Stress and Well-Being Intervention and mHealth Delivery Adaptation for Latinx Millennial Caregivers: A Qualitative User-Centered Approach

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Abstract

Background: The study aimed to adapt a stress and well-being intervention delivered via a mobile health (mHealth) app for Latinx Millennial caregivers. This demographic, born between 1981 and 1996, represents a significant portion of caregivers in the United States, with unique challenges due to higher mental distress and poorer physical health compared to non-caregivers. Latinx Millennial caregivers face additional barriers, including higher uninsured rates and increased caregiving burdens.

Objective: We used a community-informed and user-centered design approach to tailor an existing mHealth app to better meet the stress and well-being needs of Latinx Millennial caregivers.

Methods: We employed a two-step, multi-feedback approach. In step one, Latinx Millennial caregivers participated in focus groups to evaluate wireframes for the proposed mHealth app. In step two, participants engaged in usability testing for one week, concluding with short interviews for feedback. Participants were recruited through various channels, including social media and community clinics. Data were analyzed inductively using a rapid qualitative content analysis approach

Results: A total of 29 caregivers (69% women, mean age 31) participated in the study. Participants had a mean age of 31 (SD=4.10), with most (n=28, 96%) caring for an adult and one (4%) caring for children with chronic conditions. All participants completed the step one focus groups, with a subset of 3 caregivers completing usability testing in step two. The most liked features included the: 1) stress rating scale because it helped them understand stress and mental health, 2) mindfulness options because it allowed for flexible timing of activities, 3) journaling prompts because it was a way to address daily challenges and contemplate positives, and 4) resource list for its employment and financial content. One concern was that the journaling prompts may take too much time or effort to complete after a long and hard day. Some suggestions for improvement included: a better tracking system, gamification, caregiving education, a checklist of emotions to use on the journal, tailored resources, and ways to connect with a community of similar caregivers. During step two, participants noted the app was user-friendly but had some glitches and unclear privacy policies. Participants liked the meditation options, resource variety, and daily stress log but wanted more journaling space, longer meditations, and additional relaxation activities.

Conclusions: Caregivers highlighted the need for tailored resources and additional stress-relief activities. Future iterations should consider integrating more personalized and community-specific resources, leveraging platforms like podcasts for broader engagement, and the use of information-based videos to support caregiver skill acquisition. Caregivers expressed needs beyond the scope of the app, such as resource access, demonstrating the need for upstream and downstream interventions. The study underscores the importance of ongoing user feedback in developing effective mHealth interventions for diverse caregiver populations. Clinical Trial: N/A

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Trial Registration: N/A

Key Words: Latinx, family caregiver, millennial, mHealth, user-centered design

Introduction

Millennial caregivers are individuals born between 1981 and 1996 who are care providers to family members and loved ones with serious health conditions. They comprise an estimated 25% of caregivers in the United States (US).[1,2] The number of Millennial caregivers will continue to grow as people are living longer with multiple chronic health issues.[1–3] Caring for a loved one with a chronic condition can lead to adverse physical, psychological, and social outcomes.[2,4] Millennial caregivers experience higher levels of mental distress and worsened physical health than their non-caregiver peers.[3]

Millennial caregivers in the US are a more diverse group of caregivers than previous generational cohorts, with 27% identifying as Hispanic/Latinx.[1] Historically, members of the Latinx community have experienced negative determinants of health related to a lack of access to healthcare and health insurance.[5] These factors contribute to Latinx Americans being at higher risk for Alzheimer's disease, diabetes, obesity, hypertension, and kidney disease than the general US population;[4] likely increasing burdens of caregiving among the Latinx population.

Latinx Millennial caregivers are at higher risk for negative health outcomes than their non-Latinx peers. The rate of uninsured Latinx citizens is more than double the rate of non-Latinx Caucasian citizens.[5] Coupled with the low insurance rates reported by Millennial caregivers, Latinx Millennial caregivers are at increased risk of poor health outcomes and higher rates of disease.[2,5] Latinx Millennial caregivers are 34% more likely to provide higher hours of caregiving than other races/ethnicities in the Millennial caregiving population, while simultaneously working more hours per week.[1]

There is a dearth of research exploring interventions to enhance stress management and well-being among Latinx caregivers. The few interventions studied are highly varied and lack methods of adapting interventions to address the specific needs of individual caregivers.[6] Language is a significant potential barrier for this population. In the United States, 51.3% of Latinx individuals reported needing translation services in healthcare settings, yet many trainings and public health campaigns for caregivers are only provided in English.[4] While research detailing the experiences and needs of Millennial caregivers highlights the necessity for support, there is a gap regarding interventions available and tailored to this population.[7,8]

