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Perceptions of Brain Health and Cognition in Older African Americans and Caucasians with HIV: A Focus Group Study

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Abstract

As people age with HIV, cognitive problems may become more prevalent and severe, but lifestyle behaviors (i.e., physical activity) have been shown to protect brain health and cognition. We examined the perceptions that older adults living with HIV have about protecting and improving brain health and cognition through lifestyle behaviors. Qualitative data were analyzed from 4 focus groups (N = 30) of African Americans and Caucasians living with HIV and at least 50 years of age. An open-coding scheme using conventional content analysis was employed. Two results were found. First, many older adults with HIV in our study expressed a variety of cognitive complaints that interfered with daily function. Second, these participants reported few specific ideas about how such health behaviors were important to their own brain health and cognition. Education interventions may help older adults with HIV learn to improve and protect brain health and cognition as they age.

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Keywords

brain fitness; cognitive aging; cognitive fitness; HIV; HIV-Associated Neurocognitive Disorder (HAND)

With advancing age, concerns about age-related brain health and the development of cognitive disorders grow, which may be particularly troubling for those aging with HIV. By some estimates using the Frascati criteria, which is a neuropsychiatric algorithm, the prevalence of HIV-Associated Neurocognitive Disorder (HAND) may be as high as 52% to 59% (Vance, Cody, & Moneyham, 2017), with a range of various impairments observed in this HAND classification. Using the Frascati criteria, the HAND classification is based on cognitive performance values and adults with HIV consistently have worse cognitive performance and higher prevalence of HAND compared to those without HIV. People with HIV have been found to be 1.7 times more likely to be classified as having HAND (Tierney et al., 2017). Thus, as people age with HIV, the prevalence and severity of such cognitive disorders may be exacerbated due to more co-morbidities and polypharmacy, prolonged stress and depression, HIV-accelerated and/or HIV-accentuated age-related neurological changes, and prolonged exposure to HIV-associated systemic inflammation and neuroinflammation (Cody & Vance, 2016). It is important to understand how the symptoms of these cognitive disorders manifest in patients and to develop practical lifestyle interventions to protect brain health and improve cognition.

Lifestyle Factors, Brain Health, and Cognition

From the aging, HIV, and cognitive neuroscience literature, several lifestyle factors have been shown to affect brain health and cognition, including, but not limited to: (a) physical activity, (b) mental activity, (c) nutrition, (d) social engagement, (e) emotional health, (f) sleep hygiene, and (g) substance use, to name a few (Cody & Vance, 2016; Vance, Eagerton, Harnish, McKie-Bell, & Fazeli, 2011). For example, Fazeli and colleagues (2014) observed that as adults with HIV engaged in a greater number of the lifestyle factors of physical activity, mental activity, and social engagement, the prevalence of HAND decreased significantly. Their observation suggested that lifestyle factors may promote positive neuroplasticity and be neuroprotective of cognitive reserve and, thereby, benefit brain health and cognition. Various studies have demonstrated that modifying lifestyle factors and health behaviors (e.g., reducing substance use) benefit brain health and improve cognition. Although each of these lifestyle factors easily deserve their own systematic literature review, a brief example of the relationship between cognition and these lifestyle factors as they relate to HIV is provided below.

Physical Activity

The benefits of physical activity and exercise in promoting brain health and cognition are well documented in the gerontology literature (Colcombe et al., 2006). Such benefits have been observed in adults with HIV as well. In a cross-sectional study of 335 adults with HIV, Dufour and colleagues (2013) found that those who exercised were less likely to have

neurocognitive impairment compared to those who did not exercise (odds ratio = 2.63, $p < 0.05$). Similar findings have been found in older adults with HIV (Fazeli et al., 2015).

Mental Activity

Mental activities, such as those observed in educational attainment and occupational activities, are neuroprotective of cognitive disorders as people age (Cody & Vance, 2016). One type of mental activity, computerized brain fitness programs, represents another method to engage in mental activity. Vance, Fazeli, Ross, Wadley, and Ball (2012) randomized 46 middle-age (at least 40 years) and older adults with HIV to either a 10-hours of visual speed of processing training group or to a no-contact control group. Those who received the brain fitness intervention significantly improved on a measure of visual speed of processing (i.e., Useful Field of View test), which translated into improvement on a laboratory measure of everyday function (i.e., Timed Instrumental Activities of Daily Living test).

Nutrition

Many foods rich in sugar and lacking antioxidants, may be pro-inflammatory, which can impair brain health and cognition. Studies show that foods rich in antioxidants and polyphenols such as blueberries may actually improve cognitive function in adults (Miller, Hamilton, Joseph, & Shukitt-Hale, 2017). Because adults with HIV may experience more low-grade, chronic, systemic, and neuronal inflammation due to chronic stimulation of the immune system by HIV (Cody & Vance, 2016), nutritional interventions rich in polyphenols and other anti-inflammatories may exert cognitive benefit.

