

Research Report

Understanding the Perspectives and Needs of Latinx Caregivers of Persons with Alzheimer's Disease in the Appalachians: An Interpretive Phenomenological Approach

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Abstract.

Background: Alzheimer's disease and related dementias (ADRD) disproportionately impact Latinx and other communities of color in the United States. The challenges for patients with ADRD and their informal caretakers can be attributed, in part, to the gaps that exist within health care services and systems.

Objective: To understand the perspectives of barriers, beliefs, knowledge, and needs for the Latinx informal caregivers that take care of relatives with ADRD in the Upstate of South Carolina, region of Appalachia.

Methods: This study was approved by the GHS-Prisma Health and Clemson University IRB, Study #Pro00086707. In-depth phone interviews were conducted with a sample of Latinx informal caregivers. A descriptive and interpretive phenomenological approach was used for analysis. Participants were recruited through community partnerships with local organizations.

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Results: Salient themes identified in this study included the relevance of caregiver's degree of awareness about the disease and a perspective of Alzheimer's disease as a progressive and degenerative disease. Critical moments identified encompassed challenges related to patient engagement with the outside world, their attitudes, and behaviors, as well as caregiver-related challenges with access to culturally and linguistically relevant resources needed to provide proper care. Caregivers identified several culturally relevant coping strategies used and motivators in providing care for their relatives with ADRD.

Conclusions: Linguistically and culturally sensitive programs and resources that account for knowledge, assets, and needs of Latinx informal caregivers of ADRD patients are needed to improve the quality of care and decrease disparities in health outcomes for Latinx older adults.

Keywords: Alzheimer's disease, Alzheimer's disease and related dementias, assessment of healthcare needs, coping strategies, culturally appropriate services, family caregiver, informal caregiver, Latinx/Latino/Hispanic

INTRODUCTION

Alzheimer's disease and related dementias (ADRD) refers to a disease process characterized by cognitive and functional decline. ADRD is associated with aging, beginning with progressive memory loss [1], leading to the inability to perform activities of daily living (ADLs), behavioral changes, and ultimately fatality [2, 3]. The number of ADRD patients aged 65 years and older is projected to surge from 5.8 million to 13.8 million by 2050 in the United States (U.S.) [4].

As the population continues to age, chronic diseases associated with living longer, including ADRD, are expected to disproportionately impact minority groups in the U.S. [5, 6]. Studies have indicated older Black and Latinx individuals are twice as likely to have ADRD and often present with greater cognitive impairment compared to their older White counterparts [6]. In addition, disparities exist between these populations' quality of life and the number of years spent in their late life with ADRD [7].

The observed rise of ADRD among Black and Latinx groups in the U.S., and its related challenges, can be partly attributed to gaps that exist within health care services and access to care. Identifying staff who are culturally competent or speak the language necessary to communicate with the patient is a major challenge among minority groups seeking access to adequate care [8]. A review of dementia caregiver intervention initiatives shared that only 11 of those 18 caregiver interventions engaged in cultural tailoring tactics such as familism, language, literacy, protecting elders and logistical barriers [9]. Though numerous interventions have been documented, existing literature cites the need for further culturally specific approaches to address racial and ethnic related disparities in caregiver experiences for people with ADRD in the U.S. [8].

A caregiver of a person with ADRD can be defined as an informal (i.e., relatives or friends) or professional patient aid who focuses on assisting with ADLs [10]. In 2017, unpaid caregivers reported providing more than 21 hours of care per week. Within this statistic, 42% reported working an average of 9 hours with dementia patients [8]. About 75% of patients with AD living at home received care from family and friends while the remaining 25% of patients received care from services paid for by the family [11]. Statistics reveal that family caregivers are predominantly female (91%), over 65 years old, and manage more complex medical conditions than non-ADRD caregivers [12]. Research shows that caregivers face distinct challenges that can be summarized into the following categories: psychological morbidities, physical morbidities, social isolation, financial burden, and institutionalization [13].

As one study suggests, sociocultural factors, values, and family traditions are individually distinctive based on different cultural backgrounds [14]. Thus, cultural norms and traditions influence Latinx ADRD caregiving practices. Understanding the influences of caregivers is vital to providing better care for the Latinx patient population as they represent the largest minority group in the U.S [15]. In fact, according to the 2020 U.S. census, the Latinx population consisted of approximately 62.1 million Americans—primarily from Mexico which constituted 18.5% of the U.S. population [15]. In this study we refer to Latinx as a person whose origin or descent is connected to any Latin American countries. Latinx is used in this manuscript as a gender-neutral or nonbinary alternative to Latino or Latina. Socioeconomic inequalities and the social determinants of health exacerbate Latinx disadvantages with high uninsured rates, and language and cultural barriers. These disadvantages draw attention to the gap among the Latinx population when interacting with healthcare providers

to receive quality care and additional resources [16].