Due to balancing work, family, and caregiving responsibilities, Latinx Millennial caregivers may have less time to engage in coping strategies and well-being.[2,7] With the population's needs in

mind, an mHealth phone app was designed with meditation and journaling self-care exercises for the general Millennial population.[9,10] The concept for an integrated mindfulness and journaling intervention delivered through an app was inspired by the Dynamic Fit Model, which focuses on in-the-moment and long-term strategies to manage stress. Mindfulness was identified as an in-the-moment response to stress, while journaling would address the long-term sustained stress of caregiving.[11] A user-centered design approach, modeled after Still and Crane,[12] was implemented to adapt the mHealth app. Feedback from the general Millennial population identified the need for a resource list for caregivers and a daily stress measure, in addition to mindfulness and journaling exercises. Thus, a caregiver resource list was added addressing chronic disease, work, general caregiving information, and financial information. A one-item stress rating using a 10-point Likert scale was added.[10]

The purpose of this research study was to use both community-informed and user-centered design approaches to adapt a stress and well-being phone app intervention for Latinx Millennial caregivers. For this current adaptation, we continued to apply the Still and Crane[12] approach coupled with a community-engaged lens.[13] Still and Crane (2017)[12] describe the importance of engaging users early and often, designing for use in context, giving users control, keeping it simple, designing for emotion, ensuring user triangulation, and discovery before designing and delivering. Wallerstein et al.[13] describe their approach to community-based participatory research (CBPR) including contexts of research participants, partnering processes among research participants and researchers, the use of shared decision making for research design, and outcomes that center social justice, health, and equity. The current study focused on engagement rather than a full CBPR approach, but we did address contexts, partnering processes, and shared decision making throughout data collection and analysis.

Methods

Study Design and Participants

This was the second phase of a three-phase multi-method study to examine the needs and experiences of Latinx Millennial caregivers and to adapt and refine an mHealth intervention for this population. The first phase, focused on needs and experiences, is reported elsewhere.[7] This second phase was focused on adaptation and refinement of an mHealth intervention using a stepped approach. Initial qualitative descriptive analysis from focus group interviews with Latinx Millennial family caregivers were followed by user-testing and short interviews. The focus group interviews, usability testing, and short interviews were approved by the [Blinded for Review] Institutional Review Board (STUDY00002382).

Step One

Participants were recruited using purposive sampling through multiple formats. Paid social media advertising and informal advertising within online family caregiver support group platforms occurred, flyers were posted in community clinics in Texas and Utah, along with emailed flyers to professional contacts and national caregiving groups. Finally, a participant list from previous studies who have given permission to be re-contacted were sent the study information. The eligibility survey was completed through REDCap electronic data capture tools hosted by The University of Texas.[14,15] This survey required participants to meet the following inclusion criteria: born between 1981 and 1996, identify as Latinx, and provide care to a family member or friend for at least 10 hours per week. Participants were excluded if they did not have reliable internet access due to focus groups being conducted over Zoom.

Step Two

Participants were emailed about usability testing and short interviews. For this part of the study, individuals were excluded if they did not have access to a smartphone. Participants were given instructions on how to download the app from either the App Store or GooglePlay and an access code that would allow them app use for one week. App use data were collected on the back end to be sure app engagement occurred. A short Zoom interview was completed after app usability testing.

Approach

Focusing on adaptation and refinement for the Latinx Millennial caregiver population, both user-centered design and community-engaged methods were used to ensure the functionality and content were tailored to the specific needs of this population.[12,13] Two stages of interviews with Latinx Millennial caregivers were used to address stakeholder feedback, evaluate the clarity of the Spanish translation, and ensure both usability and content tailoring of the app.

Data Collection

Step One

Participants first indicated if they would participate in an online focus group in the eligibility survey. Willing and eligible participants were contacted by a graduate research assistant via email, who provided participants with a link to a Zoom meeting. The principal investigator conducted five Zoom focus groups of 60-90 minutes with between 3-10 individuals (see Table 1). At the end of the focus groups, participants reviewed four wireframes (layout of an app page that demonstrates interface components) of an mHealth app with four intervention components: a stress rating tool, mindfulness activity, journaling prompts, and caregiving resources.[16] Structured questions were asked about each wireframe, and participants were encouraged to share their opinions and perspectives (See Table 1). A trained research assistant independently recorded observations in a separate document during the focus group meetings. Focus groups were recorded and transcribed verbatim. Focus groups were sequentially held until saturation was achieved.[17] Participants were provided with a gift card for participating in the focus groups or interview. Upon completing the focus group, participants were sent a demographic questionnaire administered through REDCap, including questions about caregiving experiences.

Table 1: Interview questions.

Wireframe Questions
Based on feedback from other Millennial caregivers, we have developed an app and intervention that focuses on stress, emotional regulation, and providing resources for support. We would like some feedback from each of you about what we have so far. We are sharing wireframes on the screen. We will start with wire frame 1, which is a stress rating scale. What do you think about this scale? Would this be helpful for you? When would it be helpful? We will go to wireframe 2, which is a mindfulness activity. What do you think about mindfulness? Would this be helpful for you? When would it be helpful?

We will go to wireframe 3, which is a daily journal. It asks about what was most challenging/distressing and about what you felt most positive about for each day. What do you think about this? Would this be helpful for you? When would it be helpful? Now we will go to wireframe 4, which is a resource list. Looking at the headings, can you see any type of resource that would be helpful for you? Is there a type of resource that is missing? If you had your wish for anything to make caregiving better or easier, what would that be? Thank you so much for your time and participation in this study. Once again, we appreciate your contributions and the work you do as a family caregiver.
Usability Questions
What worked well for you with the app? What did not work well or was confusing? What did you like? What did you not like or what was missing?

Step Two

Participants engaged in a brief 15-minute Zoom interview on their experiences using the app following one week of use (See Table 1). Notes were taken during these short interviews, but interviews were not recorded or transcribed. These participants also received a gift card for their participation.

Analysis

Demographic data were analyzed for frequencies and descriptive statistics. Data from both steps were analyzed inductively using a rapid qualitative content analysis approach by the research team for coder triangulation.[18,19] Matrices were used to identify the main categories for the app and intervention revision. A summary of the recommendations for changes was then reviewed with the whole team, including the app developer. A final list of revisions was created based on user and team feedback (See Table 2). Coders and team members addressed their positionality throughout the app revision process: two of the team members identify as family caregivers, four identify as Millennials, and three identify as Latinx. Discussion of identity and how this impacts data analysis and interpretation occurred to ensure that team members remained close to the data and reflected what participants communicated.[18] Notes were kept during data analysis and each team meeting to serve as an audit trail.[18] Confidentiality was maintained by storing all study data such as notes, focus group transcripts, and data analyses within a collaborative secure cloud storage accessible solely by research team members.

Results

Results will be presented sequentially by step, and participants' quotes will be shared with designation for the participant (P) and focus group (G). Changes made after each step are presented in Table 2. Categories and participant quotes are outlined in Table 3.

Step One

For step one of the app and intervention revision, 29 participants participated. Twenty participants identified as women (69%). Participants had a mean age of 31 (SD=4.10) with most (n=28, 96%) caring for an adult (sibling/parent/grandparent), and one (4%) caring for children with chronic conditions.

Features Participants Liked

Participants described liking the app features generally, including the stress rating scale, having multiple mindfulness options, journaling prompts, and the resource list. For the stress rating scale, they describe it as being helpful in understanding stress and mental health. One participant stated it would be "a way to keep track of what was really going on with my stress level" (P1G1). The flexibility of the mindfulness activities was noted, with P4G4 noting the importance of having options for "timing for both long and short time." With a journaling question focused on the challenges of the day and a good thing that happened that day, caregivers appreciated addressing both: "you can kind of look back and be like okay well least this was one good thing, and this was the thing that was bad that happened, but you always have that good in the mix of it" (P2G4). With the integrated resources, caregivers expressed interest in the employment and financial resources: "I just want to compliment you all on the financial aspect down there because you know that was something that would have been really helpful for us in the beginning" (P1G2).

Features Participants Disliked

One concern described by caregivers was having a long journal at the end of a difficult day or having the journaling questions be mandatory: "maybe sometimes you're too stressed and depending how my day went to be able to sit down and type a long journal may be a little bit hard for me" (P1G1).

Recommended Additions

Caregivers described multiple suggestions to improve the app both for their needs and for usability.

- The need for a tracking system for stress and journaling was highlighted, including a responsive system for high stress ratings that would include app activities: "I love being able to, you know, track everything and then at the end of the month, or the end of the weekend, you can go back" (P4G2).
- Gamification, rewards, flexibility with the timing of activities, and personalized notifications were recommended to increase engagement: "there could be a little reward encouraging to do that caregiving job…also if the app could have a reminder" (P2G1).
- For the resource list, caregivers wanted more education about caregiving skills and space to document medication lists and healthcare appointments: "I think, for me, maybe like tips… we were kind of really inexperienced with, you know, how to shower my grandfather" (P1G2).
- Caregivers described having a checklist of emotions rather than completing a full journal entry on the days they were too tired or busy: "maybe on two days I can just maybe click on how I'm feeling" (P1G1).
- