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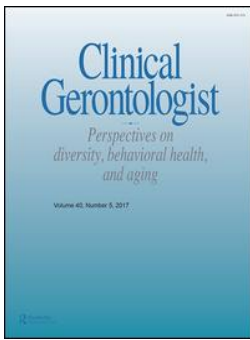
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Perceptions of and Knowledge Acquisition about Brain Health and Aging among Latin American Immigrants: A Qualitative Paper

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ABSTRACT

Objectives: Older immigrants of Latin American descent are disproportionately impacted by dementia, yet little is known about their dementia- and brain health-related knowledge. We explored perspectives on brain health and aging in this population to inform the development of culturally-relevant interventions.

Methods: Individual, semi-structured interviews were conducted with 30 Spanish-speaking immigrants over 60. Questions addressed knowledge about the brain, perceptions of healthy and unhealthy aging, ideas of how to take care of one's brain, and where knowledge was acquired. Responses were analyzed using thematic analysis.

Results: The following themes emerged: (1) Descriptions of the brain varied, from anatomy, cognition, and psychology to disease. (2) Perceptions of healthy aging included independence, memory, emotions, and orientation. (3) Ideas of how to care for the brain included physical, social, and cognitive engagement. (4) Knowledge was acquired in childhood, communities, healthcare settings, careers, and media.

Conclusions: Results showed significant variability in knowledge. Findings may be leveraged to improve interventions that address brain health literacy disparities among older Latin American immigrants.

Clinical Implications: Takeaways involve increasing education about the structure and functions of the brain, promoting realistic understandings of what nonnormative brain aging entails, and increasing knowledge of empirically-supported maintenance approaches. Dissemination may be increased via healthcare providers, community centers, churches, and media.

KEYWORDS

Qualitative research; aging; dementia; brain health; immigrant health

Introduction

The prevalence of dementia – a progressive clinical condition characterized by neurocognitive decline that affects one's ability to perform daily tasks – is increasing throughout the United States (US), posing myriad emotional, medical, and financial challenges to society (Alzheimer's Association, 2021). While dementia impacts all sectors of the US population, older individuals of some historically marginalized subpopulations are disproportionately affected. For example, evidence suggests that older adults of Latin American descent living in the US are approximately 1.5 times more likely than non-Hispanic/Latino White individuals to develop dementia (Alzheimer's Association, 2021; Gurland et al., 1999). The public health implications of this

statistic are greatly magnified when one considers that the population of Hispanic/Latino/a/x (hereafter referred to as Latinx) older adults in the US is projected to increase at nearly 3.5 times the rate of non-Latinx Whites in the coming decade, yet they represent the highest uninsured ethnic group in the country (Perales et al., 2020). Moreover, Latinx individuals are less likely to participate in clinical trials compared to other ethnic groups, thus further impacting the availability of efficacious treatments and interventions for this subpopulation (McGill, 2013; Perales et al., 2020). Latinx individuals embody diverse cultural histories, genetic ancestries, and health profiles and, as such, the higher prevalence of dementia in Latinx communities in

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the US does not primarily stem from these factors. Instead, research suggests that the heightened risk of dementia among Latinx communities stems primarily from the high prevalence of chronic exposures to a number of social determinants of health (SDOH), such as high exposure to environmental pollutants, socioeconomic hardship, traumatic and/or discriminatory life experiences, and suboptimal quality of education, among other potentially modifiable factors (Alzheimer's Association, 2021).

Key to reducing health disparities at the community level is introducing and/or increasing knowledge about the brain, dementia, and brain health – or the preservation of optimal brain integrity and cognitive function in the absence of overt neurological disorders (Perales et al., 2020; Wang, Pan, & Li, 2020). Indeed, improvements in health literacy among members of vulnerable communities can be a potent mechanism through which the negative community health effects of other SDOH are ameliorated (Coughlin, Vernon, Hatzigeorgiou, & George, 2020). Misconceptions and the lack of accurate understanding of brain health and dementia carry serious consequences for the appropriate detection, diagnosis, and treatment of dementia. Friends and family are often the first to notice behavioral symptoms, yet without a science-based framework within which to interpret these symptoms, a timely medical evaluation and diagnosis becomes challenging. Indeed, older adults themselves tend to be the least informed about etiology, symptoms, and services for dementia, highlighting the need for community-based interventions (Ayalon & Areán, 2004; Edwards, Cherry, & Peterson, 2000). Moreover, dementia-related knowledge, including beliefs about risk and protective factors, is particularly low among the Latinx population, which may thwart treatment-seeking behaviors (Roberts, McLaughlin, & Connell, 2014).

Increasing brain health knowledge in the community is a major public health priority given the growing prevalence of dementia among Latinx older adults and the disparities in brain health and dementia-related knowledge within this sector of the US population. While much is known about health disparities and epidemiological information about the Latin American immigrant population in the US, less is known about individuals' perspectives,

and beliefs about the brain and brain health. To date, most existing literature on brain-related health literacy focuses on Alzheimer's Disease (AD) and other dementias. For example, previous literature has described how Latinx older adults are more likely than non-Latinx White individuals to believe that taking vitamins can reduce the risk of AD, that AD is contagious yet curable, and that they will ultimately and inevitably develop AD (Ayalon & Areán, 2004; Roberts et al., 2014). Stigmatization of dementia, including the view that it is contagious, as well as normalization of cognitive impairment as a normal part of aging, are beliefs that can impede access to services and adequate care (Ayalon & Areán, 2004). 'Brain health literacy' has recently gained attention as a term to convey awareness and understanding of the brain, healthy aging, disease, and brain-friendly habits (Fernandez, 2018). Shifting to utilizing a positive approach for health promotion, for instance by using the words 'brain health' instead of focusing on unhealthy behaviors that increase the risk of dementia, seems prudent to decrease the impact of stigma, increase acceptance of programs, and target primary prevention (Heger et al., 2020; Yaffe, 2018). Very few studies explicitly explore the concept of brain health literacy: one demonstrated that short online brain health animations could impart knowledge and promote behavior change in older adults (Brennan, Geary, & Gallagher, 2021), and another discussed recruitment strategies for increasing engagement of Black older adults in brain health and aging research in an effort to increase brain health literacy (Gluck, Shaw, & Hill, 2018). Recently, one large cross-sectional survey described brain health literacy as inadequate in a large, representative sample of older adults in New Zealand, as participants correctly identified only six of fourteen modifiable risk or protective factors for dementia (Barak, Rapsey, & Scott, 2022). It is therefore essential that brain health literacy focuses on clearly contrasting normal effects of aging versus symptoms characteristic of nonnormative cognitive decline and increasing awareness of modifiable factors that are associated with brain health maintenance. Moreover,

research is currently lacking on brain health literacy within older Latinx communities specifically.

Beyond knowledge and perceptions of AD and other dementias, exploring older Latinx adults' concerns about their brains and their current approaches to addressing these concerns may shed some insight into appropriate intervention targets. Developing a better understanding of how Latin American older adults think about causes of brain disease or unhealthy aging can illuminate important gaps in knowledge, which may allow us to develop effective brain health promotion interventions. Identifying individuals' understanding of the brain can help us discern whether more education is needed regarding connections between what the brain is and how to take care of it. Exploring current beliefs about brain health maintenance approaches can elucidate the accuracy of knowledge regarding protective lifestyle factors. Relatedly, understanding individuals' knowledge of the structure and functions of the brain may help elucidate the extent to which older individuals understand normative versus non-normative changes that occur during aging. Finally, exploring the sources of information that older Latinx individuals are utilizing to increase their knowledge of brain health can help identify potential targets for education campaigns. Therefore, the objective of the current study was to explore perspectives on brain health and aging among Latin American immigrants living in the San Francisco Bay Area and identify where they acquired their current knowledge. Findings may be leveraged to tailor future brain health interventions to address brain health literacy disparities in this growing sector of the population.

Methods

Participants

Participants were recruited through community settings in the San Francisco Bay Area via dissemination of flyers, communication with community center leadership, and snowball sampling from community health centers and senior centers. Eligible participants were first generation Latin American immigrants, monolingual Spanish

speakers, and 60 years or older. Informational handouts were provided, and informed consent was obtained prior to engaging in research activities. Participants received a gift card following the interview. The study was approved by the Institutional Review Board (IRB) of the University of California, San Francisco (UCSF).

Procedures

Data collection

An interview guide was developed by a multidisciplinary team (neuropsychologist, neurologist, social scientists) to address the study goals of understanding knowledge, perspectives, and attitudes about the brain, brain health, and aging among Latin American immigrants, and where that knowledge was acquired. Interview questions specifically addressed knowledge about the brain, where knowledge was acquired, perspectives on healthy versus unhealthy brain aging, ideas of how to keep the brain healthy, attitudes about consequences of unhealthy brain aging, and sociodemographic factors (Appendix A). Semi-structured interviews were conducted by a Spanish-speaking research assistant at sites chosen by participants. Interviews lasted approximately 45–60 minutes and were digitally recorded and transcribed.

Data analysis

Transcripts were coded in Spanish using Dedoose Version 8.3.17, a qualitative data management and coding software (SocioCultural Research Consultants, LLC, Los Angeles, CA). The first author, who is fluent in Spanish, read and coded the interviews both deductively and inductively, using thematic analysis (Boyatzis, 1998). Given that the interview guide reflected the overarching study goals, it was first used to develop a list of *a priori* codes that comprise the four broad domains of our findings (Appendix A). Inductive codes were developed within each of these domains. Codes were reviewed and revised by the first and last authors at regularly held coding meetings. If there were any disagreements in coding, the authors compared the text that was coded, reviewed code definitions, and went through the data reviewing additional exemplary quotations for that code until they achieved coding consensus (Cohen et al., 2018). Codes were combined and organized into themes by the first and last

authors. Recurring themes, identified within each of the thematic domains, form the basis of the results presented here. Themes were reviewed and refined by the first and last authors, and illustrative quotations were identified, discussed, and translated to English. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was followed in reporting our findings (Tong, Sainsbury, & Craig, 2007) (Appendix B).

Results

Sample characteristics

The sample consisted of 30 Latinx older adults, ranging in age from 60 to 92 years old ($m = 76.4$, $SD = 7.7$). Twenty participants were female, while ten were male. Fifteen identified as being from Mexico, 6 from El Salvador, 6 from Nicaragua, 1 from Guatemala, 1 from Peru, and 1 from Ecuador. Years of formal education ranged from 0 to 20 ($m = 8.5$, $SD = 5.0$). Years living in the US ranged from 9 to 70 ($m = 34.6$, $SD = 15.1$) (Table 1, Figure 1).

Domains and themes

Four key domains were explored: (1) understanding and descriptions of the brain, (2) perceptions of healthy and unhealthy aging brains, (3) ideas of how to take care of the brain, and (4) how knowledge of the brain was acquired. While these four broad domains were developed *a priori*, themes

were generated inductively during coding. Domains and themes are discussed below, along with illustrative quotes.

Domain 1: understanding and descriptions of the brain

When asked to describe the brain, participants' responses varied, from it being a physical organ, to its role in psychology and cognition, to disease and unknowns. Participants' descriptions of the brain were not necessarily bound to a single conceptualization, but rather could span multiple categories.

Theme 1A: physical organ. Some participants' primary description of the brain was as a physical organ that drives the whole body, acts as a control center, or is involved in pumping blood and disseminating oxygen throughout the body. Some conceptualized the brain as an organ, made up of organic matter: "the brain has cells. Its cells are important because they help you move, think about what to do, seek the advice of your family, and then keep everything clean" (Participant 17). Of note, a number of participants expressed some confusion regarding the distinction between the brain and the heart. For instance, one participant said, "If something happened to the brain, one would be bad off. They wouldn't have control. The brain is the thing that helps a person. It's part of the heart" (Participant 27).

Theme 1B: psychology. Others described the brain's role in psychological processes, such as thought and emotions. Some suggested that the brain controls emotions and self-confidence, while others discussed the brain's role in focusing on positivity versus evil. For instance, one participant said that the brain makes us "think about doing constructive things, right? Not about bad intentions. Rather, in wanting to love other people . . . through the brain one does that" (Participant 17). Some linked the brain to their spirituality: when asked what they knew about the brain, one participant responded, "I officially know and think that it's something that God gave us, the best, because without the brain, or having illnesses of the brain, being a human being – you can't live how you should or how you'd like, and thank God for the brain" (Participant 28).