Social Engagement

Studies have suggested that those engaged socially perform better cognitively. For example, in a study of 181 community-dwelling older adults, Stine-Morrow, Parisi, Morrow, and Park (2008) randomized participants to receive 20 weekly sessions engaged in an active social group or a no-contact control group. Those in the active social engagement group participated as a team to solve creative problems and compete against other teams. Compared to the control group, those in the experimental group who engaged in team problem-solving exhibited a positive change in neurocognitive ability from pretest to posttest assessments. As mentioned earlier, Fazeli and colleagues (2014) observed that those adults who were engaged socially as well as engaged in employment were less likely to experience HAND.

Emotional Health

Multiple studies have indicated that adults with HIV and depression as well as post-traumatic stress disorder were more likely to experience cognitive impairments (Bryant et al., 2015; Rubin et al., 2016). Fortunately, studies have also suggested that if emotional health is restored through pharmacological or non-pharmacological treatments, cognitive function rebounds (Bryant et al., 2015). This highlights the need to address emotional health in this clinical population.

Sleep Hygiene

Good sleep hygiene is important for restoring brain function and is vital for memory consolidation (Rasch & Born, 2013). Unfortunately, more sleep disturbances, poorer sleep hygiene, and increased fatigue have been common in adults with HIV for a variety of reasons (e.g., emotional distress, co-morbidities). In a sample of 268 adults with HIV, Byun, Gay, and Lee (2016) found that poorer sleep and greater fatigue were associated with greater cognitive complaints.

Substance Use

Substance use and abuse have been shown in multiple clinical populations to detrimentally impact cognitive reserve, brain health, and cognition. In a sample of 124 men with HIV, Monning and colleagues (2016) found that those who smoked cigarettes more and drank alcohol more performed worse on neurocognitive tests. In this clinical population, detrimental effects have been found for other substances such as methamphetamine (Var et al., 2016).

Purpose

Despite potential lifestyle strategies to protect or improve brain health and cognition, it is unclear what older adults with HIV know about brain health and cognition, or even if they attempt to modify or preserve brain health and cognitive function despite daily cognitive complaints or documented cognitive disorders associated with HIV (Cody & Vance, 2016). Thus, the purpose of our qualitative descriptive study was to investigate two primary research questions. Aim 1 was *What type of cognitive complaints do older people with HIV self-report?* and Aim 2 was *What do older adults with HIV know about how to improve brain health and cognition?* To accomplish this, four focus groups (N = 30) of older (at least 50 years of age) African American and Caucasian men and women with HIV were interviewed to examine these questions. From these data, potential education and lifestyle interventions may be developed.

Methods

Participants

Participants were recruited from a university-based HIV clinic using brochures and recruitment flyers. Fifty-six patients called the recruitment office for more information and were screened over the phone to determine eligibility. Inclusion criteria included: (a) being at least 50 years of age; (b) English speaking; (c) diagnosed with HIV for at least 1 year; (d) self-report of at least one cognitive problem (e.g., forgetfulness, difficulty recalling words, foggy thinking); and (e) willing to participate in a focus group with others with HIV. Self-reported cognitive problems were added as an inclusion criterion because those with such issues may have been more motivated to discuss their own cognitive problems in a focus group setting. Participants were not assessed with a neurocognitive battery to determine whether they had HAND. Exclusion criteria included: (a) having a significant neuro-medical co-morbidity that effected cognition (e.g., Alzheimer's disease, mental retardation); (b) not living in permanent housing; and (c) being blind or deaf. Inclusion/exclusion criteria were

chosen to select those who could fully participate in the focus groups and would have an inherent interest in the topics to be discussed. Once deemed eligible, participants were placed on a waiting list until a focus group of 8 to 10 people of all African Americans or Caucasians were available; then a time was scheduled for each participant to attend. Thus, four focus groups (N = 30) were included in our study: Focus Group 1 included 9 African American women; Focus Group 2 included 9 African American men; Focus Group 3 included 8 Caucasian men and 1 Caucasian woman; and Focus Group 4 included 3 African American women (10 were scheduled but only 3 attended).

Instruments

Demographic questionnaire—This instrument assessed basic background information on participant age, race/ethnicity, gender, and so forth.

Health history questionnaire—This instrument assessed the number of self-reported comorbidities and HIV-health indicators (i.e., CD4+ T lymphocyte count).

Interview script—An interview script with 11 primary questions guided the conversation of the focus groups to address the two study aims. Prompts were used to solicit additional information about participant cognitive complaints and knowledge about how to protect or improve brain health and cognition (See Table 1). The development of the interview questions was informed by the neurocognitive and neuroscience literature from studies conducted by the researchers and others. The questions were generated from findings that had shown that the lifestyle factors and health behaviors presented in the introduction of this article were important and related to brain health and cognition (Cody & Vance, 2016; Vance et al., 2011).

Observations—Field notes were taken by a second investigator who was present in all focus group sessions. Observation notes recorded behaviors and non-verbal activities exhibited by participants during focus group sessions.

Procedure

Our study took place from December 2015 to February 2016 and was approved by the University of Alabama at Birmingham Institutional Review Board. Prior to the start of each focus group, participants were consented by the principal investigator or research assistant. Focus groups took place in a private room. Participants were given name placards on which they could use their real names or pseudonyms so that the focus group moderator and participants could easily identify and respond to each other. Participants were briefed about the study protocol and asked to speak clearly and respond one at a time. Each focus group lasted approximately 1.5 hours. The focus group conversations were digitally recorded and transcribed. Prior to data analysis, observation notes were merged with transcripts.

