true.
However, keeping your viral load undetectable and your CD4 count high could significantly decrease the chances of these issues developing or progressing.
Your Answer: ${Q24/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the memory, concentration, learning, decision-making, and other cognitive functions of people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q25/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.
Correct Answer: No, this is not true.
HAND is a spectrum of conditions that includes HIV-Associated Dementia.
Your Answer: ${Q26/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q27/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.
Correct Answer: Yes, this is true.
Your Answer: ${Q28/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q29/ChoiceGroup/SelectedChoices}

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).
Correct Answer: Yes, this is true.
Your Answer: ${Q30/ChoiceGroup/SelectedChoices}

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.
Correct Answer: Yes, this is true.
Your Answer: ${Q31/ChoiceGroup/SelectedChoices}

Display This Question:

If Would you like to know which of the knowledge questions you answered correctly? != Yes

Below are the correct answers to the knowledge questions you answered earlier.

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).
Yes, this is true
However, even if HIV-related dementia is rare nowadays due to the effectiveness of HIV

medications, as much as 50% people living with HIV/AIDS on prescribed HIV medications may still experience mild to moderate neurocognitive issues in their lifetime.

HIV can still affect my memory, concentration, learning, decision-making, and other cognitive functions even if I don't develop dementia related to HIV.
Yes, this is true.

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making and other cognitive functions are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.
Yes, this is true.
This is because in addition to HIV/AIDS itself, regular aging, accelerated aging associated with HIV/AIDS, certain HIV medications (i.e., efavirenz) and long-term use of anti-retroviral drugs, other medical conditions such as stroke and Alzheimer's dementia, and problematic alcohol/substance use could all produce neurocognitive problems in people living with HIV/AIDS.

Taking my HIV medications exactly as my doctor prescribes will guarantee that I won't experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.

No, this is not true.
However, taking your HIV medications as prescribed can significantly decrease the chances of these issues developing or progressing.

Keeping my viral load undetectable and my CD4 count high will guarantee that I won't experience any changes to my memory, concentration, learning, decision-making, and other cognitive functions as I grow older.

No, this is not true.
However, keeping your viral load undetectable and your CD4 count high could significantly decrease the chances of these issues developing or progressing.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the memory, concentration, learning, decision-making, and other cognitive functions of people living with HIV/AIDS as they grow older.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.

No, this is not true.
HAND is a spectrum of conditions that includes HIV-Associated Dementia.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.
Yes, this is true.

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).
Yes, this is true.

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.
Yes, this is true.

Page Break

Thank you for completing the online survey. We really appreciate you taking the time to complete the study for us.

The purpose of this study is to learn more about the awareness and familiarity of people living with HIV/AIDS on the condition known as HIV-Associated Neurocognitive Disorder, and its clinical and day-to-day impacts. We also want to learn more about the lived experiences of survey participants related to this condition.

All information gathered in this study will be kept confidential. No reference will be made in written or oral materials that could link you to this study. We appreciate you taking the time to answer some personal questions about your life. We realize some of the questions we asked were personal in nature but really appreciate you taking the time to participate in our survey.

If you have any questions about the study, please feel free to contact Renato Liboro, PhD (Principal Investigator) via email: renato.liboro@unlv.edu

If for any reason after taking this survey you feel that you might want to talk to someone about treatment opportunities to address some kind of problem you may be encountering, we encourage you to contact us, or local mental health resources/partners in the community directly:

Community Counselling Center of Southern Nevada
714 E. Sahara Avenue
Las Vegas, NV 89104
702-369-8700
cccofsn.org

Ryan White Program Care Services
280 South Decatur Boulevard
Las Vegas, NV 89107
(702) 759-0800
SNHD hiv care services

Information on HIV/AIDS, aging, neurocognitive functions, and HIV-Associated Neurocognitive Disorder for people living with HIV/AIDS and their service providers can be found in the following websites:

John Hopkins HAND guide
CATIE HAND information
UCSF HIV Dementia
caregiver.org HAND

In order to receive your compensation:

When you click this final next arrow you will be directed to a new page where you will enter your email address. The reason for this being separate is to better protect your information so that we cannot tie the answers you gave here to the email address you will give us. You will not be able to return to this page. When you are ready, click the next arrow.

End of Block: Answers & Resources

Appendix B: Survey Items for Healthcare/Service Providers

HAND Questionnaire - Providers

Start of Block: Consent

Thank you for choosing to participate in our study!
First we will show you some information about the study. Once you have reviewed it and provided us with your consent, we will proceed to the survey.

People typically take about 15 to 20 minutes to complete this survey.
As long as you come to this survey through the same device and browser, you will be able to pick up where you left off, should you need to stop at any time.

Page Break

INFORMED CONSENT FOR STUDY SURVEY – SERVICE PROVIDERS
Department of Psychology

TITLE OF STUDY: Awareness and Knowledge on Aging and HIV-Associated Neurocognitive Disorder: Service User and Provider Perspectives in Southern Nevada

INVESTIGATOR(S): Dr. Renato (Rainier) M. Liboro

For questions or concerns about the study, you may contact Dr. Liboro at unlvhandstudy@gmail.com or 702-895-4654.

For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted, contact the UNLV Office of Research Integrity – Human Subjects at 702-895-2794, toll free at 888-581-2794 or via email at IRB@unlv.edu.

Purpose of the Study

You are invited to participate in this research study. The aim of the study is to identify and explore the perspectives and work experiences of service providers working to support people living with HIV/AIDS on the relationships and interactions between HIV/AIDS, aging, memory, concentration, complex attention, and other cognitive functions. More specifically, the study aims to learn about the awareness and knowledge of service providers working to support people living with HIV/AIDS in Southern Nevada on the possible impact of a condition known as HIV-Associated Neurocognitive Disorder, or HAND, on the lives of their clients and service users as they age.

Participants

You are being asked to participate in the study because you fit this criteria: You work and can provide a (home or work) mailing address within Southern Nevada, are 18 years of age or older, and have been working to support people living with HIV/AIDS for six months or more.

Procedures If you volunteer to participate in this study, you will be asked to do the following: Once you have read and understood this informed consent form, and agreed to participate in the survey, you will be asked to complete a 15 to 20-minute survey. Then, you will be asked to complete a brief demographic information sheet that will ask you about your age range, race/ethnicity, gender/gender identity, sexual orientation, number of years and/or months working to support people living with HIV/AIDS, and the geographical area where you currently work. Before you start answering the survey questions and demographic information sheet, we encourage you to print and keep a copy of this consent form once you have decided to agree to participate in it.

Benefits of Participation

There may not be direct benefits to you as a participant in this study. However, we hope to learn about the levels of awareness and knowledge of service providers working to support people living with HIV/AIDS in Southern Nevada on HAND. The results of this study will help

inform, influence, and improve current and future HIV/AIDS services, programs, and policies that are dedicated to supporting racially and ethnically diverse, older people living with HIV/AIDS at risk of, or already experiencing, signs and symptoms of HAND.

Risks of Participation

Participation in this study includes only minimal risks. Some of these minimal risks may include fatigue, frustration, and/or momentary embarrassment that could occur while answering survey questions. These feelings are temporary and will quickly pass. In case you will need it, we can provide you information on where to get support for these feelings, if they persist. We can also provide you resources on how to get information about HAND, in case you are interested to learn more about it.

Cost /Compensation

There is no financial cost to you to participate in this study. The online survey will take 15 to 20 minutes of your time. You will be compensated for your time and efforts with a $15 Visa gift card upon completion of the survey. The gift card will be mailed to the mailing address you will provide to the research team over email (unlvhandstudy@gmail.com) after you complete the survey. With the exception of your name and mailing address on the envelope, and the gift card in the envelope mailed to you, there will be no other information on, or items in the envelope that may link you to this study. Once you receive the gift card in the mail, you will need to email the research team again to confirm receipt of the card so that the research team can activate and add the $15 amount to your card according to the secure and UNLV-approved Forte Payments System protocol.

Confidentiality

Information gathered from you during this study are or may be identifiable information (i.e., your name, email address, mailing address) or private information (e.g., age range, HIV status, etc.). We do not intend to share or disclose any of these identifiable and private information to anyone, and we will be employing several measures and strategies to maintain the privacy and confidentiality of these information. Only our Principal Investigator and two other members of our research team will have access to your identifiable information found in the team's email correspondences with you, which will be kept separate from your anonymized survey data. All information gathered in this study will be kept confidential. No references will be made in written or audio/video materials that could link you to this study. Findings from the study will be de-identified, aggregated, and reported in a way that will not identify any of the study participants. All physical copies of your study documents will be stored in a locked cabinet at UNLV for 5 years after completion of the study. All recordings and digital copies of your study documents will be encrypted, password-protected, and stored separately in the research team's lab computers. After the storage time, the information will be destroyed by our research team.

Voluntary Participation

Your participation in this study is voluntary. You may refuse to participate in this study, or refuse to answer any question you are not comfortable answering should you decide to participate in the survey. You may withdraw from the study at any time without prejudice to your

relations with UNLV or any opportunity to participate in future studies. You are encouraged to ask questions about this study at the beginning, or any time during the study. You are encouraged to let the researchers know if you have any concerns regarding the study at any time.

Future Use of Research Data

Identifiers might be removed from identifiable private information and, after such removal, the information in this research study could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you.

Participant Consent:

By participating in this the survey, I indicate that I am at least 18 years of age, I have read and understood the information provided, and agree to participate in the study.

Below is a link to a pdf of the consent form you just reviewed. The form will open in a new tab on your internet browser where you can then choose to download and/or print the form for your own records.

Survey Consent Form

After reviewing the above consent form, do you consent to participate in this survey?

- ○ I agree
- ○ I disagree

Skip To: End of Survey If After reviewing the above consent form, do you consent to participate in this survey? = I disagree

End of Block: Consent

Start of Block: Personal Experience

This first set of questions will ask you about some personal experiences you may have encountered working with clients/patients regarding memory, attention, learning, language, decision-making, problem-solving, and motor skills.

Remember your answers are completely anonymous and you can skip any question that you are uncomfortable answering.

Page Break

I encounter clients/patients living with HIV/AIDS who have trouble remembering important names, dates, or appointments.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have trouble remembering important names, d... = Always

Or I encounter clients/patients living with HIV/AIDS who have trouble remembering important names, d... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have trouble remembering important names, d... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have trouble remembering important names, d... = Occasionally

JS

My clients/patients living with HIV/AIDS forget important names, dates, or appointments because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who have difficulties following stories, conversations, or directions.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have difficulties following stories, conver... = Always

Or I encounter clients/patients living with HIV/AIDS who have difficulties following stories, conver... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have difficulties following stories, conver... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have difficulties following stories, conver... = Occasionally

JS

My clients/patients living with HIV/AIDS have difficulties following stories, conversations, or directions because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who experience challenges learning how to do new things on a computer.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who experience challenges learning how to do ne... = Always

Or I encounter clients/patients living with HIV/AIDS who experience challenges learning how to do ne... = Frequently

Or I encounter clients/patients living with HIV/AIDS who experience challenges learning how to do ne... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who experience challenges learning how to do ne... = Occasionally

JS

My clients/patients living with HIV/AIDS experience challenges learning how to do new things on a computer because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who have difficulties coming up with the right words to communicate their thoughts or feelings to friends and family.

- Always
- Frequently
- Sometimes
- Occasionally
- Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have difficulties coming up with the right... = Always

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with the right... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with the right... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with the right... = Occasionally

JS

My clients/patients living with HIV/AIDS have difficulties coming up with the right words to communicate their thoughts or feelings to friends and family because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who have trouble prioritizing their tasks and errands for the week.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have trouble prioritizing their tasks and e... = Always

Or I encounter clients/patients living with HIV/AIDS who have trouble prioritizing their tasks and e... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have trouble prioritizing their tasks and e... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have trouble prioritizing their tasks and e... = Occasionally

JS

My clients/patients living with HIV/AIDS have trouble prioritizing tasks and errands for the week because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who have difficulties coming up with solutions for day-to-day problems.

- ○ Always
- ○ Frequently
- ○ Sometimes
- ○ Occasionally
- ○ Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have difficulties coming up with solutions... = Always

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with solutions... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with solutions... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have difficulties coming up with solutions... = Occasionally

JS

My clients/patients living with HIV/AIDS have difficulties coming up with solutions for day-to-day problems because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

I encounter clients/patients living with HIV/AIDS who have challenges related to their balance and coordination.

- Always
- Frequently
- Sometimes
- Occasionally
- Never

Display This Question:

If I encounter clients/patients living with HIV/AIDS who have challenges related to their balance an... = Always

Or I encounter clients/patients living with HIV/AIDS who have challenges related to their balance an... = Frequently

Or I encounter clients/patients living with HIV/AIDS who have challenges related to their balance an... = Sometimes

Or I encounter clients/patients living with HIV/AIDS who have challenges related to their balance an... = Occasionally

JS

My clients/patients living with HIV/AIDS have challenges related to balance and coordination because of their:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Age	○	○	○	○	○
HIV Medications	○	○	○	○	○
HIV/AIDS	○	○	○	○	○
Other Medical Conditions*	○	○	○	○	○

Page Break

Challenges related to memory, concentration, decision-making, and other cognitive functions make it difficult for my clients/patients to:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
Shop, prepare meals, and/or do household chores	○	○	○	○	○
Use a cellphone, tablet, or computer	○	○	○	○	○
Use public transportation and keep appointments	○	○	○	○	○
Take their HIV and/or other medications correctly or on time	○	○	○	○	○
Manage their finances	○	○	○	○	○
Engage with others socially	○	○	○	○	○
Actively participate in community events and activities	○	○	○	○	○
Not feel isolated	○	○	○	○	○

Difficulties related to memory, concentration, decision-making, and other cognitive functions **are**

difficult for my clients/patients to adjust to because of their episodic and sporadic (on-and-off) nature.

- Definitely agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Definitely disagree
- Not applicable to me

Difficulties related to memory, concentration, decision-making, and other cognitive functions **leave my clients/patients with feelings of uncertainty about the future**.

- Definitely agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Definitely disagree
- Not applicable to me

End of Block: Personal Experience

Start of Block: Descriptive Text Block

The following questions will help us determine your familiarity with HIV/AIDS and cognitive functioning, as well as HIV-Associated Neurocognitive Disorder (HAND).

For each statement, please select from the options to inform us if you believe each statement is true or false, along with how confident you are in your answer.

For these questions we are interested in the type of information participants can easily recall, so it is important that you answer to the best of your ability without any outside help. Also your honesty is very important, if you don't know an answer then just select "I'm not sure" instead of guessing true or not true. We will only look at averages, not your individual answers, and your responses will have no impact on your compensation for the study. We will also provide an opportunity to see the correct answers at the end of the study so please answer honestly.

End of Block: Descriptive Text Block

Start of Block: Quiz HIV/AIDS and Cognitive Functioning

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

HIV can still affect the memory, concentration, learning, decision-making, and other cognitive

functions of my clients/patients living with HIV/AIDS even if they don't develop dementia related to HIV.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making and other cognitive functions that are experienced by people living with HIV/AIDS are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

If my clients/patients living with HIV/AIDS take their HIV medications exactly as their doctors

prescribe, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

If my clients/patients living with HIV/AIDS keep their viral loads undetectable and their CD4 counts high, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

End of Block: Quiz HIV/AIDS and Cognitive Functioning

Start of Block: Quiz HIV-Associated Neurocognitive Disorder

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the

memory, concentration, learning, decision-making, and other cognitive functions of people living with HIV/AIDS as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.

- ○ Yes, I am certain this is true.
- ○ Yes, I am somewhat certain this is true.
- ○ I'm not sure.
- ○ No, I am somewhat certain this is false.
- ○ No, I am certain this is false.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all

other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.

- Yes, I am certain this is true.
- Yes, I am somewhat certain this is true.
- I'm not sure.
- No, I am somewhat certain this is false.
- No, I am certain this is false.

End of Block: Quiz HIV-Associated Neurocognitive Disorder

Start of Block: Continuity of Care, Resources, and Support

The questions below address resources and support you may or may not know about or have experience with.

I have discussed HIV-Associated Neurocognitive Disorder (HAND) with my clients/patients living with HIV/AIDS in the past.

- Always or Almost Always
- Often
- Sometimes
- Rarely
- Never or Almost Never

If my clients/patients have (or start experiencing) difficulties related to memory, concentration,

learning, decision-making, and other cognitive functions, they can access different community sources for:

	Definitely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Definitely agree
reliable information	○	○	○	○	○
medical/clinical care	○	○	○	○	○
social services/programs	○	○	○	○	○

My clients/patients living with HIV/AIDS would feel more comfortable knowing that there are support groups in the community composed of people who have successfully managed their own challenges related to HIV-Associated Neurocognitive Disorder (HAND).

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree

I believe it is important that more service providers who work to support or provide care to

people living with HIV/AIDS should be aware of or familiar with HIV-Associated Neurocognitive Disorder.

- ○ Definitely agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Definitely disagree

I am interested in accessing more information about HIV-Associated Neurocognitive Disorder.

- ○ Yes
- ○ No
- ○ I'm not sure

End of Block: Continuity of Care, Resources, and Support

Start of Block: PLWH Demo

This final section will ask you a few demographic questions such as age and gender. When answering these, remember that your answers are completely anonymous and your information will be kept secure.

Age (please answer with digits only, such as "45")

_____

Which of these best describes your current gender identity? (select all that apply)
Cisgender: My gender matches the gender I was assigned at birth.
Transgender: My gender differs from the gender I was assigned at birth.

- [ ] Cisgender woman
- [ ] Cisgender man
- [ ] Genderqueer/Gender Non-conforming or gender fluid
- [ ] Non-binary
- [ ] Transgender woman
- [ ] Transgender man
- [ ] Prefer to self-describe _____
- [ ] Prefer not to say

Race/Ethnicity (select all that apply)

- [ ] Asian or Pacific Islander
- [ ] Black or African American
- [ ] Hispanic or Latinx
- [ ] Middle Eastern
- [ ] Native American or American Indian
- [ ] White
- [ ] Prefer to self-describe _____
- [ ] Prefer not to say

What race or ethnicity do you feel you most identify with?

_____

Sexual Orientation (select all that apply)

- [ ] Asexual
- [ ] Bisexual
- [ ] Gay
- [ ] Straight (heterosexual)
- [ ] Lesbian
- [ ] Pansexual
- [ ] Queer
- [ ] Questioning or unsure
- [ ] Prefer to self-describe _____
- [ ] Prefer not to say

Geographical area of your workplace

- ○ Boulder City
- ○ Enterprise
- ○ Henderson
- ○ Las Vegas
- ○ Mesquite
- ○ North Las Vegas
- ○ Paradise
- ○ Spring Valley
- ○ Winchester
- ○ Other _____

Highest level of education completed

- ○ Less than high school degree or equivalent
- ○ High school degree or equivalent (such as GED)
- ○ trade/technical/vocational training or certification
- ○ Some college but no degree
- ○ Associates Degree
- ○ Bachelor's Degree
- ○ Master's Degree
- ○ Doctorate Degree (includes professional degrees like JD, MD)

In order to meet their needs related to their HIV/AIDS, which of the following community-based resources have you referred or directed your clients/patients to, if any, in the last ten years? (Select all that apply)

- [ ] AIDS service organizations (e.g., Aid for AIDS of Nevada)
- [ ] Community health centers/clinics
- [ ] Counseling services (e.g., Community Counseling Center of Southern Nevada)
- [ ] Food banks
- [ ] Harm reduction programs
- [ ] HIV education programs
- [ ] Homeless shelters
- [ ] Housing services (e.g., Golden Rainbow)
- [ ] LGBTQ agencies (e.g., The LGBTQ Center of Southern Nevada)
- [ ] Southern Nevada Health District (e.g., Ryan White program)
- [ ] Case workers
- [ ] HIV specialists
- [ ] Nurse practitioners
- [ ] Online sources
- [ ] Outreach workers
- [ ] Physicians

- [ ] Psychiatrists
- [ ] Psychologists (e.g., clinical psychologists, neuropsychologists)
- [ ] Social workers
- [ ] Support workers
- [ ] Other (please specify) _____

Current job title, role, or position at work

_____

How long have you been working to support people living with HIV? Please answer with your best estimate in years and months using digits only. For example if you would like to answer 2 and a half years you would enter "2" in years and "6" in months.

- ○ Years _____
- ○ Months _____

Would you like to know which of the knowledge questions you answered correctly?

- ○ Yes
- ○ No

End of Block: PLWH Demo

Start of Block: Answers & Resources

Display This Question:

If Would you like to know which of the knowledge questions you answered correctly? = Yes

You got ${gr://SC_00dzjpnGsfRnEns/Score} answers correct out of 12.

Below are the correct answers to the knowledge questions you answered earlier.

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).
Correct Answer: Yes, this is true.
However, even if HIV-related dementia is rare nowadays due to the effectiveness of HIV medications, as much as 50% people living with HIV/AIDS on prescribed HIV medications may still experience mild to moderate neurocognitive issues in their lifetime.
Your Answer: ${Q20/ChoiceGroup/SelectedChoices}

HIV can still affect the memory, concentration, learning, decision-making, and other cognitive functions of my clients/patients living with HIV/AIDS even if they don't develop dementia related to HIV.
Correct Answer: Yes, this is true.
Your Answer: ${Q21/ChoiceGroup/SelectedChoices}

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making and other cognitive functions that are experienced by my clients/patients living with HIV/AIDS are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.
Correct Answer: Yes, this is true.
This is because in addition to HIV/AIDS itself, regular aging, accelerated aging associated with HIV/AIDS, certain HIV medications (i.e., efavirenz) and long-term use of anti-retroviral drugs, other medical conditions such as stroke and Alzheimer's dementia, and problematic alcohol/substance use could all produce neurocognitive problems in people living with HIV/AIDS.
Your Answer: ${Q22/ChoiceGroup/SelectedChoices}

If my clients/patients living with HIV/AIDS take their HIV medications exactly as their doctors prescribe, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.
Correct Answer: No, this is not true.
However, taking their HIV medications as prescribed can significantly decrease the chances of these issues developing or progressing.
Your Answer: ${Q23/ChoiceGroup/SelectedChoices}

If my clients/patients living with HIV/AIDS keep their viral loads undetectable and their CD4 counts high, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.

Correct Answer: No, this is not true.
However, keeping their viral load undetectable and their CD4 count high could significantly decrease the chances of these issues developing or progressing.
Your Answer: ${Q24/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the memory, concentration, learning, decision-making, and other cognitive functions of people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q25/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.
Correct Answer: No, this is not true.
HAND is a spectrum of conditions that includes HIV-Associated Dementia.
Your Answer: ${Q26/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q27/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.
Correct Answer: Yes, this is true.
Your Answer: ${Q28/ChoiceGroup/SelectedChoices}

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.
Correct Answer: Yes, this is true.
Your Answer: ${Q29/ChoiceGroup/SelectedChoices}

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).
Correct Answer: Yes, this is true.
Your Answer: ${Q30/ChoiceGroup/SelectedChoices}

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.
Correct Answer: Yes, this is true.
Your Answer: ${Q31/ChoiceGroup/SelectedChoices}

Display This Question:

If Would you like to know which of the knowledge questions you answered correctly? != Yes

Below are the correct answers to the knowledge questions you answered earlier.

HIV-related dementia is rare nowadays because of the availability of highly effective combination HIV medications (i.e., Highly Active Anti-Retroviral Therapy or HAART).

Yes, this is true

However, even if HIV-related dementia is rare nowadays due to the effectiveness of HIV medications, as much as 50% people living with HIV/AIDS on prescribed HIV medications may still experience mild to moderate neurocognitive issues in their lifetime.

HIV can still affect the memory, concentration, learning, decision-making, and other cognitive functions of my clients/patients living with HIV/AIDS even if they don't develop dementia related to HIV.

Yes, this is true.

It is hard to figure out if difficulties related to memory, concentration, learning, decision-making and other cognitive functions that are experienced by my clients/patients living with HIV/AIDS are due to age, HIV medications, HIV/AIDS itself, or other medical reasons such as a history of strokes or problematic alcohol/substance use.

Yes, this is true.

This is because in addition to HIV/AIDS itself, regular aging, accelerated aging associated with HIV/AIDS, certain HIV medications (i.e., efavirenz) and long-term use of anti-retroviral drugs, other medical conditions such as stroke and Alzheimer's dementia, and problematic alcohol/substance use could all produce neurocognitive problems in people living with HIV/AIDS.

If my clients/patients living with HIV/AIDS take their HIV medications exactly as their doctors prescribe, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.

No, this is not true.

However, taking their HIV medications as prescribed can significantly decrease the chances of these issues developing or progressing.

If my clients/patients living with HIV/AIDS keep their viral loads undetectable and their CD4 counts high, it is guaranteed that they won't experience any changes to their memory, concentration, learning, decision-making, and other cognitive functions as they grow older.

No, this is not true.

However, keeping their viral load undetectable and their CD4 count high could significantly decrease the chances of these issues developing or progressing.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can negatively affect the memory, concentration, learning, decision-making, and other cognitive functions of people living

with HIV/AIDS as they grow older.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is just a new or other name for HIV-Associated Dementia.
No, this is not true.
HAND is a spectrum of conditions that includes HIV-Associated Dementia

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause subtle behavioral and mood changes in people living with HIV/AIDS as they grow older.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that may cause a range of mild, moderate, to severe challenges among people living with HIV/AIDS as they age.
Yes, this is true.

HIV-Associated Neurocognitive Disorder, or HAND, is a condition that can cause challenges related to balance or coordination in people living with HIV/AIDS as they grow older.
Yes, this is true.

People living with HIV/AIDS can undergo tests to screen for HIV-Associated Neurocognitive Disorder (HAND).
Yes, this is true.

In order to figure out if someone has HIV-Associated Neurocognitive Disorder, or HAND, all other possible causes of difficulties related to memory, concentration, learning, decision-making, and other cognitive functions need to be eliminated (ruled out) first.
Yes, this is true.

Page Break

Thank you for completing the online survey. We really appreciate you taking the time to complete the study for us.

The purpose of this study is to learn more about the awareness and familiarity of healthcare or service providers working in the community to support people living with HIV/AIDS on the condition known as HIV-Associated Neurocognitive Disorder, and its clinical and day-to-day impacts. We also want to learn more about the work experiences of survey participants related to this condition.

All information gathered in this study will be kept confidential. No reference will be made in written or oral materials that could link you to this study. We appreciate you taking the time to answer some personal questions about your life. We realize some of the questions we asked were personal in nature but really appreciate you taking the time to participate in our survey.

If you have any questions about the study, please feel free to contact Renato Liboro, PhD (Principal Investigator) via email: renato.liboro@unlv.edu

If for any reason after taking this survey you feel that you might want to talk to someone about treatment opportunities to address some kind of problem you may be encountering, we encourage you to contact us, or local mental health resources/partners in the community directly:

Community Counselling Center of Southern Nevada
714 E. Sahara Avenue
Las Vegas, NV 89104
702-369-8700
cccofsn.org

Ryan White Program Care Services
280 South Decatur Boulevard
Las Vegas, NV 89107
(702) 759-0800
SNHD hiv care services

Information on HIV/AIDS, aging, neurocognitive functions, and HIV-Associated Neurocognitive Disorder for people living with HIV/AIDS and their service providers can be found in the following websites:

John Hopkins HAND guide
CATIE HAND information
UCSF HIV Dementia
caregiver.org HAND

In order to receive your compensation:

When you click this final next arrow you will be directed to a new page where you will enter your email address. The reason for this being separate is to better protect your information so that we cannot tie the answers you gave here to the email address you will give us. You will not be able to return to this page. When you are ready, click the next arrow.

End of Block: Answers & Resources

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Curriculum Vitae

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Education

PhD, Psychological and Brain Sciences *in progress*

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Peer-Reviewed Journal Publications

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

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_report_-_unlv

Poster Presentations

Bell, S., **Ranuschio, B.**, & Liboro, R. (2021, June). *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). 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), *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.

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

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.