Table 1. Participant demographics.

Characteristics	Participants (n = 30)
	Means and Percentages
Age	76.37 years (SD = 7.7)
Sex	66.7% female (n = 30) 33.3% male (n = 10)
Education	8.5 years (SD = 5.0) 20.0% Less than elementary school (n = 6) 30.0% Elementary school equivalent (n = 9) 6.7% Middle school equivalent (n = 2) 30.0% High school equivalent (n = 9) 6.7% Some college (n = 2) 6.7% College degree or higher (n = 2)
Country of Origin	50.0% Mexico (n = 15) 20.0% El Salvador (n = 6) 20.0% Nicaragua (n = 6) 3.3% Ecuador (n = 1) 3.3% Peru (n = 1) 3.3% Guatemala (n = 1)
Years Living in U.S.	34.6 years (SD = 15.1)

SD = Standard Deviation

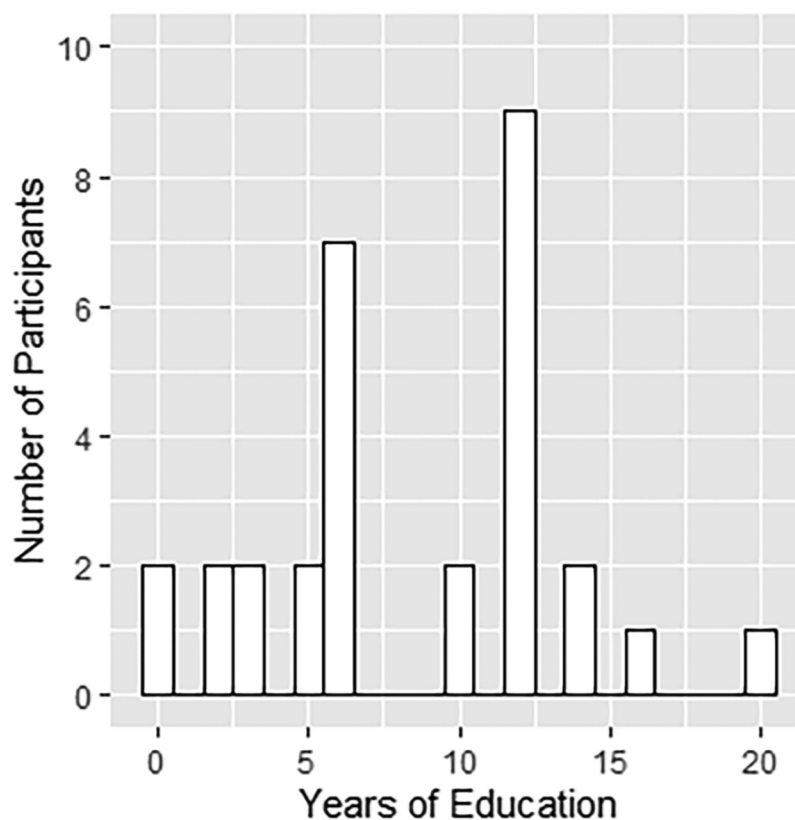


Figure 1. Years of education: frequencies of total years of education attained.

Theme 1C: cognition. Others discussed the brain's involvement in cognition, movement, learning, and behavior, including self-control. Participants mentioned the brain's role in walking, writing, getting out of a chair, and moving various body parts. Some participants described how the brain influences how one thinks, acts, and organizes. Others connected the brain to intelligence, learning to read, or learning from mistakes. One participant stated, "without the brain, we couldn't do anything . . . because the brain gives us – it drives us, it brings us wherever we go. Because it's the thing we have in order to be a responsible person, no?" (Participant 26). Some mentioned memory and orientation in relation to the brain. For instance, one participant stated that the brain "does a lot of things because one has to remember everything. In order to not forget" (Participant 7). Interestingly, while many discussed the brain's role in maintaining a good memory, some discussed its less positive tendency to keep certain unwanted memories in mind: "When a person has something that they can't – that they'd like to not feel. That comes from the brain too. For example, a bad memory that one doesn't want to have" (Participant 12).

Theme 1D: disease. A number of participants expressed an understanding of the brain's connection to disease, including both mental and physical conditions. In terms of mental health, participants connected the brain to depression, anxiety, and post-traumatic stress. For instance, one participant mentioned, "Everything comes from the brain regarding depression. Indeed, depression for anyone is bad, but it can be treated. How? With another person bringing them forward . . . because someone alone can even arrive at suicide if they have a lot of depression" (Patient 19). As for physical health, participants discussed the brain's role in epilepsy, incontinence, and stroke: "Well, the brain isn't – because, you say it can hurt, you can have a headache, and you can have a burst blood vessel and all. Many say that if my left arm hurts . . . and I have a headache, vomit and everything, well it could be a stroke" (Participant 24).

Theme 1E: an unknown. Others described the brain as mysterious or entirely unknown. In fact, seven participants specifically responded that they do not have much understanding of the brain. One said, "The brain, I wouldn't have a word to say about it,

to tell you the truth. I can't see myself from the inside" (Participant 18). Another said, "My husband got sick in the brain and I didn't understand much" (Participant 22).

Domain 2: perceptions of healthy and unhealthy aging brains

Most participants recognized certain age-related changes as part of the general aging process, without tying them specifically to brain health, when asked about perceptions of healthy and unhealthy aging. For instance, participants discussed changes in mood, thinking, and physical abilities as part of normal aging. Some described the emergence of difficult decisions, such as which country to live in as an older adult, whether to live with one's children or at a senior facility, and even end-of-life healthcare directives. Others described physical decline, such as coronary issues, loss of balance, fatigue, and incontinence as aspects of unhealthy aging. In terms of the brain, specifically, participants identified four key factors that distinguish between healthy and unhealthy aging brains: independence, memory, emotions, and orientation. While most participants had ideas about challenges related to unhealthy brain aging, only some directly connected this to dementia or Alzheimer's.