Data Analysis

Employing basic descriptive statistics using SPSS 24.1, the quantitative data were used to describe sample characteristics to provide a context in which the qualitative data could be interpreted (Table 2). For qualitative data, transcriptions of the focus groups were printed,

read, and reread to code, identify, and summarize themes relevant to the study aims. This employed an open-coding scheme using conventional content analysis (Hsieh & Shannon, 2005). A conventional approach was used because of a lack of scientific literature on the topic of brain health and cognition from the perspective of the target population. In addition, field notes were collected to record behaviors and non-verbal activities during focus group sessions. Themes were coded manually as opposed to using qualitative software because of the size of the project and the preferences of the lead author. Summaries of the themes are presented in the chronological order in which the interview script was structured (Table 1). Data saturation was achieved as evidenced by no new themes emerging within the four focus groups; responses across all focus groups were similar regardless of race.

Results

Sample Characteristics

As seen in Table 2, the mean age of the sample was 56.38 years. Seventy percent of the sample were African American and 43.3% were women. The mean years of education was 12.13 years (range = 8–16 years) and the mean household income level was 1.43, which translated to approximately \$14,300 USD per year. The mean years diagnosed with HIV was 16.95 years (range = 4–31 years). The mean self-reported CD4+ T lymphocyte count was 609 cells/mm³ and the mean self-reported viral load was 464.10 copies/mL. These values indicated that as a group, our participants had healthy immune systems and that the virus was most likely being suppressed by medication. In addition, a number of co-morbidities were present in this group; these values are presented by summing the number of cases that reported these conditions: Diabetes ($n = 2$; 6.6%), heart disease ($n = 6$; 20%), hypertension ($n = 15$; 50%), kidney disease ($n = 1$; 3.3%), liver disease ($n = 1$; 3.3%), hepatitis C ($n = 2$; 6.6%), and a history of stroke ($n = 4$; 13.3%).

Cognitive Complaints (Aim 1)

As seen in Table 2, participants in all four focus groups expressed typical cognitive complaints that were common to everyday function such as misplacing items, walking into a room and forgetting why, forgetting names and appointments, having difficulty recalling words (dysnomia), and not being able to learn or retain information. For example, one African American man expressed,

I misplace stuff a lot; like my keys, my phone, the remote control. I search the house looking for it and it'll be sitting right there. I mean, it'll be somewhere real close, but I'll be looking everywhere for it all around. I do that a lot.

A Caucasian man indicated when reflecting on another participant's cognitive complaint, "I have the same thing with not being able to think of the word that I know fully well"; this is an example of dysnomia. Other cognitive complaints were rapid forgetting of what they or others had just said, as one participant remarked, "My short-term memory is messed up. I can ask my wife something and 5, 10 minutes later, I forgot what I asked her." In compensating for such rapid forgetting, this participant mentioned that his psychiatrist gave him some medication, "But it don't seem like that's working. I mean, I'm still having lapsed memory at times. I mean, I'm dealing with it." It seemed to be the general opinion of

participants, that they were “dealing with it” by just accepting it and compensating for it, not realizing that there might have been strategies to improve their brain health and cognition. Yet, participants provided typical compensation strategies for such cognitive complaints; for instance, as one African American man said,

Oh, for me, I try to write it down and organize things, try and have it organized, put stuff in a certain spot where I know where it is. My important messages and things I need to remember, I write it down. I have to write it down on the calendar.

List making, calendars, and relying on family and friends were mentioned as common cognitive compensations.

Concerns were expressed as to the cause of cognitive complaints; as one African American woman remarked, “Well, I am not able to memorize stuff like I used to. I don’t know if that has anything to do with aging or the virus, whatever it might be.” Meanwhile, others remarked that their cognitive complaints might have been due to past drug use or other co-morbidities such as fibromyalgia. Regardless, participants were aware of cognitive deficits and how they impacted everyday life. For instance, one Caucasian man mentioned, “I have trouble concentrating when it comes to (filling out) forms and, like, questionnaires at the clinic ... It wrecks my mind.” In a more severe example of this, an African American woman indicated that her driving was affected:

Yes. I can be driving ... “Where am I going?” Sometimes I have to pull over and regroup ... It’s really scary. I have not told my children that. I thought about, “Maybe you need to stop driving.” I stopped driving at night because of that.

In this example, limiting driving was another form of cognitive compensation.

As expected, many people expressed the fear that increasing frequency and severity of cognitive complaints might signal dementia and Alzheimer’s disease. As one participant said, referencing her aunt with Alzheimer’s disease, “I have the same problem. I’m not diagnosed with it (*Alzheimer’s disease*), but my auntie said she had CRS (*Can’t Remember Shit*). [Laughter] Y’all don’t want to know what it stands for.”

Knowledge of Lifestyle Factors (Aim 2)

Everyone was in agreement about the importance of brain health and cognition, as stated by one African American woman,

Brain health is important ... gotta have that function. All of that’s important ... I just want it to function right and be healthy ... so I can just be as independent as long and can think better. Be on top of things, because I don’t want the kids thinking they’re getting one over on me, you know?

Yet, when asked outright if they had heard about anything that was good for brain health and cognition, one African American woman aptly said, “I’m sure I have. I just can’t think. There’s that brain again. Just can’t think what it is.” That statement summarized the underlying tone of the focus groups; that is, they had some general understanding about brain health and cognition, but it was not a topic typically discussed.

Physical activity—There was some disagreement in the focus group participants as to whether physical activity was actually effective in improving and/or protecting brain health and cognition. One African American man mentioned, “I really don’t get the connection between you doing physical exercise for your brain.” Others also seemed confused about how exactly physical activity could improve brain health and cognition as they expressed difficulty articulating this connection. Regardless, several others clearly articulated the relationship between physical activity and brain health. As one African American woman explained,

When you exercise, you stimulate the brain. You stimulate molecules in the brain to function properly, your cognitive and all that other good stuff. Heart rate is pumping up, so you get blood going through the brain—to the brain in order for the brain to function, and oxygen when you do a lot of exercise.

Likewise, a Caucasian man indicated, “To get oxygen to the brain, you need to do some kind of exercise, at least walking.” Similarly, others remarked that physical activity could have indirect effects on the brain such as reducing stress. For example, as one African American man said, “Yeah, but I love to do that (exercise), because that eases my mind a whole lot. If I’m stressed, I get on that bike and ride.”

The kinds of physical activity people engaged in ranged from walking, biking, and just staying physically active around the house (e.g., housework, gardening). The level of physical activity reported was low impact, and many said that they were unable to exercise either due to physical or health limitations or lack of a proper space to exercise. When asked if they would do physical activity if told that it would be good for brain health and cognition, one participant summarized for the group, “It depends on what it is.” Furthermore, some mentioned that they were not good at engaging in physical activity alone, and that they would be more motivated if they could exercise in a group with others similar to themselves. Finally, many remarked that their clinicians encouraged them to be more physically active but, despite good intentions, this did not appear to be a priority.

Mental activity—Many participants agreed that mental activity was important for maintaining brain health and cognition, which was a message that they had heard repeatedly on the news and media and seemed to accept. Yet, participants expressed a wide range of activities that they considered intellectual exercise (e.g., social media/surfing the Internet, computer classes, reading, participating in focus groups, crossword puzzles, playing cards, hobbies, gardening, listening to music, and adult coloring books). For example, one African American man expressed, “I know something that’ll make anybody in here brain go to work and exercise their brain, that’s the game of checkers or chess.” Likewise, a Caucasian man remarked,

And I love to do crosswords and can usually solve most of them, but I don’t know if they’re really helping in real life. But it keeps my mind active I guess. I don’t know if that helps or not.

Reading as a mental activity was commonly reported as a way to support brain health and cognition, although one Caucasian man stated, “I have trouble concentrating when I read a book.” Interestingly, what was not expressed by participants was how much mental activity

is needed in terms of dosage and what mental activities are better than others. In general, the consensus appeared to be that as long as one stayed active, that was sufficient mental activity unto itself to benefit brain health and cognition; this sentiment was epitomized by this African American woman, “Of course, everything’s gonna be good for the brain (to) keep us motivated, moving, thinking, learning.”

Despite the accepted belief that engaging in mental activity was important to brain health and cognition, some participants indicated difficulty doing this. As a Caucasian man mentioned,

And I know in my mind that I need mind exercise, but I don’t do anything to help it. All I do is sit in my chair and watch TV. But listening to you about the stuff that some of you are doing makes more sense than not doing nothing. I have no responsibilities. I have nothing to get me out of that chair.

This participant reflected, as many did, that there was little motivation to engage in activities on a daily basis that might be of cognitive benefit.

Related to mental activity, participants were asked about their knowledge of and preference for computerized brain fitness programs. Many participants said that they had heard of certain brain fitness programs on TV and that they would be interested in trying them if they had the opportunity, but no one had tried them. As mentioned by one African American woman,

Like you say, if there’s anything we can do to make it (brain health) better, some kinda program or something online, which they do have—they even had a TV show about (the) brain and how you could improve it ... They have little brain games and stuff like that. All that makes a difference ... Brain health is extremely important.

One participant in particular mentioned that he played games on the computer and that he used that as mental activity. In general, some expressed concerns about cost, while others said that they were “old school” and that they did not like computers. Clearly, during this dialogue, many participants expressed a general fear of computers and a lack of familiarity with brain fitness programs.

Nutrition—By and large, participants were aware of the importance of a good diet in supporting brain health and cognition. They understood that protein and fat from fish were good “brain foods,” which they had learned from TV or from a health care provider— “Well, my doctor told me that eating salmon and tuna is good.” In fact, one participant commented on the benefits of omega-3-fatty acids, but also indicated that he disliked the taste of the supplements. Many were also aware that what they ate could also be bad for brain health and cognition as expressed by this participant,

I’m not gonna cook the eggs and the grits and the bacon and stuff. I want the pig ears ... I went for the sweets when I came in here (to the focus group). I know that’s not healthy for the brain because I know I need healthy food for it, but I eat anything that will keep me from having to do a lot of fixing when I already know that’s fixed.