This qualitative study targeted the experiences of Latinx informal caregivers taking care of persons with ADRD in the Appalachia region in South Carolina. Latinx are the fastest-growing minority population in the Appalachia region (5.8% in 2021, from 4.2% in 2010) [17]. Semi-structured interview questions were informed by clinical practice and expertise within the areas of dementia care, informal caregiver support, and qualitative research: 1) What is the meaning of ADRD in the lives of Latinx informal caregivers within the Appalachian region? 2) What are the critical moments associated with the management of ADRD? 3) What do Latinx informal caregivers understand about ADRD and the ways to manage it? 4) What strategies do Latinx informal caregivers describe as being helpful to them in managing ADRD? 5) What social/cultural factors influence informal caregiver perspectives and expectations of ADRD care?

Through this descriptive and interpretive phenomenological approach, we sought to understand the phenomenon as it is experienced in life with the following assumptions: 1) there is an essential understanding of ADRD and the ways in which to manage it and 2) the narratives of the participants would offer insight into the contextual components of the experience of ADRD in their lives [18, 19].

MATERIALS AND METHODS

Theoretical framework

For this study, a descriptive (eidetic) and interpretive (hermeneutic) phenomenological approach was used as a foundation. Phenomenology has the primary objective of describing the phenomena of interest as it is consciously experienced, free of preconceptions [19]. According to Husserl (1970) [20], the subjective information in human actions and motivations is important because these attributes are what someone perceives to be real. Therefore, a scientific approach is needed to arrive at the essence of the lived experience. Heidegger postulated that the focus of inquiry goes beyond the description of core concepts to focus on the people or phenomena and the meaning of their lived experiences [21]. A combined approach was used to advance research on Alzheimer's care by understanding of the Latinx informal caregiver experience with research

questions to grasp the essential meaning of the phenomenon.

Participants

This study was approved by the GHS-Prisma Health and Clemson University IRB, Study #Pro00086707. A purposive selection of Latinx informal caregiver was utilized with the goal to enroll participants who cared for older adult family members 65 years and older with ADRD. In this study, an informal caregiver was defined as an adult over the age of 18 years old, of reported Latinx origin or descent, who was the spouse, biological relative, or close friend of an elderly family member who required their assistance with managing ADRD. The requirement that caregivers be instrumental in the management of ADRD is critical to understanding the experience. The goal was to interview between 5-30 informal caregivers; however, sample recruitment was challenged due to COVID-19 Pandemic, and ultimately 11 Latinx informal caregivers participated in an in-depth phone interview. Regardless of the number of participants, phenomenological research often uses small samples sizes because of the extensive nature of the interview [21]. Previous qualitative studies that explored the Latino ADRD caregiver experience also used smaller sample sizes when conducting in-depth interviews and gathering data on cultural phenomena [22–25]. Table 1 details socio-demographic and caregiving related data of the Latinx caregivers who participated in the study. All 11 participants self-identified as Latinx females and their average age was 47 years (Range: 19–80 years). About half of them have completed a college or master's degree and less than a quarter of participants did not complete high school. Around half of the ADRD patients receiving care were the caretaker's mother, grandmother, grandfather, and their average age was 77 years (Range: 59–91).

Recruitment

Informal caregivers were recruited through community leaders from local churches, support groups, and community-based organizations as well as patient partnerships through the GHS-Prisma Health Patient Engagement Studio. A bilingual and trained team member contacted referred participants via phone to confirm their interest in participating in the study. The time was determined at the convenience of the participants. The flexibility in timing

Table 1
Study participants' socio-demographic and caretaking related data

Variables	Categories	Participants (n = 11)
Percent (n)		
Gender	Female	100 (11)
Race/Ethnicity	Latino/Hispanic	100 (11)
Education	Did not complete high school	18 (2)
	Completed high school/GED	18 (2)
	Some college	9 (1)
	Completed junior college, associate degree, technical training	18 (2)
	Completed college/bachelor's degree	18 (2)
	Completed graduate degree	18 (2)
Relationship to the person they care for	Spouse/significant other	9 (1)
	Mother	25 (3)
	Grandmother/Grandfather	25 (3)
	Sister	9 (1)
	Aunt	9 (1)
	Friend	9 (1)
Length of caregiving	Less than a year	9 (1)
	1-5 years	55 (6)
	6-10 years	36 (4)
Caretakers' age (Years); Mean = 47, Range 19 – 80		
Patients' age (Years); Mean = 77, Range 59 – 91		

and scheduling reduced the caregiver's burden by affording the opportunity to make the necessary arrangements (e.g., alternative care for care recipients).

Data collection

Originally, the research team planned to conduct in-person interviews; however, the COVID-19 Pandemic imposed restrictions that led the team to opt for conducting phone interviews instead. The research team developed the questions with a conversational approach that could reflect the *sympatia* and *respect*—which are recognized cultural values among U.S. Latinos. Table 2 includes all questions asked in the interview. The research team opted for selecting an interviewer who is also of Latinx origin and descent (Mexican/Salvadorian), and who has also been trained in cultural competence and humility in health care, to connect with Latinx people from various countries with differing cultural beliefs. According to Van Manen (1997) [26], semi-structured questions assist the researcher in being focused with general probing follow-up questions as appropriate [27]. Informed consent was obtained prior to beginning the semi-structured phone interviews. The 11 phone interviews were separately conducted at a day and time convenient to the participant. The interviews lasted between 60 to 90 minutes

and were tape recorded. To ensure privacy and confidentiality, audio recordings were securely stored, and pseudonyms were used in both the recordings and study documents. Audio recordings were destroyed within 72 h of the interview being transcribed. Participants received a \$45 gift card for completing the phone interview. No follow-up calls were performed.

Data analysis

All audio-recordings were transcribed verbatim in Spanish and translated to English by an independent provider trained in qualitative research methods. Transcriptions and translations were verified by a bilingual research team member for a qualitative analysis. Themes were identified using the Van Manen approach [26]. Four research team members conducted data analysis. After consensus was reached for the coding protocol and theme development, team members divided the questions and conducted a first pass codification. Subsequently, the entire team met to review and to discuss the preliminary coding and develop corresponding themes together as a team. Nine meeting sessions were required to arrive at consensus on the codification and themes derived from the data. The team developed an audit trail (field notes, raw data, coding themes, etc.) that was available to other research team members, thus promoting the study's content validity.

Table 2
Questionnaire to conduct the study interviews

1) **What did you think about when you first realized your loved one had dementia?**

2) **What comes to mind when you think of:**

- ... your role experience as a caregiver of a person with dementia?
- ... "any" factors that influence you experience as a caregiver of a person with dementia?
- ... "any" cultural or historical traditions that influence your experience as a caregiver of a person with dementia?
- ... "any" rewarding aspects of being a caregiver of a person with dementia?
- ... "any" challenging aspects of being a caregiver of a person with dementia?
- ... "any" resources or supports from family, health care providers, and/or community that would help you in your role?"

3) **Take me back to a time, if you can remember, when you successfully managed a situation related to your loved one's dementia. What was that like for you?**

4) **Tell me about your most challenging experience.**

5) **What sustains you in your role? What keeps you going?**

6) **How prepared have you felt to manage dementia in your loved one?**

7) **Tell me, what is your understanding of dementia? How do you treat it?**

8) **What do you think causes dementia?**

9) **How much control do you think you have over your loved one's dementia?**

10) **What advice have you received about dementia when discussed with a doctor or healthcare provider?**

11) **What support or assistance have you received to help you with managing dementia?**

12) **What support or assistance would you like to receive?**

13) **How much of your time is spent each day in managing your loved one's dementia?**

14) **What changes have you made in your life because of it?**

15) **Have we missed anything that helps us to identify your perceptions about your caregiver role and needs to fulfill it?**

RESULTS

The purpose of this qualitative study was to gain insight into the cultural perspectives and experiences of Latinx ADRD caregivers within the Appalachian region of Upstate SC and inform the future development of culturally sensitive interventions. The results section is organized by the five research questions that guided this study. Table 3 includes a summary of codes, themes, and selected quotes identified by the research team.

Relevance of caregiver's degree of awareness about the disease, perspective of Alzheimer's as a progressive and degenerative disease, and expectations on the manifestations of the disease are themes that emerged from analyzing the first research question: What is the meaning of ARDR in the lives of Latinx informal caregivers within the Appalachian region? Two participants reported having awareness of the disease due to previous knowledge of dementia. One caregiver reported a lack of awareness, both in the family and in her culture. She stated, "*I just knew it was going to be very challenging and a lot of work was going to go behind it because I guess just the topic of dementia in our family it is not well known . . .*" On the perspectives of Alzheimer's as a progressive and degenerative disease, one caregiver exclaimed, "*Alzheimer's we know that it comes and goes and advances . . . it affects certain parts of the brain and becomes degenerative, and your body becomes the part that forgets*

to function, right." Regarding expectations of the disease, a participant mentioned changes in physical movements and the brain saying, "*I knew at that time that she was going to lose motor faculties and that she was forgetting things . . .*"

Challenges to facilitate patient's engagement with the outside world, caregiver-related needs and challenges, patient's attitudes and behaviors, caregiver role and traits, and resources needed for caregivers/patients are five themes that emerged from the second research question: What are the critical moments associated with the management of ADRD? Common critical moments among caregivers were associated with the aiding of the ADRD patient's social interaction. One caregiver expressed social coexistence as a challenge, "*...social coexistence not with the family but with the outside world. That is a challenge for me . . .*" When addressing caregiver needs and challenges, four caregivers expressed the importance of self-care and rest. One caregiver exclaimed, "*...the people who take care of them must have those moments like rest and reflection . . .*" Along similar expressions, two caregivers felt that dealing with personal and emotional conflicts with the patient significantly affected their ability to care for the patient. One caregiver emphasized, "*one thinks that you will never learn from a disease and the most important challenge was just learning from an illness to learn to understand the person better*". Another challenge identified by caregivers was the

Table 3

Summary of themes, codes, and sample quotes from the study "Understanding the perspectives and needs of Latinx caregivers of persons with Alzheimer's disease in the Appalachians."

Research questions	Themes	Codes	Sample Quotes
(1) What is the meaning of ADRD in the lives of Latinx informal caregivers within Upstate South Carolina?	Relevance of caregiver degree of awareness about the disease	<ul style="list-style-type: none"> ● Already aware due to: <ul style="list-style-type: none"> ○ Previous knowledge about dementia ○ The hereditary nature of the disease ● Lack of awareness ● Dementia is a constant condition. ● Alzheimer's comes and goes and is degenerative. ● Dementia is progressive decline in cognitive function, deterioration. ● Difficult to diagnose. ● Weakness of the brain. 	<p>"I just knew it was going to be very challenging and a lot of work was going to go behind it because I guess just the topic of dementia in our family it is not well known at least in my family or in our culture."</p> <p>"Alzheimer's, we know that it comes and goes and advances, advances and advances and for the same reason that it normally goes on, it affects certain parts of the brain and becomes degenerative, and your body becomes the part that forgets to function, right."</p>
	Alzheimer as a progressive and degenerative disease	<ul style="list-style-type: none"> ● Dementia affects a person's brain. ● Anterograde amnesia (forgets the things of the present, but not the things of his past) 	<p>"I knew at that time that she was going to lose motor faculties and that she was forgetting things until that moment I knew that later."</p>
(2) What are the critical moments associated with the management of ADRD?	Expectations on the manifestations of the disease	Change in physical movements.	
	Challenges to facilitate patient's engagement with the outside world	Facilitating patient' social interaction <ul style="list-style-type: none"> ● Controlling and assisting patient outside 	<p>"Well, another challenge was social coexistence not with the family but with the outside world. That is a challenge for the caregiver, and it is a super important challenge."</p>
	Caregiver related needs and challenges	<i>Psychological well-being</i> <ul style="list-style-type: none"> ● Self-care (moments of relaxation, rest, and reflection) ● To have a hobby to relax and to cope when patients is no longer with them. ● Need to have a lot of patience. <i>Emotional impact</i> <ul style="list-style-type: none"> ● Ability to understand the patient. ● Sadness for the patient' situation. ● History of conflicts with the patient. <i>Material and personal</i> <ul style="list-style-type: none"> ● Economic challenges (inability to work) ● Access to learning resources ● Limited access to online resources to keep patient's mind active. ● Language barriers (educational materials) ● Time availability (adaptations to care for the patient, schedule disruptions, and marital relationship changes) <i>Self-efficacy</i> <ul style="list-style-type: none"> ● No or minimal control (8 participants) ● A degree of control (a)90%, (b)80%, (c)50% 	<p>"... the people who take care of them must have those moments like rest and reflection. That is very important so that the person who is caring for [the patient] doesn't get tired, doesn't get upset, I don't know what the word would be —doesn't want to run away..."; "I think that the caregiver has a super important role to survive right. Sure, yes self-care."</p> <p>"...when I correct her about something, when I tell her that she can't do something, she looks at me badly, she treats me badly, then the teacher who advises me tells me that it's normal because of the disease and that it is not her that is the disease, but since we had situations like that before, so sometimes I feel that if it is personal that she has something like evil against me..."</p> <p>"One thinks that you will never learn from a disease and the most important challenge was just learning from an illness to learn to understand the person better."</p> <p>"There is no control at all. Because for the simple reason as I tell you, there is no control because the dementia is already there."</p>

	Patient's attitudes and behaviors	<p>Patient's negative attitudes: aggressivity, being difficult, mood changes.</p> <ul style="list-style-type: none"> • The patient forgetting that he/she has being fed. • Patient's loss of attachment with the caregiver. 	<i>"When she gets aggressive when she gets difficult, I have to know how to deal with it".</i>
	Caregiver role and traits	<p>Understanding the disease</p> <ul style="list-style-type: none"> • Educating the family about the disease • Having patience and love • Education • Compassion 	<i>"Here the most important thing is education and lots of compassion. For the person who is the caregiver — if the caregiver does not have that it is very difficult for the caregiver and for the person who is being cared for."</i>
	Resources needed for caregiver/patient	<p>Role of organizations and associations in providing moral support to caregivers</p> <ul style="list-style-type: none"> • More resources for Latinx communities (guidance in Spanish for patients and caregivers, linguistically appropriate services for patients [seniors centers therapy] and caregivers • Pension funding 	<i>"There are people who perhaps need more support in like talking and listening. Sometimes the caregiver needs to cry, laugh, and that is good for the other support associations that exist right now, they are the only ones that listen to you, it is good."</i>
(3) What do Latinx informal caregivers understand about ADRD and the ways to manage it?	Knowledge/Awareness of the disease	<p>Knowledge of disease</p> <ul style="list-style-type: none"> • Awareness of disease progression • Perceived availability of help 	<i>"Well during that time in the beginning (when) we discovered my grandmother's illness, we did not know that there was a help center."</i>
	Ways to handle situations – creativity and proactivity in searching for a solution	<p>Carrying out activities of daily living in role play</p> <ul style="list-style-type: none"> • Creative ways to make food. • Identifying early potential breakdowns (strategies to calm the patient) 	<i>"She did not allow us to dress her, so we arranged her closet as if it were a boutique."</i>
	Ways to handle situations – knowing Patient tendencies and patterns	<p>Looking to various outlets to please the patient (music).</p> <ul style="list-style-type: none"> • Triggering memory with patient's familiar words. 	<i>"When she came to my house, I tried to put music on. It's what she likes."</i>
	Prepared – reasons for being prepared	<p>Developing a routine to adapt to new responsibilities.</p> <ul style="list-style-type: none"> • Building compassion and love towards the patient • Studying about caregiving role 	<i>"Because number one, because I had studied for care and one of the things that I saw is that I made the decision for myself to learn to work as a nurse's assistant and all that thing because obviously one has to be aware."</i>
	Coping mechanism (strategies to regain control)	<p>Attempt to exercise the patient's brain.</p> <ul style="list-style-type: none"> • Using daily puzzles. • Maintain calmness. 	<i>"I try to get her to do mental exercises, for example, draw. Either do Word Searches, or I try to talk about her about what we did during the day or what is the happiest moment of her day to try to get her to use her brain."</i>

(Continued)

Table 3
(Continued)

Research questions	Themes	Codes	Sample Quotes
(4) What strategies do Latinx informal caregivers describe as being helpful to them in managing ADRD?	Fulfillment from ability to contribute	Sharing knowledge of the disease to raise awareness. <ul style="list-style-type: none"> ● Feeling of Reciprocity of care (giving back to someone that cared for them, "returning the favor") ● Fulfilling familial and religious responsibilities ● Family union of love ● Improved the relative's quality of life. ● Love for the relative (patient) 	<i>"We have had to help more people to give advice to more people. I am very involved in helping people with Alzheimer's."</i> <i>"The most gratifying aspect would be to be able to return the care, the love and care that they had with me when I needed them."</i> <i>"Love. In that she is your grandmother and her mother. I think it was the family union of love, affection the union, I think that subconsciously, I think it was two different things to my mother when we talked about my mother, she did not want to lose her."</i>
	Patient outcomes and reactions	Gratitude from the patient <ul style="list-style-type: none"> ● Moments of recognition and recovered memory 	<i>"But the other part is when I hear him thank me and it's like a moment when I just want to get my video camera and just video tape him so that later I can see it again."</i>
	Health system resources	Health advocacy support groups (e.g., Prisma Success Program) <ul style="list-style-type: none"> ● Referral to general practitioners (medical care and advice when accessible) ● Access to study material ● Home health professionals (nurses and therapists) ● Rehabilitation therapies (ambulation) 	<i>"They gave me a study guide so that I could refer to it every time I have a problem, well, there I can at least search any of the inconveniences I have with her daily."</i> <i>"At home, many nurses came to check on her, let's say therapy because there was a time when she no longer wanted to get up."</i>
	Internet resources	Readily available information (more resources available in the last 20 years)	<i>"The resources that come to mind is really those if it wasn't for my laptop, my phone, or the internet."</i>
	Religiosity	Responsibility of caretaking comes before God. <ul style="list-style-type: none"> ● Religious Beliefs 	<i>"... [m]y mother always said that God always knew why that had happened to us because our grandmother loved us so much –that we help her in all we can she always told us that when you feel frustrated turn to God, get closer [to God]."</i>
	Support services	Family <ul style="list-style-type: none"> ● State (Medicaid) ● Medications 	<i>"Thank God... I have a family that helps me a lot and helps my grandmother very much who loves my grandmother a lot so for example when my grandmother has medical appointments my mom or my dad always try to go with me and with our grandmother um the family that lives far away always sends financial resources for us — For our grandmother, for us to have money to feed her whatever medical needs she has or there are things that the grandmother needs, so that's good."</i> <i>"Well, my grandmother has Medicaid, so that is something that has helped her a lot ... "</i>

	Changes made by caretakers to adapt their lifestyle to the patient	Home adaptations (doors, kitchen) <ul style="list-style-type: none"> ● Safety (necklace, Alzheimer's Association) ● Dietary changes (less fried food) ● Add exercise (walks) 	<i>"We had to limit the kitchen which was a dangerous space for my grandmother because she could get up and grab things and cook and we were very afraid that she could leave the stove on. The stove is not like here it was electric the stove in my mother's house was with gas so we couldn't—she could turn the stove and leave the gas on, so we had to make adaptations."</i>
(5) What social/cultural factors influence informal caregiver perspectives and expectations of ADRD care?	Sense of obligation to care for parents	Idea of Family Responsibility (moral obligation to provide for parents from the Hispanic Culture) <ul style="list-style-type: none"> ● Importance of family unity ● Rejection of residential homes' placement (familial abandonment) ● Family size (distribution of care responsibility among siblings) 	<i>"Culturally in our family we have the idea of being the people responsible for our parents . . .".</i> <i>"Sending a parent to live in a nursing home is considered that the son is abandoning his mother."</i> <i>"I think that in American culture many times one looks for more help in places—like residential for people who can no longer care for themselves"</i>
	Cultural Values	Respect (respect for elders— caregiver referenced being from rural Mexico) <ul style="list-style-type: none"> ● Familism (family unity - referring to the emphasis on supporting one another, family reliance—physical help or otherwise) 	<i>"I am from the countryside of, Mexico, so one grows up with a lot of respect for grandparents,' parents, and everyone."</i> <i>"My family. My family and well, she is my mother and I want to try to give her a good quality of life and although she is not very aware of that then seeing her calm, seeing her happy and to also see my family, well despite the inconveniences that we can have, that we are all well, that is the motivation."</i>
	Lifestyle and pre-existing medical conditions as precursors of the dementia	Smoking <ul style="list-style-type: none"> ● Alcohol use ● Diet ● High blood pressure ● Stroke ● Febrile seizure ● Neurological factor (wear and tear) 	<i>"Alcohol intake, she was that person who drank a lot so I don't know to what extent that could also have that influence"; "first the alcoholic beverages, from having hmn taken it for many years, hmn the blood pressure because she suffered from high blood pressure, she had a series of illnesses with very high fevers that made her convulse."</i>
	Individual factors	Hereditary/Genetics <ul style="list-style-type: none"> ● Age 	<i>"In her case, I do not know if it was hereditary by my grandmother's case or if it was because of the sudden stroke that we think she had"; "it can be genetic, it can be hereditary..."; "some say it is hereditary because I think that this is done in the brain and also in the thyroid."</i>
	No factors	Something that simple occurs, no explanation (no cultural factors) <ul style="list-style-type: none"> ● no behavioral factors (anyone can be affected) 	<i>"I don't know, well I've been reading and so far, I don't think there is an explanation. It is something that simply occurs."</i>

lack of control, *“there is no control at all. Because for the simple reason as I tell you, there is no control because the dementia is already there.”*

Patients' attitudes and behaviors, loss of attachment with caretaker changes, and mood changes, were also identified critical moments expressed by caregivers. A caregiver said, *“when she gets aggressive when she gets difficult, I have to know how to deal with it.”* In relation to the caregiver role and traits, many caregivers expressed the need for understanding and compassion for their patient. For instance, a caregiver said, *“here the most important thing is education and lots of compassion. For the person who is the caregiver—if the caregiver does not have that it is very difficult for the caregiver and for the person who is being cared for.”* The need for more support organizations for caregivers was identified by three caregivers as a common critical moment. For example, a caregiver explained, *“there are people who perhaps need more support in like talking and listening. Sometimes the caregiver needs to cry, laugh, and that is good for the other support associations that exist right now. They are the only ones that listen to you, it is good.”*

Knowledge/awareness of the disease, ways to handle situations—creativity and proactivity in searching for a solution, ways to handle situations—knowing patient tendencies and patterns, reasons for being prepared, and coping mechanisms to regain control are themes that emerge from the third research question: What do Latinx caregivers understand about ADRD and ways to manage it? Knowledge and awareness of the disease proved to be an important influence on caregivers' experience. For instance, one caregiver recounted her experience from the beginning, *“... during that time in the beginning (when) we discovered my grandmother's illness, we did not know that there was a help center.”* Creativity in searching for solutions became a prominent method as one caregiver explained. For example, their use of role playing to manage their patients' needs: *“... [she] did not allow us to dress her so we arranged her closet as if it were a boutique.”* Identification of patients' tendencies and patterns were mentioned to manage ADRD patients. One caregiver identified music as helpful: *“When she came to my house, I tried to put music on. It's what she likes.”* Awareness was found to be a reason for being prepared. One caregiver stated, *“...I made the decision for myself to learn to work as a nurse's assistant and all that thing because obviously one has to be aware.”* Coping mechanisms or strategies were reported by two caregivers as tools to

provide care. A caregiver said, *“I try to get her to do mental exercises, for example, draw. Either do word searches, or I try to talk with her about what we did during the day or what is the happiest moment of her day to try to get her to use her brain.”*