Theme 2A: independence. Participants consistently identified independence and the ability to continue with normal routines as a sign of healthy brain aging. For instance, one participant explained that her brain is still working because "one of my daughters tells me, 'mom, if you can still pay your bills, you personally do your checks, that means you're good in your brain'" (Participant 26). On the other hand, loss of function and self-control were related to loss of independence, which were described as indicators of unhealthy brain aging. For instance, participants mentioned the inability to make one's own food, shower, put on makeup, use the restroom, and take care of oneself as important factors in unhealthy brain aging. One participant stated, "I've seen the cases of people that have Alzheimer's, they even become violent. They don't eat, because they don't want to accept that they can't eat alone, so they don't eat. That would be very sad for me" (Participant 30). Similarly,

physical limitations were often associated with an unhealthy brain, including dizziness, pain, and mobility restrictions. When asked how they thought their family would react if something happened to their brain, one participant responded, "well, honestly it's really hard for the family to see someone maybe in a wheelchair, disabled, and unable to remain standing anymore" (Participant 17). Additionally, some participants discussed struggles with the health system and finances, particularly in the context of insurance status, that may emerge in light of unhealthy brain aging.

Theme 2B: memory. Many participants made a clear distinction between sustained memory abilities in healthy brain aging, versus loss of memory in unhealthy brain aging. Participants suggested that a functioning memory is a clear sign that a brain is aging healthily; for instance, on participant said, "Now I feel, let's not say strong, but I feel agile, attentive with my memory and everything. My brain is working in that. It's made of wood" (Participant 18). In unhealthy aging, some participants specifically mentioned the possibility of not remembering one's own family members. Others discussed having a harder time learning, forgetting new information quickly, and repeating the same things over and over: "You start to repeat yourself. And you start to ask 'and where are you going, where did you go?' and, even though they already told you. But that's how it starts" (Participant 6).

Theme 2C: emotions. Some participants volunteered that positive mood and emotions, such as happiness and gratitude, were indicative of healthy brain aging. Others discussed the maintenance of strong social skills as an indicator of a healthy brain. When asked how they knew their brain was functioning well, one participant responded, "I don't get upset. I'm already going to be 80, but thank God I have my good spirits. I mean to say happiness. I like music and I like going out" (Participant 14). Meanwhile, some participants recognized personality and mood changes, like becoming grumpier or less interested in socializing, as elements of unhealthy brain aging. Some discussed the negative impact that these changes can have on social relations, particularly when behavioral changes involve yelling, scolding, or hitting

others. One suggested that when a person has an unhealthy brain “they look bored. They don’t feel pleasure in life. Nothing. They’re negative. Right? So, you can’t even communicate with those people because you already know they’ll say ‘no’ to everything” (Participant 12). Others mentioned the need for increased support from family, friends, and community in the context of cognitive decline. In general, many participants discussed their confidence that their own family members would support them if their brain health were to decline: “I think that they’d try to help me, my children, my husband” (Participant 8). On the other hand, participants expressed fear about how they would be treated in the larger community: “Nobody’s going to take charge or take care of me or have patience for me” (Participant 14)

Theme 2D: orientation. Many participants discussed orientation to the world as a marker of healthy brain aging. Some discussed being aware of one’s surroundings or having their senses about them, and other discussed being organized. For instance, in describing someone with a healthy brain, one participant explained, “she knows that on Mondays she has to be there at 6:00, so her brain is active. And on Wednesdays she goes to another meeting there, she has her life organized, what she’s going to do each day, like on Sundays she goes to mass” (Participant 5). On the contrary, participants mentioned loss of awareness, decision-making, and linear thinking abilities as features of unhealthy brain aging. For instance, participants described someone with an unhealthy brain as unaware of what they are saying, where they are, or what they are doing. They also described such a person as not having the insight to recognize that something is wrong: “sometimes if a person has dementia, they don’t realize that they’re sick” (Participant 18). Some even mentioned the possibility of cognitive impairment being associated with heightened vulnerability to abuse.

Domain 3: ideas of how to take care of the brain

Participants identified various modifiable health behaviors related to brain aging. These ideas can be divided into three themes: physical health, social engagement, and cognitive health.

Theme 3A: physical health. Participants expressed an understanding of the importance of managing their physical health through both engagement with the formal medical system as well as via other more informal means. Some expressed managing their physical health by going to medical appointments, while others discussed managing chronic conditions, taking appropriate medications and vitamins, and practicing good personal hygiene. For instance, one participant said, “you have to have your vitamins, and you have to buy multivitamins, that have everything the body needs” (Participant 18). Many participants also discussed the benefits of engaging in healthful activities, such as exercise, nutritious diet, sufficient sleep, staying active, and taking care of things at home. One participant stated, “the most important thing that you can do is try to be close to exercise, to not stay seated or laying down, so the body can have oxygen and function better” (Participant 25). Some discussed specific dietary considerations: “Because if someone eats – if they say ‘I’m going to be eating pork, meat and – no, well this is what does damage to you. Also lots of food with oil, butter, and all that” (Participant 10). Some suggested the importance of limiting personal ‘vices,’ such as drugs and alcohol.

Theme 3B: social engagement. Many participants discussed the beneficial effects of staying socially active as they age, including surrounding themselves with people that love them, and being kind to family and friends. When asked how to take care of the brain, one participant responded, “socializing with other people. That maintains you, because when you’re talking with others, you learn from each other” (Participant 5). Others mentioned the benefits of participating in the community, such as getting involved at a community center, or volunteering at church, hospitals, or with children. One participant explained, “I try to keep my mind occupied, because if you aren’t busy with something, your mind will just play tricks on you. You have to help yourself. Spend time with people” (Participant 14).

Theme 3C: cognitive health. Some participants endorsed engagement in mentally stimulating activities as beneficial for brain health maintenance. For instance, participants discussed playing Bingo

or tablet-based games. One participant described her meditation and relaxation practices as maintenance approaches: “I don’t really feel old, maybe because of the studying I’ve done aside from this, of yoga. I know exercises of breathing, concentration, meditation” (Participant 18). Another discussed the benefits of learning new things: “Literature too, reading. If you don’t want to read books, now people that know about tablets, older people can entertain themselves on tablets” (Participant 5).

Domain 4: how participants learned about the brain

Respondents endorsed learning about the brain from five primary sources: upbringing, current communities, healthcare providers, professional experience, or the media. Some participants identified multiple sources of information (Table 2).

Theme 4A: upbringing. Some participants explained that their brain-related knowledge originated in their families or their childhood communities. One participant explained that this knowledge “comes from the education that you receive when you’re growing up, with your parents” (Participant 23). A number of participants mentioned the influence of institutions like school or church in their education about the brain. For instance, one participant said they learned about the brain “at school, at church, and in the family” (Participant 2).

Theme 4B: current communities. When asked where they had learned about their brains, some participants mentioned educational opportunities in their current communities. For instance, some discussed events and talks at their senior centers: “Where my mom lives, since it’s a building for seniors, we had a teacher that gave us psychology . . .

And every Tuesday he gave us different themes. About behavior, getting along with people, helping someone who needs it, supporting yourself, greeting people. And part, about the brain, dementia, and Alzheimer’s, all that. All that a person stores in the brain” (Participant 6).

Theme 4C: healthcare professionals. Others mentioned learning about the brain from their doctors or nurses. One participant said, “Because it’s like, I’ve gone with the cardiologist, with the psychologist. With the ophthalmologist, because it affected my vision a little, too. And in this way, I’ve gone, little by little, acquiring more knowledge about all the problems of the brain, that it’s so important” (Participant 30). One participant explained that they only began to learn about the brain once they had their own health concerns: “I hadn’t known the definition of the illnesses, like now I do now that I’ve struggled with one myself, the stroke” (Participant 25).

Theme 4D: professional life. Some participants shared that their brain-related knowledge originated in professional situations. “They gave us a training at our work, but of course nurses arrive that have studied medicine to give us some knowledge about illnesses. We’ve studied illnesses of people that have dementia, Alzheimer’s, how to treat patients like that” (Participant 5). Another explained that they knew about the brain because “I was a professor for 25 years, and I studied the anatomy of the human body” (Participant 4).

Theme 4E: media. Some participants explained their acquisition of brain-related knowledge through various media sources, such as television, books, and magazines. Some explained that they were self-taught on matters of the brain. For example, one participant said they learned about the brain “from books, and I used to watch a television program about traumas” (Participant 19), and another said they learned “from books from the Hindus, who have a lot of wisdom . . . and from philosophers too, I’ve read a lot of that” (Participant 18). Others discussed having a hard time learning about it on their own; for instance, one participant said, “When I’ve read about the brain before it seems very complicated to me.

Table 2. Knowledge acquisition: where understanding of the brain originated.

Where did you learn about brain?	Frequency
Talks/Senior Center	8
Family/Community (upbringing)	8
Career/Professional Experience	3
Media (TV, books, magazines)	4
Healthcare Providers (doctors, nurses)	5
Institutions (school, church)	6
Self-Taught (reading)	13

I can't understand it . . . When I've seen it on TV, I like to listen. I don't change the channel, I like to see what they say about the brain" (Participant 3).

Discussion

Our study explored perceptions of brain health and aging in older Latin American immigrants via in-depth personal interviews. A number of themes were identified, including knowledge of the brain, perspectives on healthy and unhealthy aging brains, attitudes regarding taking care of the brain, and how participants' understanding of the brain was acquired. Overall, our study results showed tremendous variability in participants' conceptions of brain health and dementia, demonstrating the need for more education in this area.

Generally, participants' understandings of the brain were rich and elaborate. Nevertheless, participants' responses demonstrated mixed knowledge, including a lack of clear and consistent understanding of the structure and functions of the brain. Several participants even expressed confusion about how the brain and the heart differ. This lack of awareness of the relationship between the brain and the heart is consistent with prior research that demonstrated that older Chinese Americans were less likely than younger Chinese Americans to recognize that some types of dementia are caused by cardiovascular disease (Liu & Woo, 2013). Shared frameworks of health knowledge can help potentiate patient-doctor relationships and facilitate community-based brain health literacy education efforts. Gaps in brain knowledge, such as those identified in our study, may represent a threat to brain health among members of some Latinx communities. Therefore, streamlined approaches for communicating the brain's primary functions may help facilitate the development of shared frameworks of understanding the brain, which may lead to improved brain health outcomes in vulnerable communities. For instance, education may be needed on the brain's role in various abilities (e.g. memory, language, executive functions, emotions), the basic underlying mechanisms (e.g. information collected from the outside world travels along nerve pathways to the brain, which processes information in different regions), the key brain regions involved

(e.g. hippocampus, prefrontal cortex, cerebellum), and the relationship between the brain and other organs like the heart (Alzheimer's Disease Fact Sheet, n.d.; Weaver II, n.d.). Knowledge of these concepts may help individuals conceptualize the brain as a body part that needs to be taken care of, can help clarify what brain changes are to be expected in normal aging, and may increase awareness of signs of nonnormative brain aging.

In terms of perspectives on healthy and unhealthy aging brains, participants successfully identified a number of key clinical neurocognitive changes observed in unhealthy brain aging, such as memory loss, disorientation, and early loss of independence. That said, many participants held incomplete perceptions about what brain health is and about what a disorder of the brain may entail. For instance, a number of participants understood memory loss to be the only symptom of dementia. While memory impairment is a key feature of Alzheimer's Disease, changes in functional abilities, thinking skills, personality, behavior, language production and comprehension, and sleep may also be implicated in different types of dementias (Alzheimer's Association, 2021). Individuals' perspectives on what healthy and unhealthy brain aging entails reflects their knowledge and understanding of the brain itself, reinforcing the importance of increasing knowledge of the brain's multiple and complex functions. Further, participants did not make a clear distinction between normal cognitive changes related to aging and disease-related changes to the brain, which is consistent with previous research with Latinx older adults (Valle, Yamada, & Matiella, 2006). It is important to note that normal aging is associated with impaired cognitive abilities (e.g. processing speed, working memory, executive functions) that make it difficult to differentiate between normative, age-related cognitive decline and neurodegenerative diseases such as Alzheimer's disease (AD), yet distinguishing between the two at the earliest stages of decline allows for more thorough clinical characterization and treatment opportunities (Denver & McClean, 2018). Given that dementia is less likely to be diagnosed in a timely and comprehensive manner among older individuals from historically marginalized populations as compared to non-Latinx Whites (Alzheimer's Association, 2021; Tsoy et al.,

2021), it is essential that information is disseminated more efficiently on this topic, so that affected individuals and their family members know when they should seek an expert medical evaluation. This represents an urgent public health need given the recent emergence of disease-modifying therapies for dementia, which are indicated only for individuals with very early disease manifestations (NIH National Institute on Aging (NIA), 2021).

Generally, participants appeared to hold positive attitudes toward the importance of maintaining brain health. Many participants' ideas about how to take care of the aging brain were aligned with current research, such as physical activity, healthy diet, cognitive stimulation, and socialization (Livingston et al., 2020; Yaffe, 2018). This may be due to brain health educational workshops that some participants had attended at their senior centers, which is encouraging. On the other hand, many promoted maintenance approaches that have not received much investigation or support. Similar to results of prior literature, many participants highlighted the importance of vitamins in maintaining brain health. In a prior study, adults who identified as Hispanic were 1.56 times more likely to report that taking vitamins or supplements could lower the risk of developing Alzheimer's disease (Roberts et al., 2014). This may be worth exploring further, as it may relate to an increased vulnerability to marketing of unproven "anti-aging" or "memory boosting" supplements. Moreover, some participants discussed tools like magnets and auras as potential ways to take care of the brain. In contrast to some of these beliefs, research consistently supports the impact of modifiable risk factors such as obesity, smoking, physical inactivity, and cognitive inactivity on the development of dementia (Yaffe, 2018). Thus, it is important to engage with community members' existing narratives, while simultaneously promoting science-based brain health maintenance approaches.

Seeing as respondents endorsed obtaining brain health information from their healthcare providers, community centers, and the media, these spaces should continue to be leveraged to increase knowledge. The finding about mass media's role in disseminating dementia information was consistent with prior work with older Chinese Americans, which highlighted that radio, television, YouTube series, and social media outlets can be important

means through which to increase dementia awareness (Shu & Woo, 2020; Woo, 2017). Within the Latinx community, specifically, prior research demonstrated the utility of dementia-oriented *foto-novelas* and Facebook campaigns to increase dementia knowledge (Friedman et al., 2016; Valle et al., 2006). Therefore, developing more media awareness campaigns may prove beneficial for increasing awareness and understanding. Future investigations may also explore the accuracy of the information that older adults gather from media outlets. Additionally, consistent with prior research among Latinx older adults and professionals serving them (Friedman et al., 2016; Perales et al., 2020), our findings suggest that educating healthcare professionals to disseminate appropriate information and increasing the occurrence of aging education at senior centers would likely prove fruitful. Previous research supports leveraging "lunch-and-learn" sessions at community centers or expert panel conversations at coffee shops or other public places to increase knowledge among professionals (Friedman et al., 2016; Perales et al., 2020). Moreover, seeing as some participants discussed spirituality in their conceptualizations of the brain, as well as learning about the brain at church, it may be worthwhile to utilize partnerships with churches and religious centers in the community as a viable resource for disseminating brain health education. We explored this topic in a prior manuscript (Weiner-Light et al., 2021), and we see this as an important opportunity for collaboration with community partners.

While this qualitative study provided a rich and complex exploration of sample participants' brain health-related beliefs and illuminated gaps that require follow-up, several study limitations should be mentioned. Our findings are limited to represent the lived experiences of 30 participants from one geographic region and are not generalizable to all Latin American immigrants living in the US. All research is shaped by the social positions and personal backgrounds of those engaged in the work. Despite bilingualism and extensive experience with Latinx communities, it is important to acknowledge that neither coder identifies as Latinx. Further, this population represents a wide range of educational attainment; it is possible that those with lower levels of education may benefit the most from programming on brain health. More in depth exploration is

warranted to understand the impact of this disparity in years of formal education on knowledge of brain health. The investigation was exploratory in nature, and more research is needed to understand the impact of these findings. Extending this work to include more older Latinx individuals hailing from diverse countries and regions, living in different regions of the US, and who represent varying levels of acculturation status, would be worthwhile, as would extending this study to other underrepresented populations to identify similarities and differences.

Given the high prevalence of dementia among the older Latin American immigrant population, interventions that aim to educate and increase knowledge are imperative for addressing brain health disparities. Collecting information from the stakeholders prior to the design and implementation of interventions is key for ensuring social and cultural appropriateness; our formative investigation may lead to the tailoring of brain health promotion messages that resonate with the target audience and are more likely to produce desired outcomes. Some key takeaways involve developing a more concise and clear way of communicating the structure and functions of the brain, promoting realistic understandings of what nonnormative brain aging entails, and disseminating more information on empirically-supported maintenance approaches. It is important to note that the heterogeneity revealed in participants' narratives about the brain and dementia is an expression of each participant's individual background, knowledge, and identity. This rich heterogeneity emphasizes the sample's diversity of life experiences, age, education, and acculturation levels. Moreover, it highlights the diversity of individuals of Latin American descent and opposes the notion of one unitary Latinx culture. Therefore, while it would be impractical to tailor an educational approach that realistically addresses all of these multifaceted experiences, findings can be leveraged to inform approaches that center on clarity of communication and science-based information in people's native languages. While our results did not directly point to community partnerships, literature suggests that it will be important to actively engage community partners in the intervention work (Gluck et al., 2018; McGill, 2013; Perales et al., 2020; Valle et al., 2006). Particularly among historically marginalized groups, engagement with community partnerships is

key to building trust, ensuring effective implementation that best suits specific communities' needs, and fostering a sense of empowerment and connectedness to the cause (Gluck et al., 2018; Michener et al., 2020). Important work is currently being done in the realm of community brain health education with programs such as the Global Brain Health Institute (GBHI) and the Community Outreach Program at the UCSF Memory and Aging Center, and our work will further improve these existing educational approaches.

Clinical implications

- Key takeaways involve developing a more concise and clear way of communicating the brain's role in various abilities, the underlying mechanisms, key brain regions involved, and the relationship between the brain and other organs.
- Additionally, interventions may promote more complete understandings of what normative vs. nonnormative brain aging entails, the various features of dementia beyond memory impairment, and empirically-supported brain health maintenance approaches.
- Dissemination of brain health information may be increased via collaborations with healthcare providers, community centers, community classes, and churches or other religious centers, as well as through various media outlets.

Data availability statement

The data that support the findings of this study are available from the corresponding author, SWL, upon reasonable request.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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or concept discussed in this article. The data that support the findings of this study are available from the corresponding author upon request.

References

- Alzheimer's Association. (2021). Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 17(3):5-78.
- Alzheimer's Disease Fact Sheet. (n.d.). National Institute on Aging. Retrieved from <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>
- Ayalon, L., & Areán, P. A. (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry*, 19(1), 51–57. doi:10.1002/gps.1037
- Barak, Y., Rapsey, C., & Scott, K. M. (2022). Clusters of dementia literacy: Implications from a survey of older adults. *The Journal of Prevention of Alzheimer's Disease*, 9(1), 172–177. doi:10.14283/jpad.2021.66
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development* (pp. xvi, 184). Thousand Oaks, CA, US: Sage Publications, Inc.
- Brennan, S., Geary, U., & Gallagher, S. E. (2021). Online videos promote brain health literacy. *Health Promotion International*, 36(5), 1243–1252. doi:10.1093/heapro/daaa142
- Cohen, D., Crabtree, B. F., Damschroder, L., Hamilton, A. B., Heurtin-Roberts, S., Leeman, J., . . . Reisinger, H. S. (2018). *Qualitative methods in implementation science* (Bethesda, MD, USA: National Cancer Institute) (pp. 31).
- Coughlin, S. S., Vernon, M., Hatzigeorgiou, C., & George, V. (2020). Health literacy, social determinants of health, and disease prevention and control. *Journal of Environment and Health Sciences*, 6(1), 3061.
- Denver, P., & McClean, P. L. (2018). Distinguishing normal brain aging from the development of Alzheimer's disease: Inflammation, insulin signaling and cognition. *Neural Regeneration Research*, 13(10), 1719–1730. doi:10.4103/1673-5374.238608
- Edwards, A. B., Cherry, R. L., & Peterson, J. (2000). Predictors of misconceptions of Alzheimer's disease among community dwelling elderly. *American Journal of Alzheimer's Disease*, 15(1), 27–35. doi:10.1177/153331750001500103
- Fernandez, A. (2018, March 2). Let's improve brain health literacy during brain awareness week 2018. *SharpBrains*. Retrieved from <https://sharpbrains.com/blog/2018/03/02/lets-improve-brain-health-literacy-during-brain-awareness-week-2018/>
- Friedman, D. B., Gibson, A., Torres, W., Irizarry, J., Rodriguez, J., Tang, W., & Kannaley, K. (2016). Increasing community awareness about Alzheimer's disease in Puerto Rico through coffee shop education and social media. *Journal of Community Health*, 41(5), 1006–1012. doi:10.1007/s10900-016-0183-9
- Gluck, M. A., Shaw, A., & Hill, D. (2018). Recruiting older African Americans to brain health and aging research through community engagement: Lessons from the African-American brain health initiative at Rutgers University-newark. *Generations (San Francisco, California)*, 42(2), 78–82.
- Gurland, B. J., Wilder, D. E., Lantigua, R., Stern, Y., Chen, J., Killeffer, E. H., & Mayeux, R. (1999). Rates of dementia in three ethnorracial groups. *International Journal of Geriatric Psychiatry*, 14(6), 481–493. doi:10.1002/(SICI)1099-1166(199906)14:6<481::AID-GPS959>3.0.CO;2-5
- Heger, I., Köhler, S., van Boxtel, M., de Vugt, M., Hajema, K., Verhey, F., & Deckers, K. (2020). Raising awareness for dementia risk reduction through a public health campaign: A pre-post study. *BMJ Open*, 10(11), e041211. doi:10.1136/bmjopen-2020-041211
- Liu, J., & Woo, B. K. (2013). Older adults are less accurate than younger adults at identifying cardiovascular disease as a cause of dementia in the Chinese American community. *International Psychogeriatrics*, 25(6), 1033–1034. doi:10.1017/S1041610213000112
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., . . . Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet (London, England)*, 396(10248), 413–446. doi:10.1016/S0140-6736(20)30367-6
- McGill, N. (2013). As Hispanics lag in clinical trials, health researchers take action: Outreach expands. *The Nation's Health*, 43(7), 1–16.
- Michener, L., Aguilar-Gaxiola, S., Alberti, P. M., Castaneda, M. J., Castrucci, B. C., Harrison, L. M., . . . Wallerstein, N. (2020). Engaging with communities—Lessons (Re)Learned from COVID-19. *Preventing Chronic Disease*, 17, E65. doi:10.5888/pcd17.200250
- NIH National Institute on Aging (NIA). (2021, July 8). How is Alzheimer's disease treated? *National Institute on Aging*. Retrieved from <http://www.nia.nih.gov/health/how-alzheimers-disease-treated>
- Perales, J., Moore, W. T., Fernandez, C., Chavez, D., Ramirez, M., Johnson, D., . . . Vidoni, E. D. (2020). Feasibility of an Alzheimer's disease knowledge intervention in the Latino community. *Ethnicity & Health*, 25(5), 747–758. doi:10.1080/13557858.2018.1439899
- Roberts, J. S., McLaughlin, S. J., & Connell, C. M. (2014). Public beliefs and knowledge about risk and protective factors for Alzheimer's disease. *Alzheimer's & Dementia*, 10(5S), S381–S389. doi:10.1016/j.jalz.2013.07.001
- Shu, S., & Woo, B. K. P. (2020). Digital media as a proponent for healthy aging in the older Chinese American population: Longitudinal analysis. *JMIR Aging*, 3(1), e20321. doi:10.2196/20321
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. doi:10.1093/intqhc/mzm042
- Tsoy, E., Kiekhof, R. E., Guterman, E. L., Tee, B. L., Windon, C. C., Dorsman, K. A., . . . Possin, K. L. (2021). Assessment of racial/ethnic disparities in timeliness and comprehensiveness of dementia diagnosis in California. *JAMA Neurology*, 78(6), 657–665. doi:10.1001/jamaneurol.2021.0399

- Valle, R., Yamada, A.-M., & Matiella, A. C. (2006). Fotonovelas. *Clinical Gerontologist*, 30(1), 71–88. doi:10.1300/J018v30n01_06
- Wang, Y., Pan, Y., & Li, H. (2020). What is brain health and why is it important? *BMJ*, m3683. doi:10.1136/bmj.m3683
- Weaver, E. A., II (n.d.). *How does the brain work?* Dana Foundation. Retrieved from <https://dana.org/wp-content/uploads/2019/05/fact-sheet-3-5-how-does-brain-work.pdf>
- Weiner-Light, S., Rankin, K. P., Lanata, S., Possin, K. L., Dohan, D., & Bernstein Sideman, A. (2021). The role of spirituality in conceptualizations of health maintenance and healthy aging among Latin American immigrants. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 29(11), 1079–1088. doi:10.1016/j.jagp.2021.04.017
- Woo, B. K. (2017). Dementia health promotion for Chinese Americans. *Cureus*, 9(6), e1411. doi:10.7759/cureus.1411
- Yaffe, K. (2018). Modifiable risk factors and prevention of dementia: What is the latest evidence? *JAMA Internal Medicine*, 178(2), 281–282. doi:10.1001/jamainternmed.2017.7299

Appendix A. Interview Guide – English version

INTERVIEW GUIDE

(1) The Brain

- a. What do you know about the brain?
- b. How did you gain this knowledge?
 - i. Prompt: Did you get this information from any sources or any person? Who did you get this information from?
- c. Have you heard other views or information about the brain? Where do these views come from?
- d. How do you think your brain will change as you get older?
- e. How do you know if your brain is healthy? Not healthy?
- f. What do you think would change about you and who you are if your brain was not healthy?
- g. What are things you think you can do to keep your brain healthy as you get older?
- h. How would people view you if something happened to your brain?

(2) Aging

- a. What can you do to take care of your health as you get older?
- b. Can you think of an older person in your life who is aging well or in a healthy way? Please describe . . .
 - i. How do you know? What does that mean? What is that like? What problems do they have?
- c. Can you think of an older person in your life who is not aging well or in a healthy way? Please describe?
 - i. How do you know? What does that mean? What is that like? What problems do they have? What problems do they not have?

(3) Closing

- a. Is there anything else you would like to add, or anything you feel you did not get a chance to say?
- b. If you think of anything in the future, feel free to e-mail or call me.

Appendix B. Consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist

No.	Item	Guide questions/description	Response/page number
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
1.	Interviewer/facilitators	Which author/s conducted the interview?	Page 6 (Procedures): Reported in Methods under Procedures section.
2.	Credentials	What were the researcher's credentials?	Page 6 (Procedures): The interviewer was a research assistant (bilingual, trained at the MA level in global health with experience in qualitative research).
3.	Occupation	What was their occupation at the time of the study?	Page 6 (Procedures): The interviewer was a research assistant at the time of the study.
4.	Gender	Was the researcher male or female	Page 6 (Procedures): The interviewer identified as female.
5.	Experience and training	What experience or training did the researcher have?	Page 6 (Procedures): The interviewer is bilingual and has experience in qualitative research, with an MA in global health. She also has experience as a translator and leading Spanish-language outreach programs.
<i>Relationship with participants</i>			
6.	Relationship established	Was a relationship established prior to the study commencement?	The interviewer had no prior relationships with the research participants. SWL, ABS, and SL had prior relationships with some of the community centers where recruitment occurred, based on outreach work.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? E.g. personal goals, reasons for doing the research.	Research participants were aware of the goals of the study based on information provided by the interviewer at the time of recruitment and consent.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.	No characteristics were reported to participants.
Domain 2: Study design			
<i>Theoretical framework</i>			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis.	Page 6–7 (Data Analysis): Qualitative content analysis was used to identify key themes.

(Continued)

(Continued).

No.	Item	Guide questions/description	Response/page number
<i>Participant selection</i>			
10.	Sampling	How were participants selected? E.g. purposive, convenience, consecutive, snowball	Page 5–6 (Participants): We used purposive and snowball sampling to recruit participants.
11.	Method of approach	How were participants approached? (e.g. face-to-face, telephone, mail, e-mail)	Page 5–6 (Participants): We used ads, flyers, and a face-to-face approach.
12.	Sample size	How many participants were in the study?	Page 7 (Sample Characteristics): 30 participants were interviewed.
13.	Nonparticipation	How many people refused to participate or dropped out? Reasons?	Not applicable – all who signed up for interviews took part. No one dropped out.
<i>Setting</i>			
14.	Setting of data collection	Where was the data collected? E.g. home, clinic, workplace	Page 6 (Procedures): interviews were conducted at community sites chosen by the participants.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Not applicable – no other people were present during the interviews.
16.	Description of sample	What are the important characteristics of the sample (e.g. demographic data)	Page 7 (Sample Characteristics); Table 1
<i>Data Collection</i>			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 6 (Procedures): Interview guide was developed by a multidisciplinary team based on a review of literature and topics identified during brain health education outreach.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Not applicable – interviews were only conducted once.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 6 (Procedures): Audio recordings were collected.
20.	Field notes	Were field notes made	Not applicable – the data consisted of interview transcripts.
21.	Duration	What was the duration of the interviews or focus groups?	Page 6 (Procedures): Interviews lasted 45–60 minutes.
22.	Data saturation	Was data saturation discussed?	Page 6 (Data Analysis): Data saturation was reached.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Not applicable – transcripts were not returned to participants.
Domain 3: Analysis and findings			
<i>Data analysis</i>			
24.	Number of data coders	How many data coders coded the data?	Page 6–7 (Data Analysis): Data was analyzed by two coders (SWL, ABS) using content analysis to identify key themes.
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Page 7–16 (Results)
26.	Derivation of themes	Were themes identified in advanced or derived from the data?	Page 6–7 (Data Analysis): Themes were derived both inductively and deductively.
27.	Software	What software, if applicable, was used to manage the data?	Page 6 (Procedure): Interviews were analyzed in Dedoose Version 8.3.17.
28.	Participant checking	Did participants provide feedback on the findings?	Not applicable – participants did not provide feedback on the findings.
<i>Reporting</i>			
29.	Quotations presented	Were participant quotations presented to illustrate the themes/findings? What each quotation identified? E.g. participant number.	Page 7–16 (Results)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Page 7–16 (Results): Findings presented represent the data.
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Page 7–16 (Results): Major themes are presented in our results.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 7–16 (Results): Within each theme, we also discuss a diversity of responses.