Qualitative Analysis of the Experiences of Latino Caregivers of People with Dementia with the Pilot Study of the Culturally Adapted STAR-Caregivers Virtual Training and Follow-up Intervention

Miguel Angel Mariscal

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Committee:
Maggie Ramirez
Hendrika W. Meischke

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Abstract

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Miguel Angel Mariscal

Chair of the Supervisory Committee:

Maggie Ramirez

Department of Health Systems and Population Health

Background:

Latino caregivers are at an increased risk of negative health outcomes due to the responsibilities of caring for someone with dementia. Although interventions exist to address caregiver burden, they often do not meet the cultural needs of Latino caregivers. To address the lack of tailored interventions for Latino caregivers of dementia, a cultural adaptation of STAR-Virtual Training Follow-up (STAR-VTF) was conducted. STAR-VTF is an online training program based on an evidence-based program (STAR-Caregivers), designed to teach family caregivers strategies to reduce behavioral distress and manage behavioral and psychological symptoms of dementia. The cultural adaptations of the STAR-VTF learning modules were pilot-tested with Latino caregivers of persons with dementia.

Objective:

This qualitative analysis aims to understand to what extent Latino caregivers found the cultural adaptation of the STAR-VTF pilot study helpful and how the program can be improved to meet Latino caregiver needs.

Methods:

A thematic analysis was conducted of semi-structured interviews with Latino caregivers of persons with dementia who completed the 7-week pilot study (N=14). A codebook was developed using an inductive approach to code the transcribed interviews.

Results:

Latino caregivers found the program content beneficial and relatable to their caregiving experiences. Components that caregivers found helpful included the dementia education component, the ABC problem-solving component, and the information on self-care. Participants also expressed their satisfaction with the design of learning modules and accompanying workbooks. Areas of improvement highlighted by the participants include adding additional information on dementia care resources, making learning modules more engaging, and enhancing the narration of learning modules. Latino caregivers also shared how they valued the information learned from the modules and would share what they learned with others in their families. Participants also suggested expanding the intervention's reach by partnering with trusted Latino and caregiving organizations.

Conclusion:

The findings of this qualitative study suggest that the cultural adaptations of the STAR-VTF intervention were viewed favorably by participants. Feedback provided by participants will help inform future refinements of the STAR-VTF intervention. Although further research is needed to test the efficacy of the culturally adapted STAR-VTF intervention, this qualitative analysis provides a helpful insight into caregivers' experiences with the cultural adaptations of the online learning modules.

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Introduction

In the United States, Latino populations are disproportionately impacted by Alzheimer’s disease and related dementias (ADRD). Compared to White adults, Latinos are 1.5 times more likely to have ADRD (Martinez & Gonzalez, 2022). By 2060, the number of Latinos with ADRD is expected to grow by 832 percent, which is the steepest increase in ADRD compared to any other racial or ethnic group, and projections show that by 2060, 3.5 million Latinos will be living with dementia (Quiroz et al., 2022; Wu et al., n.d.). Latinos with dementia primarily rely on family members for their care due to the high cost of formal dementia care, legal status, lack of awareness of dementia care services, language barriers, and cultural preferences (Balbim et al., 2020; Martinez et al., 2022).

Latino caregivers comprise 21% of the estimated 40 million family caregivers in the United States (Martinez & Gonzalez, 2022). Caregiving for someone with dementia can be particularly challenging as ADRD can cause changes in personality and behavior, losses in judgment, orientation, and the ability to understand and communicate effectively (Alzheimer’s Association, 2023). Managing dementia symptoms requires intense supervision and physical support, and compared to other populations, Latino families provide more intense caregiving in terms of level of care and hours (Martinez & Gonzalez, 2022). Caregiving for a person living with dementia (PLWD) also places Latino caregivers at increased risk of negative health implications, including high levels of stress, depression symptoms, less engagement in physical activity, sleeping problems, and social isolation (Balbim et al., 2020; Luchsinger et al., 2015). Compared to caregivers from other racial and ethnic groups, Latino caregivers experience a higher risk of developing depression(Balbim et al., 2020). Although evidence-based caregiver interventions exist to help address the negative impacts of caregiver burden, they often do not meet the unique cultural needs of Latino families (Garcia et al., 2024). Due to the negative health implications of dementia caregiving, it is crucial to support Latino caregivers through culturally adapted evidence-based interventions.

STAR Caregivers (STAR-C) is an evidence-based systematic training program designed to teach family caregivers strategies to reduce behavioral distress and manage behavioral and psychological symptoms of dementia (Garcia et al., 2024). Caregivers are taught effective communication strategies, ABC (activator-behavioral-consequence) behavioral problem-solving strategies, and how to identify and use pleasant activities to reduce behavioral disturbances (McCurry et al., 2017). STAR-C has been demonstrated to significantly reduce caregiver burden and depression and improve the quality of life of persons with ADRD (Lindauer et al., 2018). Since the original randomized controlled trial of STAR-C in 2005 (Teri et al., 2005), the program has been adopted in various settings to meet caregivers' needs. One of the early adoptions of the STAR-C program in a real-world setting was conducted by the Oregon Department of Human Services-State Unit on Aging and Area Agencies of Aging, which served both rural and urban locations in Oregon (McCurry et al., 2017; Teri et al., 2012). In this implementation of STAR-C, the training was provided at home by trained professional health consultants to family caregivers. The program has since been adapted to teach caregivers the STAR-C lessons remotely. Tele-STAR, the telehealth-based adaptation of STAR-C, was created to increase access to anyone with a computer and Internet connection and to reach rural populations (Lindauer et al., 2019). Tele-STAR utilized video conferencing to connect nurse consultants with family caregivers to guide them through the STAR-C lesson plans. The tele-STAR study found that with the transition from in-person training to remote, the family caregiver burden was reduced, and it retained good program and treatment fidelity to STAR-C (Lindauer et al., 2019). Video-conferencing technology has also been used in the Illinois-based CRIS’ Memory Care Program (MCP), an adapted STAR-C intervention developed by CRIS Healthy Aging, a non-profit organization in East Central Illinois that serves older adults primarily in rural communities and of lower income (Satz et al., 2023). The latest adaptation of STAR-C in a clinical setting has been STAR-Caregiver Virtual Training and Follow-up (STAR-VTF), which is being tested in an ongoing trial at Kaiser Permanente Washington (Ramirez, Duran, et al., 2023). STAR-VTF is a 6-to-8-week program comprised of six online training modules that caregivers complete asynchronously. It also includes 30-minute weekly check-ins with a program coach. Support from program coaches is provided as needed for up to 6 months via secure messaging in the Kaiser Permanente Washington patient portal.