Fulfillment from ability to contribute, patient outcomes and reactions, health system resources, internet resources, religiosity, support services, changes made by caregiver to adapt their lifestyle to the patient, and sense of obligation to care for parents are themes that emerged from the fourth research question: What strategies do Latinx informal caregivers describe as being helpful to them in managing ADRD? When caregivers explained helpful strategies to manage their patients, the theme of fulfillment and ability to contribute was common. One caregiver expressed, *“the most gratifying aspect would be to be able to return the care, the love and care that they had with me when I needed them.”* One participant stated that *“... but the other part is when I hear him thank me and it's like a moment when I just want to get my video camera and just video tape him so that later I can see it again.”* Six participants felt that health systems resources were helpful. A caregiver stated that one resource provided by the healthcare system was a study guide, *“I could refer to it every time I have a problem, well, there I can at least search any of the inconveniences I have with her daily.”* Another stated that, *“[a]t home, many nurses came to check on her; let's say therapy because there was a time when she no longer wanted to get up.”* The Internet was also mentioned as a helpful resource by one caregiver: *“[T]he resources that come to mind is really those if it wasn't for my laptop, my phone, or the internet.”* Some caregivers equated their responsibility of caretaking to religiosity. A caregiver stated, *“my mother always said that God always knew why that had happened to us because our grandmother loved us so much that we help her in all we can. She always told us that when you feel frustrated turn to God, get closer [to God].”*

The relevance of financial support and other services were reported by three caregivers. One caregiver stated, *“[w]ell, my grandmother has Medicaid, so that is something that has helped her a lot.”* Changes among caregivers to adapt to the lifestyle of the patient were identified. One caregiver explained, *“[w]e had to limit the kitchen, which was a dangerous space for my grandmother; because she could get up and grab things and cook and we were very afraid that she could leave the stove on. ... she could turn the stove and leave the gas on, so we had to make*

adaptations." The obligation to care for parents was influenced by culture for eight caregivers. One caregiver said, "*culturally in our family we have the idea of being the people responsible for our parents . . .*" Another stated, "*sending a parent to live in a nursing home is considered that the son is abandoning his mother.*"

Cultural values, lifestyle, and pre-existing medical conditions as precursors for dementia, individual factors, and no factors identified were four themes that emerged from the fifth research question: What social/cultural factors influence informal caregivers' perspectives and expectations of ADRD? Four caregivers expressed ideas related with the cultural values of respect and familism. One caregiver said, "*I am from the countryside of Mexico, so one grows up with a lot of respect for grandparents, parents, and everyone.*" The cultural value of familism was implied when a caregiver said, "*. . . she is my mother and I want to try to give her a good quality of life, and although she is not very aware of that, then seeing her calm, seeing her happy and to also see my family, well despite the inconveniences that we can have, that we are all well, that is the motivation.*" Caregiving differences between Hispanic and American culture were mentioned by one caregiver who stated, "*I think that in American culture many times one looks for more help in places—like residential for people who can no longer care for themselves*". Another caregiver's response to sending their loved ones to residential homes was that it is "*familial abandonment.*"

Social related factors influenced caregiver experiences. One caregiver stated, "*. . . alcohol intake, she was that person who drank a lot so I don't know to what extent that could also have influenced (the disease).*" Pre-existing medical conditions were mentioned by two caregivers as a social factor. For example, one participant stated, "*. . . first the alcoholic beverages, from having hmm taken it for many years, hmm the blood pressure because she suffered from high blood pressure, she had a series of illnesses with very high fevers that made her convulse.*" Hereditary/genetic factors were mentioned by one caregiver as social influences. This caregiver stated, "*[i]n her case, I do not know if it was hereditary by my grandmother's case or if it was because of the sudden stroke that we think she had*"; "*it can be genetic, it can be hereditary.*" In contrast, two caregivers mentioned that no factors were associated with development of the disease. One caregiver stated, "*I don't know, well I've been reading and so far, I don't think there is an explanation. It is something that simply occurs.*"

DISCUSSION

Findings of this study revealed key components of Latinx caregivers' feelings, thoughts, and knowledge of ADRD, as well as the impact that the disease has on their lives. Overall, caregivers demonstrated a range of knowledge regarding ADRD, the course of the disease, and its impact on a patient's life. In general, caregivers consistently mentioned the progressive and degenerative nature of ADRD. In contrast, some caregivers stated that they were not aware of the disease or what to expect. The lack of knowledge of Latinx caregivers about the nature and behavior of ADRD is consistent with previous research findings showing the persistence of Latinx communities' challenges to access health promotion and disease management resources. These challenges are primarily due to various social determinants of health including, but not limited, to lower level of education, lower socioeconomic status, lack of culturally and linguistically competent health care providers [8, 28–30].

Previous research indicates that caregivers experience higher levels of perceived stress, sleep deprivation, and mental health challenges [6, 14, 31, 32]. In this study, although Latinx caregivers informed that they share their caregiving duties with other family members, they also expressed feelings of social isolation and lack of control over the course and effects of the disease. There was also a common theme emphasizing the importance of psychological well-being, self-care, and rest. In addition to psychological well-being, caregivers described education and culturally relevant supportive services as necessities for patient care and for guiding their role as caregivers—which is consistent with previous research [25] showing that different cultural backgrounds are an influential factor in attributing values and norms to care practices.

Not only are there numerous challenges that Latinx caregivers face to achieve their role, but many gaps also still exist to support caregivers in the management of patient care. Consistent with previous research [7], a major challenge for minority groups continues to be obtaining access to resources/staff that were able to speak the language necessary to communicate with their patients. There is a growing need for more resources for Latinx communities including guidance in Spanish for patients and caregivers and linguistically appropriate services for patients. Some caregivers, however, reflected on not knowing about available resources during the onset of

their patient's disease. A reported higher prevalence of ADRD that disproportionately affects minority groups [5, 6] raises concerns when community members do not have access or knowledge about available resources. Reducing disparities that limit access to resources may increase caregivers' understanding of ADRD [7, 33]. This study highlights the vital need for better advertisements and ways to reach caregivers in a linguistically and culturally appropriate manner.

Latinx caregivers identified several cultural aspects that motivated them to care for their patients with ADRD, including sense of obligation, religion, and familism related attitudes. Caregivers felt fulfilled to contribute and give back to their loved ones in need of care. Many felt that they were able to "return the favor" and carry out familial responsibilities—reflecting on the influence of cultural values on Latinx caregivers' practices [8, 25]. A study's finding suggested that the sociocultural factors, values, and family traditions are attributable to the care provided to an individual based on different cultural backgrounds [9, 25]. Similarly, findings of this study portrayed caregivers' perspectives pertaining to their culture and traditions (e.g., family responsibility, family unity, and respect) as major influences in their expectations of their role as caregivers for ADRD patients.

Health advocacy support groups, referrals to practitioners, home health professionals, and rehabilitation therapies, were listed by caregivers as healthcare resources that were helpful to their role. Overall, caregivers signaled that there were many useful resources to better care for their patients. However, some caregivers reported a need for creating additional resources to support their role which consequently may reduce the time invested in caregiving duties. Providing easily accessible resources for caregivers is essential in supporting them as they work, on average, 9 hours a day [8].

Findings of this study provide relevant recommendations for policy makers, public health practitioners and health care providers including the need of understanding Latinx caregivers' challenges to access health promotion and disease management resources. The results demonstrate that the challenges are primarily due to various social determinants of health and the importance of promoting helpful coping mechanisms (e.g., psychological well-being, self-care, rest, etc.) to increase caregivers' resilience in handling their caregiving duties as well as to prevent negative outcomes for caregivers. The study also illuminated the importance of understanding

and incorporating cultural values and norms (e.g., familism, respect, family unity, etc.) when designing interventions to assist Latinx caregivers caring for patients with ADRD. Finally, the answers given showed a need for increasing access to more resources for Latinx communities including guidance in Spanish for patients and caregivers and linguistically appropriate services for patients.

These study results should be interpreted considering its limitations. Due to the COVID-19 pandemic, in-depth phone interviews were conducted as opposed to in-person interviews. While the number of participants fell within the study goal of 5 to 30 participants, findings represent the testimonials of these 11 Latinx caregivers and may not be generalizable to the knowledge and experiences of all Latinx caregivers in the Appalachian region of Upstate of S.C. Additionally, all participants in this study were females, thus, the experiences of Latinx male caregivers were not represented in this study. Despite these limitations, the current study analyzes the perceptions, knowledge, and experiences of Latinx informal caregivers of ADRD patients in Appalachia and can serve as a reference of the ADRD caregiver's challenges and situation of other Latinx immigrant populations in the U.S.

All participants self-identify of Latinos or Hispanics, and although we did not collect information on the country of origin of the participants, statistics show that about a 65% of Latinx residents in the Appalachian Region are of Mexican origin or descent [17]. This study does not represent the diversity of the Latinx community in the U.S.; however, it represents a start in hearing the voice of this community. Further studies should characterize the nuances and specificities within the many aspects of diversity of the Latinx community including country of origin, immigrant generation, acculturation level and other characteristics related with the rich diversity of this community. Our work encourages the care team to create an environment that responds with respect and sensitivity to the needs of the Latinx Caregiver.

ADRD are common and burdensome conditions impacting Latinx and other communities of color at a higher frequency than other race/ethnic groups in the U.S. Linguistically and culturally sensitive programs and resources that incorporate the perceptions, knowledge, assets, and needs of Latinx informal caregivers of ADRD are needed with the purpose of improving the quality of their care and to decrease disparities in health outcomes for Latinx older adults with ADRD.

CREDIT AUTHOR STATEMENT

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CONFLICT OF INTEREST

Dr. Melissa Bailey-Taylor is an employee of Eli Lilly and holds stock. Dr. Bailey-Taylor participated in this research study prior to working at Eli Lilly. The perspectives and conclusions presented in this study are independent of Eli Lilly. The other authors do not have any conflict of interest regarding the present study.

DATA AVAILABILITY

The data supporting the findings of this study are available within the article.

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