Others suggested practical nutrition approaches to support brain health and cognition such as eating fruits and vegetables and staying hydrated. Others suggested unorthodox “brain foods,” for example:

Two things that I had started incorporating in my diet was cinnamon and ginger. That keeps me woke. The cinnamon, I’m diabetic, it just filters some of the sugar out of my bloodstream. Doing that, I’m observant. I can see (observe) things.

Upon further reflection, others remarked that they would like help from a nutritionist to coach them or have some instruction as to what to eat for general health and for brain health and cognition. One African American woman mentioned,

If there was a system that would print out a daily menu that you eat two eggs, one piece of toast and this right here, this equals up to this many calories, I would love that system. I would buy it cuz I need that.

Social engagement—Many participants remarked about the need for social engagement and that it was important for brain health and cognition. As one African American woman remarked, “I like interacting with other people because that challenges my brain to think of viewing stuff in a different angle.” Yet, this point of social interaction was stressed by many as an important point for health in general, especially for people with HIV who felt disenfranchised and stigmatized. As one African American woman remarked,

You do need people. You can’t be by yourself. You do get in deep funks. They just had on the news a couple of days ago about this young girl killed herself, because she wasn’t socially interactive ... You need people. Just like we need air, food.

The type of social interaction was varied, however. One Caucasian man indicated that for him, “I think having a pet helps a lot with responsibility and caring. It keeps me coherent.” Others preferred one-on-one contact or group interactions such as provided in the focus group itself. Others engaged in social media, but several participants expressed a disdain for social media: “Then with that Facebook and stuff, they put too much information out there. It just turns me off.” Much of the social engagement mentioned was closely aligned to emotional health as well; “Family. Definitely family plays a real big part in your well-being.” Although the importance of social engagement was clearly mentioned as important for emotional support, direct connections between social engagement and brain health and cognition were not clearly articulated by participants.

Interestingly, social engagement was also a source of compensation for cognitive complaints, as one Caucasian man remarked,

I do a lot of double checking myself and I have a friend who helps me with things. We often go shopping together. He finds things that I can’t find and so it helps to have another person you know – two brains are better than one.

Emotional health—Emotional support was highly valued by the participants. Many were explicit about their anger management classes, antidepressants, support of family/friends, prayer/meditation, listening to spiritual/religious music, and other techniques for dealing with stress, depression, anxiety, and other mood problems. For example, as one Caucasian

woman remarked, “And I would find it very helpful, but just stay busy I think, doing anything is very important to keeping (happy/positive).” Likewise, one Caucasian man commented about making art to deal with emotional problems and keeping away from thinking negative thoughts,

It helps to get out of your own headspace, sometimes ... We can always get in our own heads sometimes and we can be our worst enemy. And if we get out of own headspace and do something (i.e., make art), it doesn't matter if it's good or not, but if you find out that you just enjoy that you're doing it, you know, who gives a damn if it looks good or not?

At this point in the focus groups, participants frequently remarked about dark emotional periods in their lives, expressing the need for emotional support from others, reflecting on past traumas and stigma, and summarizing ways to overcome such emotional turmoil. This was highlighted by one woman,

My name is Joy and I can relate to what John said and what he was saying about a couple of years ago that was early in my recovery and I'm just over 2 years clean and, you know, early in recovery. I was isolated, you know, and I would keep to myself and I was worried, always worried personally. Now this is just me, I don't know if you feel that way, about what people think, you know.

At times, the focus groups morphed briefly into support groups. Although our focus groups were not designed to be therapeutic sessions, some participants even commented that focus groups like these helped them to deal with emotional problems. Despite how well participants were able to verbalize many of the emotional obstacles they had and continued to experience, the relationship between mood/emotional health and brain health and cognition was not clearly articulated by any of the participants, perhaps because of the overwhelming priority to address their emotional health first.

Sleep hygiene—Many sleep problems were reported, as confirmed by participants providing suggestions to each other about how to address problems such as sleep medications, bedtime habits, and relaxing music. Participants were clear that when their sleep was compromised, their cognitive function was likewise compromised. The connection between sleep hygiene and brain health and cognition was clearly articulated by most participants. As commented by several participants, “Cuz your mind's not moving” or “I be confused” or “When I sleep well, I'm more sharp.” One participant further reflected,

I function better. I'm more alert, you know, as long as I (got) a good amount of sleep. So yeah, I do believe it makes a huge difference mentally and in your brain actually. That's me.

But not everyone agreed. As one Caucasian man remarked, “I'm getting less sleep now than I use to. And I'm also forgetting things a lot but I don't know that the two are related.” Participants did not reflect on the side effects of sleep medications, which obviously can also negatively impact brain health and cognition.

Substance use—Several participants said that substance use, especially substance abuse, was bad for brain health and cognition. In fact, many participants were very candid about

recovery experiences and how past substance abuse had negatively impacted their ability to think. As one African American man in recovery mentioned,

Certain parts of my brain we ain't gonna never get back, 'cause it's been destroyed. When you destroyed so many brain cells, and it takes years and years for it to grow back. I mean, I was reckless when I was out there, too reckless. I mean, I did some horrible things to my brain. I guess that's why my thinking is off right now.

Another participant alluded to how Alzheimer's disease medications might not be effective in adults with HIV if they have had past substance use:

It's a pill that either can slow down the progress of it (Alzheimer's disease) — yeah, that's what it's for, to slow it down. ... The first thing they call it is, I believe, is dementia. Depending on where you are at in your illness or in your recovery, depending on how many brain cells you have burned out, you don't know if you could be a good candidate later on down the road for that.

Others expressed similar concerns about how past substance use impacted brain health and cognition. Absent in these discussions, however, was: (a) how certain substances were more damaging to the brain than others, (b) how abstinence and recovery could actually improve brain health and cognition, or (c) what people in recovery should do to support brain health and cognition. The general tone of the discussions was that once damage was done by substance use and abuse, there was no or little recovery of brain health and cognition.

Discussion

We assessed what cognitive problems older adults with HIV had and solicited what participants knew about the effects that lifestyle and health behaviors exerted on brain health and cognition. It was important not only to identify what participants knew about brain health and cognition, but also what they did not know. In other words, it was equally important to examine what participants knew about brain health and cognition (positive finding), and what they failed or were unable to report (negative finding). In fact, it was what our participants did not say or mention that might have been particularly relevant, especially in planning education interventions to protect and improve brain health and cognition as people age with HIV.

Cognitive Complaints (Aim 1)

In general, the cognitive complaints expressed by these older adults with HIV appeared to be generally typical (e.g., forgetting names, misplacing items). In many cases, such subjective cognitive impairments reflected objective everyday functioning problems such as shopping and driving difficulties. These findings were not unexpected and have been observed in other older adults with HIV (Marcotte et al., 2004). Despite being aware of such cognitive complaints, participants voiced more passive acceptance of their problems rather than treating or ameliorating them. In fact, cognitive compensation strategies to address their cognitive complaints were primarily expressed instead of remediation or prevention techniques; this may reflect that the older adults with HIV in our sample were unaware of strategies to protect or improve their brain health and cognition. Furthermore, as observed in

the gerontology literature, concerns about dementia and Alzheimer's disease with advancing age are not uncommon (Léon, Pin, Kreft-Jaïs, & Arwidson, 2015). These concerns were also clearly expressed in our study.

Knowledge of Lifestyle Factors (Aim 2)

When asked what lifestyle factors are good for brain health and cognition, participants expressed varying levels of understanding, depending on the particular lifestyle factor. For physical activity, mental activity, nutrition, social engagement, sleep hygiene, and substance use, there was at least a cursory understanding and acceptance that the symptoms were somewhat related to brain health and cognition. Yet, for many of these lifestyle factors, details were lacking about how exactly lifestyle could affect brain health and cognition. Several participants indicated that they engaged in some of these behaviors anyway (e.g., biking, reading, playing computer games), but motivations for the activities appeared to be for enjoyment, rather than to maintain brain health and cognition. Furthermore, many participants expressed that although it was important to engage in healthy lifestyle behaviors, they often did not, as was expressly voiced in relation to physical activity and nutrition.

An interesting observation during the focus groups was that, compared to other lifestyle factors, participants seemed to have more suggestions about how nutrition could improve general health as well as brain health and cognition. As food is an important component of culture as well as a common topic of conversation between people and the media (Kittler, Sucher, & Nahikian-Nelms, 2017), it was not surprising that more emphasis was placed on what to eat to improve brain health and cognition. Foods that are salty, sweet, or have saturated fats can contribute to diabetes, systemic inflammation, hypertension, and heart disease, and all of these can contribute to poorer brain health and cognitive problems (Sartori, Vance, Slater, & Crowe, 2012; Wärnberg, Gomez-Martinez, Romeo, Días, & Marcos, 2009). And, while many participants were aware of several practical approaches to eating healthy, no one commented on the role that some foods have in reducing inflammation (or neuroinflammation) or the role of food to promote healthy gut microbiota that can also support brain health and cognition (Gareau, 2016), providing a potential, novel area for patient education. Furthermore, there was little, if any discussion, on what not to eat to protect brain health and cognition.

Finally, although our participants expressed some knowledge about how certain lifestyle factors and health behaviors influenced brain health and cognition, a general understanding of neuroplasticity was never mentioned. Neuroplasticity refers to the brain's ability to continue to build and strengthen connections between neurons, which is important for building cognitive reserve and maintaining brain health and cognition (Cody & Vance, 2016). Neuroplasticity is facilitated by lifestyle factors and health behaviors. Despite its continued importance for successful cognitive aging, this basic concept was not expressed by participants in the focus groups. This concept may represent another area for health education that not only helps patients understand how lifestyle and health behaviors impact neuroplasticity to support brain health and cognition, but also reveals that neuroplasticity

may be an empowering concept for informed decision-making to protect or improve the ability to think and function.

Study Strengths and Limitations

Two study strengths are noted. First, this is the first study to examine what older adults with HIV know about the relationship between lifestyle, behaviors, and brain health and cognition. As such, it propels this area of research forward by revealing possible education strategies to empower patients. Second, we used open-ended questions to discover what older adults with HIV knew about how each lifestyle behavior is related to brain health. Leading questions were not asked, which could have biased responses from participants. Unfortunately, that meant that when participants did not report information, it was interpreted as a gap in their knowledge. In actuality, perhaps participants knew more than what they reported in the focus groups but were unable to recall at that time. This approach was also considered a study limitation requiring another method consideration (mentioned below).

Three main study limitations are noted. First, as just mentioned, a formal evaluation of what participants knew about lifestyle factors and brain health and cognition was not administered; perhaps a more detailed questionnaire would have provided information about what older adults with HIV know specifically about brain health and cognition. Second, there was an overrepresentation of African Americans and an underrepresentation of Caucasians, especially Caucasian women. Albeit unsuccessful, attempts were made to recruit more Caucasians by asking other participants to encourage their Caucasian friends to participate. As such, the information presented may not reflect the views of these groups. However, as the comments in both groups seemed to complement each other and were reflective of data saturation, this may not have been a severe limitation. Nevertheless, further study is warranted. Further, the views presented here were reflective of the HIV epidemic in the Southeastern United States where the study was conducted; therefore, these findings may not reflect the views of others outside of this region. And third, although an inclusion criterion for this study was that participants had to indicate some type of cognitive complaint, an objective neurocognitive battery was not administered to participants to assess a HAND classification. Perhaps those with more severe cognitive impairments might have a different profile of cognitive complaints and be more motivated to engage in focus groups or hold different views and knowledge about brain health and cognition compared to those who do not have HAND.

Future Directions

Despite the well-documented subjective and objective cognitive impairments observed in adults with HIV, especially as they age, few interventions, especially behavioral interventions, have been investigated to protect or improve brain health and cognition (Cody & Vance, 2016). No other study has assessed the knowledge of people living with HIV about this topic, which shows a gap in patients' health knowledge and brain health literacy. Numerous studies on HIV document the importance of educating people about safe sex practices, substance use, medication adherence, and other health-related outcomes (Cox & Brennan-Ing, 2017), but such education about brain health and cognition in this clinical

population has been non-existent. Our study lays the foundation about how to begin to develop an education and/or behavioral protocol to protect and improve brain health and cognition in cognitively vulnerable older adults with HIV. This study demonstrated that adults with HIV who report at least one cognitive complaint may have only a cursory knowledge of how certain lifestyle choices influence brain health and cognition. Equipped with more information and education, aging adults with HIV may be empowered to change lifestyle and health behaviors to improve their own cognitive function.

Building on this premise, Vance and colleagues (2011) proposed a behavioral modification lifestyle intervention, called Cognitive Prescription, in which patients with cognitive disorders (e.g., HAND, traumatic brain injury, mild cognitive impairment), or even those wishing to protect or maintain cognitive function, could modify various lifestyle and health behaviors to support neuroplasticity and brain health in order to improve cognition. In Cognitive Prescription, behavior modification goals (e.g., go for a 30-minute walk 3 times/week, read 5 hours/week, visit friends 2 times/week) are set to improve capacity in several areas. These lifestyle and behavioral areas correspond to the same areas examined in our focus group study (i.e., physical activity, mental activity). In addition, the behavior modification goals target the lifestyle and behavioral factors shown in the cognitive and neuroscience literature to support neuroplasticity, brain health, and cognition. The Cognitive Prescription protocol is designed to be individualized to the patient's goals and desires in order to provide motivation for adherence to the treatment protocol. Results from our focus group study suggest that a formal education intervention informing patients of the relevance and details of each lifestyle factor on brain health and cognition could be a necessary first step in introducing the Cognitive Prescription.

Emerging cognitive studies also suggest that other multi-modal approaches similar to the Cognitive Prescription protocol, which modifies two or more lifestyle factors, may exert added benefit in protecting or improving brain health and cognition (Bredesen, 2014; Lynch et al., 2014). For example, in the Agewell Trial, the goal of the study was to change lifestyle factors in 75 HIV-uninfected community-dwelling adults (at least 50 years of age) to support successful cognitive aging and avoid dementia over a 12-month period (Clare et al., 2015). Goal setting focused on behavior goals to improve health and nutrition, in order to facilitate cognitive, physical, and social activities that support neuroplasticity. Participants were randomly assigned to either a control group ($n = 27$), a goal setting group ($n = 24$), or a goal setting with mentoring group ($n = 24$). Those in the goal setting groups improved on measures of executive function, memory, aerobic activity, cholesterol measures, balance, agility, flexibility, and grip strength. Similar studies have investigated ways to reduce the risk of Alzheimer's disease in HIV-uninfected adults as well (Anstey, Bahar-Fuchs, Herath, Rebok, & Cherbuin, 2013; Bredesen, 2014).

Nursing Implications

Our findings have implications for nursing practice and further research. Nurses who work with patients living with HIV are uniquely positioned to assess levels of cognitive change and patient knowledge regarding factors that influence cognitive health. Based on these assessments, nurses can provide tailored patient education about lifestyle factors and health

behaviors to empower patients to reduce these changes and to protect brain health. Within a holistic nursing care approach, during each patient's clinic visit, a nurse could assess cognitive complaints and provide education regarding strategies that could help patients protect or improve brain health and cognition. Because HIV is a chronic disease, nurses working with these patients also get to know them well over time. As such, nurses can be instrumental in working with interprofessional teams to develop individualized protocols that take the individual factors of each patient into consideration as well as to make needed referrals to neurologists or psychologists.

Conclusions

As adults age with HIV, many express a vulnerable cognitive phenotype, exposing them to diminishing everyday function, quality of life, and independence. Although many documented lifestyle and health behaviors can protect or even improve brain health and cognition, it appears that those in this clinical population may not be knowledgeable or apply this health information to their daily lives. In fact, as people with HIV receive health education from nurses and clinicians about the importance of medication adherence, safe sex, and other health-related behaviors that can improve health-related outcomes, educating patients about the relationship between lifestyle, health behaviors, and cognitive reserve may empower them to improve and protect their brain health and cognition over time as well. A health education focus represents a novel clinical and research area to investigate, especially as adults with HIV continue to age.

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Key Considerations

- Approximately 50% of adults living with HIV will experience HIV-Associated Neurocognitive Disorder (HAND), which can compromise everyday function and quality of life.
- With the aging of the HIV population, age-related cognitive declines may exacerbate HIV-related cognitive deficits.
- Many lifestyle and health behaviors can protect or improve brain health and cognition as people age, and may be of use for those aging with HIV.
- Adults living with HIV may not know about or incorporate lifestyle and health behaviors into their daily lives in order to protect or improve their cognition.
- Adults with HIV may benefit from education about how lifestyle and health behaviors may improve brain health and cognition as they age.

Table 1**Focus Group Questions**

Primary Questions	Prompts
Q1: What kinds of problems with thinking and remembering are you experiencing in your life?	• How does this affect your daily activities? Please provide examples.
Q2: Please describe the problems you are having with memory and thinking in general. Is it good or bad?	• Do you think as well as you used to? • How mentally sharp do you feel?
Q3: What sort of things do you know of that affects your brain and thinking?	• Can you improve brain health and your ability to think? • And how do you know? • What strategies do you know of that can improve brain health and your ability to think?
Q4: What do you know about physical activity and brain health?	• What motivates you to be physically active? • What keeps you from being physically active? • Would you consider exercising during commercials when you watch TV?
Q5: What do you know about mental exercise and brain health? Q6: What types of mental exercises do you do?	• What motivates you to mentally exercise? • What keeps you from mental exercise? • Do you consider TV as mental exercise? • What types of TV shows are mentally stimulating? • Do you consider computer games as mental exercise? • What do you think about those computer programs designed to improve brain health?
Q7: What foods are good or bad for brain health? And why?	• What sort of help would you like to have to eat healthier?
Q8: What do you know about sleep and brain health?	• What sort of problems do you have going to sleep or staying asleep? • How do you deal with sleep problems? • What do you know about sleep and brain health? • What sort of help would you like to have to sleep better?
Q9: What do you know about substance use and brain health?	• What do you know about substance use and sleep?
Q10: What do you know about social interaction and brain health?	• What prevents you from being as social as you want? • What kinds of help or support would help you socialize more? • What strategies do you use to reach out to others? • Do you use the Internet to make new friends?
Q11: What do you know about mood and brain health?	• What are some strategies you use to improve your mood? • What sort of help would you like to have to improve your mood? • Would you like to participate in a telephone support group? • Would you like an occasional e-mail from a counselor?

Table 2 Participant Characteristics of the Focus Groups (*N* = 30)

Variable	Frequency (%)	<i>M</i> (<i>SD</i>)	Range
Age (years)		56.38 (3.97)	51–64
Race			
African American	21 (70.00%)		
Caucasian	9 (30.00%)		
Gender			
Female	13 (43.30%)		
Male	17 (56.70%)		
Education (years) [‡]		12.13 (1.72)	8–16
Household Income (\$10,000 USD increments) [‡]		1.43 (0.84)	1–3
Years Diagnosed with HIV		16.95 (6.67)	4–31
Current Self-Reported CD4+ Lymphocyte Count (cells/mm ³)		609.40 (441.98)	100–2,138
Current Self-Reported HIV Viral Load (copies/mL)		464.10 (1,251.71)	0–4,000
Number of Comorbidities		1.50 (1.33)	0–5

Note. *SD* = standard deviation; USD = U.S. dollars;

[‡]Education (1 = 1st grade ... 12 = completed high school or GED [General Equivalency Degree]; 13 = some college/vocational training; 14 = associates degree; 16 = bachelor's degree; 18 = master's degree; 20 = doctoral degree).

[‡]Household Income before Taxes (1 = \$0–\$10,000 USD; 8 = +\$70,000 USD).