Although STAR-C has been adapted in a variety of ways to expand access to caregivers, it has yet to be tested in large populations of Latino caregivers. To address the need for culturally appropriate evidence-based interventions for Latino caregivers of PLWD, our research team recently adapted STAR-VTF to improve its cultural relevance and linguistic appropriateness for Latino caregivers (Garcia et al., 2024; Ramirez, Duran, et al., 2023). To test the culturally adapted online learning modules from the STAR-VTF intervention, we conducted an 8-week pilot study. Latino caregivers of people with ADRD participated in qualitative interviews at the end of the pilot study to share their experience with the culturally adapted online learning modules. This article reports findings from these qualitative interviews with Latino caregivers who participated in the pilot study. This qualitative analysis aims to understand to what extent Latino caregivers found the online training modules helpful and what can be improved to meet Latino caregiver needs. The findings will help improve future iterations of STAR-VTF for Latino caregivers and, more generally, advance our understanding of modifying evidence-based interventions to better serve Latino caregivers of persons with dementia.

Methods

The framework for the cultural adaptation of evidence-based interventions developed by Barrera and Castro guided the methods of this study (Barrera Jr. & Castro, 2006). The framework includes the following stages in creating a culturally adapted evidence-based intervention: (i) gathering information to identify ideas about needed adaptations, (ii) conducting preliminary adaptations based on these ideas, (iii) conducting pilot studies of the preliminary adaptations, and (iv) refining adaptations based on results from pilot studies. Our research team has completed the first two stages (Garcia et al., 2024; Ramirez, Duran, et al., 2023). This article presents findings that are part of the stage 3 process of pilot testing cultural adaptations (see diagram 1).

Pilot Study of the Preliminary Adaptations

Adaptations used in this pilot were based on findings from previous qualitative studies that interviewed Latino caregivers of persons with dementia and healthcare and social service providers of older Latinos on improving the cultural relevance of STAR-VTF (Garcia et al., 2024; Ramirez, Duran, et al., 2023). Based on the findings of prior studies, adaptations, including revising language viewed as problematic, expanding content to enhance understanding of dementia, and adding cultural examples that reflect family involvement in caring for relatives with dementia and multigenerational living, were included in the present culturally adapted STAR-VTF online training modules (Garcia et al., 2024; Ramirez, Duran, et al., 2023). Additional refinements made to the current STAR-VTF program after testing preliminary training modules with Latino caregivers, include adding empathetic messaging that highlights the importance of viewing the world from the perspective of the PLWD, incorporating additional problem-solving examples to demonstrate diverse challenges, and emphasizing caregiver self-care to ensure caregiver's mental and emotional health is prioritized (Garcia et al., 2024).

For the current pilot study, participants were recruited to participate in the culturally adapted STAR-VTF program for eight weeks and complete weekly online feedback surveys, pre and post-outcome surveys, and a semi-structured qualitative interview with study staff over the phone following the completion of the program. For this qualitative analysis, the only data that will be analyzed will be from the semi-structured interviews post-program completion. In this single-arm pilot study, participants were provided access to the online training modules via email or text. The current pilot study was focused on testing the content of online training modules. Therefore, caregivers did not receive the coaching component of the STAR-C intervention. There are seven online training modules in total. Caregivers were instructed to complete one module per week. Table 1 includes the content covered in each module.

Table 1: Content of Online Training Modules

Module 1	Provides an understanding and overview of dementia.
Module 2	Introduces caregivers to the behavioral treatment of dementia, realistic expectations, and effective communication.
Module 3	Covers the ABC (antecedents, behaviors, consequences) approach to problem-solving, including rationale and development of an ABC plan.
Module 4	Instructs caregivers to review the ABC plan and revise as needed.
Module 5	Covers pleasant events and managing negative thinking.
Module 6	instructs caregivers to review the ABC plan, pleasant activities schedule, and to revise as needed.
Module 7	Covers coping with caregiving and maintaining the use of caregiving strategies.

The length of online training modules ranges between 7 and 16 minutes. The modules use text, pictures, and illustrations with a voiceover presentation. Caregivers received the online training modules in their preferred language (English or Spanish). They also received a workbook to accompany the lessons.

Ethical Approval

The Advara Institutional Review Board approved this study (Pro00055053). Study participants provided digital or written informed consent.

Participant Recruitment

Potential study participants (i.e., Latino caregivers) were identified using the UW Medicine electronic health record, UW Alzheimer’s Disease Research Center Registry, Alzheimer’s Prevention Registry maintained by the Banner Alzheimer’s Institute, and through distribution of recruitment flyers through professional networks. Potential study participants were reached on the phone or email to explain the study and answer their questions about study participation. If interested, participants were screened for eligibility, and informed consent was obtained from those eligible. To be eligible to participate, participants had to identify as Hispanic/Latino, be 18 years of age or older, be taking care of a patient with dementia, live with or within five miles of the patient, spend at least 8 hours a week with the patient, and indicate that the patient is experiencing at least three symptoms related to dementia occurring at least three times in the past week. Participants were provided a $40 gift card for their participation.

Participant characteristics

In total, 16 participants participated in the pilot study of the culturally adapted STAR-VTF online learning modules. However, only 14 participants completed a qualitative interview with the research study staff. One participant was lost to follow-up, and another declined to participate in the interview due to their limited availability. Table 2 provides further demographic characteristics of study participants who completed a qualitative interview (see Appendix).

Data Collection

Semi-structured interviews were conducted with Spanish and English-speaking Latino caregivers (N=14) who participated in the pilot of the culturally adapted STAR-VTF program. All interviews with participants were conducted over the phone with bilingual research team members (C.G. and L.Z.). The interview guide included questions about their opinions on the program training components, suggestions for improving course content and design, and the quality of the Spanish translation of online training modules (see Appendix). The average length of interviews was approximately 30 minutes. Interviews with participants were audio recorded, and the transcription of the interviews was done by a professional transcription service.

Data Analysis

Interview transcripts were coded and analyzed in their original language (English or Spanish) by bilingual research team members (M.M., C.G., M.R.). The transcripts of interviews with Latino caregivers were coded using Dedoose Version 9.2.007, a cloud application for managing, analyzing, and presenting qualitative and mixed-method research data (*Dedoose*, 2024). To analyze qualitative data, methods outlined by Miles, Huberman and Saldaña were used (Miles et al., 2014). First, bilingual team members (M.M., C.G., M.R.) read the transcripts and wrote brief notes of what was in the data. Next, a codebook was developed as a team, and an inductive coding approach was used to code the interviews. To create the preliminary codebook, bilingual researcher team members (M.M., C.G.) independently coded transcripts using inductive codes. They convened weekly with the senior researcher (M.R.) to discuss the application of codes, refine the codebook, and reach a consensus on coding discrepancies.

After coding three transcripts, the codebook was comprehensive, and a few additional codes needed to be added.

The first author individually coded the remaining transcripts, with guidance from the senior author as needed. Descriptive and in-vivo codes were used in the coding process.
The first author identified preliminary themes based on the inductive codes by collating and reviewing excerpts of each code. During this process, relationships among codes and relationships within and among themes were assessed. A collection of relevant excerpts for each theme was pulled from the data while reviewing coded excerpts. Recommended areas of assessment in the third stage of Barrera and Castro’s framework on cultural adaptations of evidence-based interventions, such as satisfaction with intervention elements and suggestions for improvement, were used to help guide theme creation (Barrera Jr. & Castro, 2006). The preliminary themes were iteratively refined with assistance from research team members (C.G. and M.R.) to ensure that sub-themes within the themes were relevant to the parent theme and that the final themes were distinguishable.

Results

Theme 1: Latino caregivers were satisfied with the STAR-C intervention content and design elements of the online training modules and accompanying workbook.

Latino caregivers were generally satisfied with the content covered in the STAR-C intervention, including components on dementia education, ABC problem-solving, and caregiver support strategies. They also expressed satisfaction with the design of the online training modules and the accompanying workbook.

Dementia Education Component

Latino caregivers found the dementia education information beneficial in understanding their relatives’ dementia condition and how it can progress. There was also a consensus among most caregivers that they liked the empathetic messaging embedded within the dementia education component. Caregivers felt that it was helpful to be reminded that their family member has a condition of the brain and that some of the things their family member says or does are not on purpose, and for the caregiver to have more patience and be more understanding. A caregiver providing care to their father said the following about the messages reminding caregivers to be empathetic:

> *And I felt like it was an important reminder because I guess just like with anything else, even as a parent of young children, I get caught up in the day-to-day and the getting things done, and there's deadlines, and there's work and home life and all sorts of things. And so it is nice to have that reminder that it's not just-- not to take things personally and not to be so quick to react. But just a gentle reminder, there may be another reason why my dad is saying something or not doing something. And yeah, just not to take it personally, so that was a helpful reminder.* -ID11

ABC Problem-Solving Component

Many Latino caregivers expressed that the ABC problem-solving strategy of the online training was helpful and found the examples used to demonstrate how to implement the strategy to be relatable to their own caregiving experience. One of the online learning modules demonstrated a hypothetical caregiver using the ABC problem-solving strategy to address the PLWD wandering. When asked about their thoughts on this example, one of the caregivers stated:

So I thought it was very relatable. And then sort of just kind of showcasing what happened, I think, made it relatable in the sense that you can sort of put yourself in that situation. And then for me, I was like, "Okay, yeah. I could see how this happens, and then what can you do to utilize those ABCs to then basically make it useful for your own personal experience in a similar situation.- ID 14

Latino caregivers also shared how the ABC problem-solving strategy was successful in helping them manage their relative's behavioral and psychological symptoms of dementia and provided anecdotes of their experience applying the ABC problem-solving strategy. For example, one of the caregivers described how they used the strategy to address their mother's experience washing dishes. The caregiver said:

So my mom would get really upset and would complain of dizziness around the same time every day. And I thought that was odd. And then when I was doing this and I took the ABC, I realized that the reason my mom was getting upset was because she would wash the dishes at the same time every day at, and sometimes I would go by and tell her, "Oh, turn the water higher," or, "Oh, put more soap." And I think me trying to coach her was upsetting her because it made her feel like she didn't know what she was doing. So she would go, and she would say she's dizzy, and she would start to cry. And then because I noticed the timing, what happened before and after, I stopped doing that. I just let her wash the dishes. -ID27

Caregiver Support Strategies Component

Latino caregivers overwhelmingly related to the caregiver support strategies encouraging caregivers to practice self-care. Caregivers expressed the importance of caring for themselves to care for others. They also acknowledged the importance of taking time for themselves. For example, a Spanish-speaking caregiver providing care to his wife explained the reasons why it was important for caregivers to prioritize their own self-care.

It's good that you made us see what we need, also we need to take care of ourselves to be able to provide care. In my case, my wife needed me to be good so I could take care of her well. One needs to sleep well and eat well to give the best help to the sick. (translated quote)-ID06

Design of Online Training Modules and Accompanying Workbook

Latino caregivers were satisfied with the design of the online training modules and the accompanying workbook. Some caregivers said they liked the pacing of the online training modules and the images used. One caregiver shared the following about the online training modules:

I like the pace of it, and I liked the way that it was almost like going through a PowerPoint presentation. I liked that there were slides that kind of bulleted the info that I could either read along to or that it included images that were-- let me see. Images of people of color and not just an elderly white family. -ID 11

Some of the caregivers described the workbook as a helpful resource to refer to information and strategies that had been covered in the online learning modules. For example, one of the caregivers planned to continue referencing the workbook after the research study ended. They stated:

So I think for me it's [the workbook] going to be a helpful guide now that I don't have access to the videos to go through it and remind me of things and I can share it with my other family *members who are also trying to help with caring with my mom. So I feel like the workbook is kind of the legacy of those classes.* -ID 27

Theme 2: Suggestions for improving program content and making online training more engaging.

Although Latino caregivers were generally satisfied with the STAR-C intervention, some caregivers shared suggestions that they felt would enhance the intervention. The areas for improvement that Latino caregivers suggested are the inclusion of information on additional resources, improving the interactivity of online training modules to make videos more engaging, and improving the narration for the training videos.

Including information on additional resources.

Latino caregivers expressed wanting additional information on resources outside of the program that they can access to help support PLWD. Although some resources were presented in the training videos, caregivers shared they would like more resources on dementia care and community organizations serving PLWD and their families. For example, one caregiver shared:

"Maybe what might be helpful is if you had-- now this would be just-- I guess you'd have to make it unique for every state, but maybe give them some resources of where they might be able to reach out to. There's different Medicaid programs that might be eligible for. There might be local dementia associations that they could contact, those types of things, right? So resources that people might be able to reach out to, especially ones that offer services in Spanish" – ID17

Improve interactivity to make videos more engaging.

Some Latino caregivers provided suggestions for improving the interactivity of online training modules to make learning program content more engaging. A suggestion to improve the interactivity of program content was to include knowledge checks or short quizzes in which caregivers can test their knowledge of the material covered. As one caregiver shared:

having something that's a little more interactive where it's not just a video, but almost like a course where you watch a video and then… having both options like an actual paper workbook or having the option to select multiple choice or just to keep the viewer engaged in the video. So even if it's like, "Here's a summary. Which of these apply?" Select A, B, C, or D, all of the above, or something like that, just so that it really just keeps the viewer engaged. – ID 11

Latino caregivers also felt there were areas in which the online training modules could be improved visually to make them more engaging. A suggestion that was shared by caregivers was including video reenactments to demonstrate how strategies learned can be used in real-world situations. For example, one caregiver shared they liked the ABC strategy examples in the online training module but mentioned if they were recreated in a video depicting a role-play of the scenario, it would be more engaging. As the caregiver explains:

I feel like an actual video example of the dialogue would go a lot further than the pictures with the text-next-to-them pictures. If I remember correctly, that's what they were. They were pictures of the humans, of the woman and the person, her caregiver, and then there was just dialogue text next to them. It made sense. It just seems very dry. It seemed very dry. And I didn't really feel like I was paying attention as much as I should have in those moments. - ID24

Some caregivers also suggested the importance of including testimonials from fellow caregivers of dementia patients about their experiences with caregiving and how they applied the STAR-C training. One caregiver shared how incorporating caregiver testimonials can help demonstrate how to implement strategies covered in the online training, such as the importance of caregiver self-care:

I think probably maybe interviewing some caregivers and having them share their journey from not knowing what's going on with your mother - she's crazy - to understanding what's happening and the realization that it is an illness and examples of how they continued on with taking care of their health. It's very stressful. It's very stressful. I mean, it creates a physical response in your own body. And so I think it's just the affirmation from others that what they've done to manage their own time and their own feelings and examples like that and reassuring us that it's okay. It's okay to leave them and do something fun like go to a movie with your husband instead of feeling guilty about it." - ID 28

Narration of the Online Training Module

Another area of improvement described by the caregivers was the narration of the training videos. Latino caregivers shared that the narrator would, at times, stumble over their words and need to make corrections to a word that was misspoken. One caregiver shared that these mishaps would be distracting for them when viewing the training videos.

I guess what I would say is sometimes the-- and this is just my personal pet peeve, right, but sometimes, the narrator would stumble over their own words. And sometimes that was a little bit distracting to me. - ID 17

For the Spanish online training videos, most Latino caregivers felt that the translation was well done. However, some Latino caregivers shared that, at times, words in Spanish were mispronounced by the narrator, and some shared that the narration could sound less scripted to make videos more engaging. As one Spanish-speaking caregiver shared:

> *The Spanish was missing something, it was like someone was reading a brochure, and recording their voice reading the information. At times they could not pronounce words in Spanish correctly. I imagine if the Spanish voice was more fluent and less scripted, it would make the videos more interesting and more appealing*. -ID12 (translated quote)

Theme 3: Caregivers share dementia care information with others and suggest outreach strategies

Latino caregivers shared how they have increased the awareness of dementia care strategies by sharing the information they learned in the online training modules with relatives. Caregivers generally shared program content by word of mouth or sharing the link to the online training videos that was provided to them. Latino caregivers suggested additional avenues to spread awareness of the STAR-C program, such as working with community partners and using social media.

Sharing Information with relatives

Multiple Latino caregivers shared that they valued the information provided in the training and that they shared this information with family members who assist in the care of the PLWD and with family members who are in a similar caregiving role. For example, one caregiver said:

So I shared the videos with a group chat for the seven-week period. It was a group chat of my caregivers for my Nana, including myself. So it's going to be my sisters, my two sisters, my two cousins, my father, my uncle, and my aunt. And all of us took part in that group chat, and I shared it with them every time I got a new video because I felt like it was something that we could all benefit from. We all share the same struggle right now. And even though we're not in the same place, as far as mentally, taking care of my grandmother, this is a step to getting us all on the same page. And it seemed like the right thing to do to share the information that I was getting and make sure that my family understood why I was doing what I was doing. - ID 24

Community Outreach Strategies

To further improve the STAR-C program outreach, some caregivers shared that it is important to partner with trusted Latino community organizations, community health workers, religious centers, and caregiving organizations. As one caregiver explains, to reach Latino communities, it is important to consider partners who have established trust in the community to establish the credibility of the program. The caregiver said:

so often Latinos they feel more trusted with people that they know, so family and friends or church or organizations. So if you can tap into those kind of communities to share it, I think, will probably be your best bet in getting the word out. Even my mom, she's very hesitant to go to the doctor. I have to take her because she grew up in a generation where they kind of mistrust doctors, but they trust their sisters or cousins. And if they come at them with information, they're more apt to use it than if it comes from a really formal setting. So to say that word of mouth, that community-centered family groups, community groups, churches, any kind of groups that have a good connection to the Latino community, I think they're more apt to use the information you're providing. - ID 27

Some caregivers also suggested advertising the intervention in medical facilities and partnering with health professionals. As one Latino caregiver shared:

working with the community health workers, they can put it out (information on intervention) or maybe have something in the rural area at the doctors. I know they have a lot of doctors. So if it's just one doctor's office, if you have some handout or a little small TV screen that's on loop playing some of that information, it would be good. - ID 09

Some Latino caregivers also shared the importance of the STAR-C program building an online presence by posting online training modules on social media such as Facebook to reach Latino populations. Caregivers believed delivering the STAR-C program through these platforms would increase the reach of the program. For example, one caregiver shared:

You can put them (online training videos) on Facebook, on social media, and then when you're on social media, you could pop up and-- because you could be on social media on the weekends, and then your study would pop up, or your videos would pop up on the weekends and-- because people are always on social media day, morning, night, weekends, holidays, so if you had your content available on social media, then they would be able to view it. -ID 08

Discussion

This study aimed to pilot-test the culturally adapted STAR-VTF online training modules among Latino caregivers of PLWD. The qualitative analysis of interviews with Latino caregivers who completed the 8-week program revealed their high satisfaction with the training modules and components on dementia education, ABC problem solving, and caregiver support strategies. The study also identified areas for improvement in the training modules, such as providing caregivers with information on additional resources, enhancing the engagement of training videos, and improving the narration of videos. The study also provided valuable insights on expanding the intervention's reach, including through word of mouth, partnerships with community organizations, and social media. These findings will significantly contribute to the refinement of the culturally adapted STAR-C online training modules for Latino caregivers and enrich the literature on culturally adapted evidence-based interventions.

The findings of Latino caregivers' satisfaction with training components in this pilot study were consistent with the identified needs and wants of caregivers who participated in a qualitative study to test low-fidelity versions of the culturally adapted training modules. In the pilot study, Latino caregivers expressed how the module on dementia education was especially beneficial to their understanding of dementia, this finding aligned with caregivers' perspectives of wanting more dementia education in the previous study of low-fidelity training modules (Garcia et al., 2024) . The desire to learn about ADRD from Latino caregivers of PLWD is also consistent with findings from a qualitative study that examined barriers and facilitators to increasing engagement of Hispanics/Latinos in clinical trials on ADRD (Marquez et al., 2022). In this study, a majority of caregivers expressed an eagerness to receive information about ADRD, including information on the different types of ADRD, specific risk factors for Latino communities, and hereditary characteristics (Marquez et al., 2022).

Another aspect of the training modules that resonated with Latino caregivers, which was highlighted in our previous qualitative study, was the inclusion of reminders for caregivers to be empathetic towards PLWD. Our findings on caregiver satisfaction with the caregiver support strategy component are also similar to findings from our previous study in which caregivers highlighted the importance of self-care (Garcia et al., 2024). The need for information on self-care by Latino caregivers was also highlighted in a qualitative study that explored the needs of Latino caregivers of relatives with early-onset Alzheimer's (Withers et al., 2021). This study found that among their 27 participants, they overwhelmingly expressed the need for additional information concerning self-care, especially mental health care strategies and stress management (Withers et al., 2021). Caregivers' high satisfaction with the training components piloted in this study suggests that we effectively integrated feedback from Latino caregivers to meet their needs in the training content.

Regarding our findings regarding areas of improvement, Latino caregiver needs for additional dementia care-related resources is consistent with findings from a mixed methods study on the health information-seeking behavior of Latino Caregivers of PLWD. The study on health-seeking behaviors found that Latino caregivers desire to seek various types of dementia information, including the availability of community resources and healthcare services and treatment (Ramirez, De Anda, et al., 2023). Caregivers in our pilot study also suggested improving training videos by making them more engaging with video reenactments of caregiving scenarios, knowledge checks, and caregiver testimonials. This aligns with findings from our prior qualitative study wherein Latino caregivers who viewed the low-fidelity modules expressed the idea of having real people in the videos to depict caregiver scenario examples (Garcia et al., 2024). Multiple studies have found that using video vignettes in the form of telenovelas, Spanish soap operas, is an acceptable and effective method of delivering health information to Latino caregivers (Cruz-Oliver et al., 2016; Gallagher-Thompson et al., 2015; Kajiyama et al., 2018). Furthermore, a study that evaluated the acceptability of a web-based course for caregivers of older adults found that caregivers liked having post-module quizzes, and they also had a caregiver suggest the use of caregiver testimonials in course modules (Rottenberg & Williams, 2021). Our findings show that these preferences in web-based training are also warranted among a sample of Latino caregivers.

Limitations

A limitation of this study is that caregivers had trouble recalling details about earlier training modules. A caregiver shared that since it was over a month since they viewed the first couple of training modules, it was difficult to remember some of the specific details of the content covered. When conducting interviews with participants, the research assistant (C.G.) would, at times, need to help remind caregivers about earlier training modules. The time gap between viewing the earlier training modules and being interviewed can result in recall bias, and participants may have omitted important details regarding their experience as a result. An additional limitation of this study is that 10 of the 14 interviews were conducted by the same research assistant who recorded the voiceover for the modules. If participants recognized that it was the same person, it may have led to social desirability bias as participants may have provided answers that would be viewed favorably by the research assistant.

Conclusions

Overall, this study highlights the acceptability and areas of improvement of the cultural adaptation of the STAR-VTF intervention. The feedback provided by Latino caregivers will help inform decisions during the fourth stage (Adaptation refinement) of the Barrera and Castro framework on the cultural adaptation of evidence-based interventions (Barrera & Castro, 2006). Although future research is still needed to test the efficacy of the culturally adapted STAR-VTF program, this pilot study provided valuable information about Latino caregivers' perspectives on the culturally adapted STAR-C online training modules.

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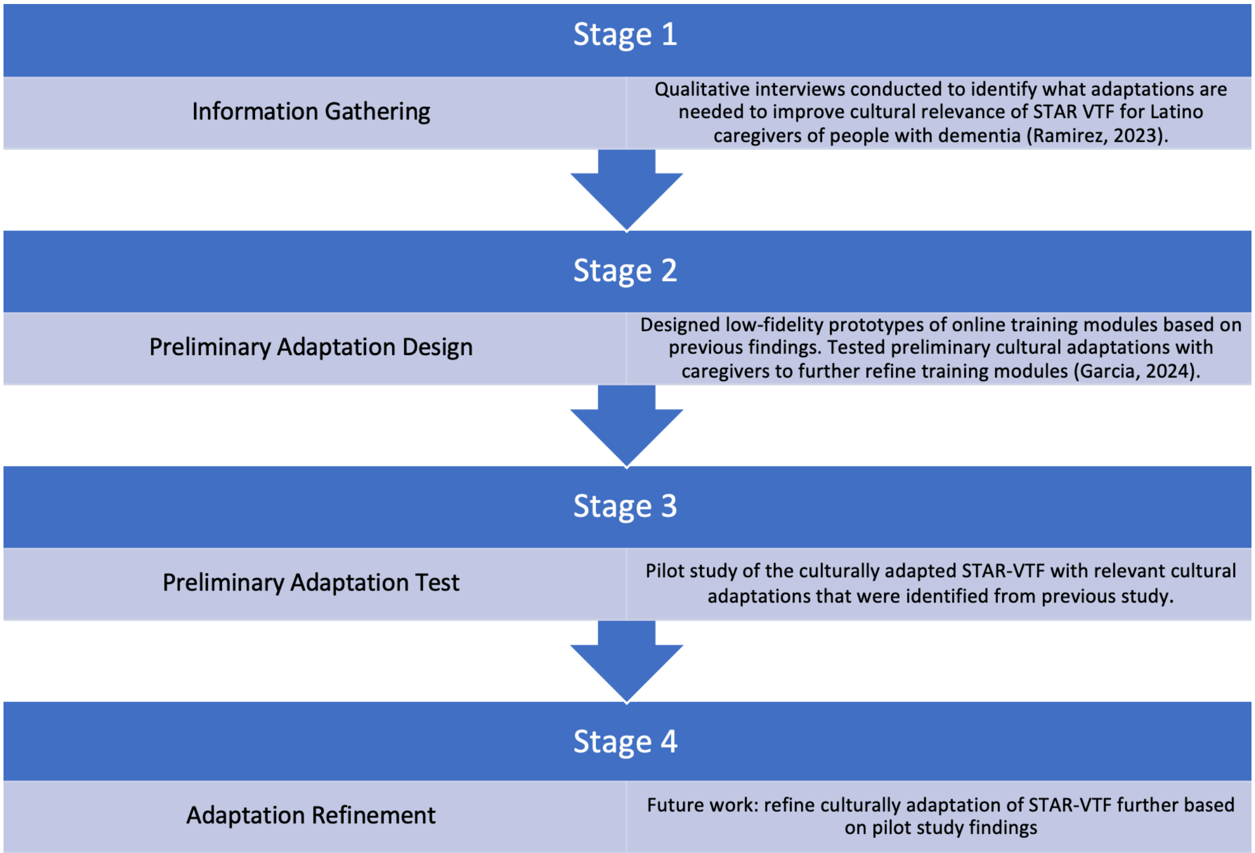
Appendix:

Diagram 1:



Stage 1

Information Gathering

Qualitative interviews conducted to identify what adaptations are needed to improve cultural relevance of STAR VTF for Latino caregivers of people with dementia (Ramirez, 2023).

Stage 2

Preliminary Adaptation Design

Designed low-fidelity prototypes of online training modules based on previous findings. Tested preliminary cultural adaptations with caregivers to further refine training modules (Garcia, 2024).

Stage 3

Preliminary Adaptation Test

Pilot study of the culturally adapted STAR-VTF with relevant cultural adaptations that were identified from previous study.

Stage 4

Adaptation Refinement

Future work: refine culturally adaptation of STAR-VTF further based on pilot study findings

Table 2: Baseline Characteristics

	N	Percent	Average	SD
Age			51.19	13.16
Gender				
Male	3	21.4		
Female	11	78.6		
Hispanic/Latino Origin				
Mexican American, Chicano/a	10	71.4		
Puerto Rican	1	7.1		
Other	3	21.4		
Race				
Black or African American	1	7.1		
White	11	78.6		
Other	2	14.3		
Highest level of education				
Associate's degree	2	14.3		
Bachelor's degree or higher	8	57.1		
Primary level education	1	7.1		
Secondary level/GED/Equivalent	2	14.3		
Some college	1	7.1		
Household income				
Less than $15,000	1	7.1		
Between $15,000-$19,999	1	7.1		
Between $20,000-$24,999	1	7.1		
Between $25,000-$34,999	1	7.1		
Between $35,000-$49,999	2	14.3		
Between $50,000-74,9999	2	14.3		
$100,000 or above	6	42.9		
Current Occupation Status				
Employed	7	50		
Retired	2	14.3		
Stay at home caregiver	2	14.3		
Unemployed	3	21.4		
Current Marital Status				
Married	11	78.6		
Never Married	1	7.1		
Separated	1	7.1		
Divorced	1	7.1		
Primary Language spoken at home				
English	7	50		
Spanish	7	50		
Caregiver English Fluency				
Very Well	6	42.9		
Well	3	21.4		

Not well	3	21.4		
Unknown	2	14.3		
Relationship to PLWD				
Close family member	3	21.4		
Parent	8	57.1		
Spouse or partner	3	21.4		
Gender of PLWD				
Male	3	21.4		
Female	11	78.6		
Lives with PLWD				
Yes	8	57.1		
No	6	42.9		
Years in caregiver role			4.3	3.3
Caregiver hours per week			60.2	50.9

Interview Guide

*****Start recording*****

Introduction

Before we begin, I'd like to remind you that your participation in this study is completely voluntary. You can choose at any point to stop the interview.

As part of the study, you used the CUIDA program for the past 2 months. The program involved 7 videos and a workbook. The program was designed to help family caregivers, like yourself, learn how to manage symptoms of dementia.

As part of the study, you were also asked to complete surveys online.

During this interview, I want to ask you about your experience with the CUIDA program and with completing surveys online. We ask that you provide your honest opinion because it will help us make the program better for family caregivers who use it in the future. We are very interested in your thoughts on how we can make the CUIDA program better for <u>Latino</u> families.

With that said, do you have any questions before we begin?

General Questions

I'll start by asking general questions about the CUIDA program.

1. What do think about the program?
    a. Probe: How helpful were the <u>videos</u> for you?
    b. Probe: How helpful was the <u>workbook</u> for you?

2. What did you like about the program?
    a. What did you like most about the <u>videos</u>?
    b. What did you like most about the <u>workbook</u>?

3. Was there anything missing from the program that you would have liked to see?
    a. How do you think we could make the <u>videos</u> better in the future?
    b. How do you think we could make the <u>workbook</u> better in the future?

4. [If caregiver received intervention in Spanish]: What did you think about the Spanish language in the intervention?
    a. How accurate was the Spanish?
    b. How easy or hard was it to understand the Spanish?
    c. What suggestions do you have for us to improve the CUIDA program in Spanish?

Dementia Education

You might recall that the first video in the program provided information about dementia. It talked about what dementia is, the stages of dementia, and how as dementia progresses, people are less able to control their behavior.

5. What did you think about this first video?
    a. What information did you find particularly helpful?
    b. What other topics about dementia do you wish would have been discussed?

Empathy

Some caregivers have said that they like to be reminded that their family member has a condition of the brain, that some of the things their family member says or does are not on purpose, and for the caregiver to have more patience.

6. Do you relate to this? Why or why not?

7. Do you recall times when the videos had these types of reminders? For example, one of the videos said, "It's important to remember that the changes happening to your family member are not on purpose."
    a. If yes: What did you think about it?
    b. If no: Move on to the next question.

ABC Problem Solving

The next set of questions are about the ABC problem-solving strategy you learned about in the CUIDA program.

8. Did you try using the ABC strategy for one of your family member's symptoms?

    If yes:
    a. For what symptom(s)?
    b. How did it go?
    c. What problems did you encounter with using the ABC strategy?

    If no:
    a. What is the reason?

9. How easy or hard is it to remember what "ABC" stands for? Please explain.

10. What did you think about the example in the videos of how a caregiver used the ABC strategy? The example of Doña Lucha and Don Juan.
    a. What did you like about the example?
    b. How can we make the example better?

Caregiver's Health & Wellbeing

Now we'll move on to a different set of questions. Some caregivers have said that it would be helpful if the CUIDA program emphasized the caregiver's own health and well-being. Caregivers said they needed to be well to take good care of another person.

11. Do you relate to this? Why or why not?

12. Do you recall the times the last video in the program that talked about this topic? For example, it said, "We understand how hard it is to provide care to a family member with dementia. For that reason, it is very important to take good care of yourself too."
    a. If yes: What did you think about it? What could have made it better?
    b. If no: Move on to the next question.

Intervention Delivery

Now we'll move on to the next set of questions related to using technology to participate in the CUIDA program.

13. Did you prefer to sit down and watch the videos, or just listen to the audio while you were doing something else?
    c. Can you explain your preference?

14. How did you receive the videos? (e-mail, WhatsApp, text message, etc.)

15. What device did you use to watch the videos? (Cell phone, tablet, laptop, etc.)
    a. What problems did you encounter with viewing the videos?

16. We want to make these videos more available to family caregivers. What do you think are some ways that we can reach more *Latino* caregivers in particular?

17. Some caregivers have said that they shared the videos with their family members and friends. Did you ever share any of the videos with *your* family members or friends?

    If yes:
    a. Who did you share the video with?
    b. What motivated you to share the video?
    c. What did they think about the video?

    If no:
    a. Do you think other members of your family or any friends that help with caregiving might be interested in the CUIDA program? Why or why not?

18. What did you think about the design of the videos?
    a. What did you think about the:
        i. Colors?
        ii. Audio/voice/narration?
        iii. Pictures?
        iv. Text?

19. How can we make the videos more appealing for family caregivers?

Redcap Surveys

The last set of questions are about the surveys you completed online.

20. What was your experience like completing the surveys online?
    a. What device did you use?

21. What problems did you encounter with completing the surveys online?

Closing Question

We're down to the final question before we end the interview.

22. Is there anything else that we can do to make the CUIDA program better for Latino caregivers?

*****Stop recording*****

Interview Guide (Spanish)

*****Start recording*****

Introducción

Antes de comenzar, me gustaría recordarle que su participación en este estudio es completamente voluntaria. En cualquier momento puede dejar de participar en la entrevista.

Como parte del estudio, usted utilizó el programa CUIDA durante los últimos 2 meses. El programa constaba de 7 videos y un libro de trabajo. El programa fue diseñado para ayudar a los cuidadores familiares, como usted, a aprender a manejar los síntomas de la demencia.

Como parte del estudio, también se le pidió que completara encuestas en línea.

Durante esta entrevista, quiero preguntarle sobre su experiencia con el programa CUIDA y con la realización de encuestas en línea. Le pedimos que brinde su opinión honesta, ya que nos ayudará a mejorar el programa para los cuidadores familiares que lo utilicen en el futuro. Estamos muy interesados en conocer sus ideas sobre cómo podemos mejorar el programa CUIDA para las familias latinas.

Dicho esto, ¿tiene alguna pregunta antes de que comencemos?

Preguntas Generales

Comenzaré haciendo preguntas generales sobre el programa CUIDA.

1. ¿Qué piensa del programa?
    a. ¿Qué tan útiles fueron los videos para usted?
    b. ¿Qué tan útil fue el libro de trabajo para usted?

2. ¿Qué le gustó del programa?
    a. ¿Qué le gustó más de los videos?
    b. ¿Qué le gustó más del libro de trabajo?

3. ¿Hubo algo que faltara en el programa y le hubiera gustado ver?
    a. ¿Cómo cree que podríamos mejorar los videos en el futuro?
    b. ¿Cómo cree que podríamos mejorar el libro de trabajo en el futuro?

4. ¿Qué opinó sobre el idioma español en la intervención?
    a. ¿Qué tan precisa fue la traducción al español?
    b. ¿Qué tan fácil o difícil fue entender el español?
    c. ¿Qué sugerencias tiene para mejorar el programa CUIDA en español?

Educación sobre la demencia

Tal vez recuerdes que el primer video del programa proporcionaba información sobre la demencia. Hablaba sobre qué es la demencia, las etapas de la demencia y cómo, a medida que avanza, las personas tienen menos control sobre su comportamiento.

5. ¿Qué opinó sobre este primer video?
    a. ¿Qué información le resultó particularmente útil?
    b. ¿Qué otros temas sobre la demencia le hubiera gustado discutir?

Empatía

Algunos cuidadores han dicho que les gusta que se les recuerde que su familiar tiene una condición cerebral, que algunas de las cosas que su familiar dice o hace no son intencionales y que el cuidador debe tener más paciencia.

6. ¿Se identifica con esto? ¿Por qué sí o por qué no?

7. ¿Recuerda momentos en que los videos tenían este tipo de recordatorios? Por ejemplo, uno de los videos decía: "Es importante recordar que los cambios que ocurren en su familiar no son intencionales".
    a. Si respondió sí: ¿Qué piensas sobre esto?
    b. Si respondió no: Pasemos a la siguiente pregunta.

Las Tres Cs Para Prestación de Cuidados

Las siguiente preguntas son sobre la estrategia de "las tres Cs" para resolver problemas que aprendió en el programa CUIDA.

8. ¿Intentó utilizar la estrategia "las tres Cs" para alguno de los síntomas de su familiar?

    Si respondió sí:
    a. ¿Para qué síntoma(s)?
    b. ¿Cómo le fue?
    c. ¿Qué problemas encontró al utilizar la estrategia "las tres Cs"?

    Si respondió no:
    a. ¿Cuál es la razón?
    b. ¿Qué problemas encontró al utilizar la estrategia "las tres Cs"?

9. ¿Qué tan fácil o difícil es recordar qué significa "las tres Cs"? Explique, por favor.

10. ¿Qué piensa del ejemplo en los videos sobre cómo un cuidador utilizó la estrategia las tres Cs? El ejemplo de Doña Lucha y Don Juan.

    a. ¿Qué le gustó del ejemplo?
    b. ¿Cómo podemos mejorar el ejemplo?

Salud y Bienestar del Cuidador

Ahora pasaremos a un conjunto diferente de preguntas. Algunos cuidadores han dicho que sería útil si el programa CUIDA enfatizara la salud y el bienestar del cuidador. Los cuidadores dijeron que necesitaban estar bien para cuidar bien a otra persona.

11. ¿Se identifica con esto? ¿Por qué sí o por qué no?

12. ¿Recuerda los momentos en el último video del programa que hablaban sobre este tema? Por ejemplo, decía: " Entendemos lo difícil que es cuidar a un familiar con demencia. Por eso, es *muy* importante que usted también se cuide".
    a. Si respondió sí: ¿Qué piense sobre esto? ¿Qué podría haberlo hecho mejor?
    b. Si respondió no: Pasemos a la siguiente pregunta.

Entrega de La Intervención

Ahora pasaremos al siguiente conjunto de preguntas relacionadas con el uso de la tecnología para participar en el programa CUIDA.

13. ¿Prefirió sentarse a ver los videos o simplemente escuchar el audio mientras hacía otra cosa?
    c. ¿Podría explicar su preferencia?

14. ¿Cómo recibió los videos? (correo electrónico, WhatsApp, mensaje de texto, etc.)

15. ¿Qué dispositivo utilizó para ver los videos? (teléfono celular, tableta, computadora portátil, etc.)
    a. ¿Qué problemas encontró al ver los videos?

16. Queremos hacer estos videos más accesibles para los cuidadores familiares. ¿Qué cree que son algunas formas en las que podemos llegar a más cuidadores latinos en particular?

17. Algunos cuidadores han dicho que compartieron los videos con sus familiares y amigos. ¿Alguna vez compartió alguno de los videos con sus familiares o amigos?

    Si respondió sí:
    a. ¿Con quién compartió el video?
    b. ¿Qué le motivó a compartir el video?
    c. ¿Qué pensaron ellos sobre el video?

Si respondió no:

   a. ¿Cree que otros miembros de su familia o amigos que ayudan con el cuidado podrían estar interesados en el programa CUIDA? ¿Por qué sí o por qué no?

18. ¿Qué te pareció sobre el diseño de los videos?
    a. ¿Qué pensaste sobre:
        i. Los colores?
        ii. El audio/voz/narración?
        iii. Las imágenes?
        iv. El texto?

19. ¿Cómo podemos hacer que los videos sean más atractivos para los cuidadores familiares?

Encuestas en Redcap

El último conjunto de preguntas se refiere a las encuestas que completó en línea.

20. ¿Cómo fue su experiencia al completar las encuestas en línea?
    a. ¿Qué dispositivo utilizó?

21. ¿Qué problemas encontró al completar las encuestas en línea?

Pregunta Final

Llegamos a la última pregunta antes de terminar la entrevista.

22. ¿Hay algo más que podemos hacer para mejorar el programa CUIDA para los cuidadores latinos?

*****Stop recording*****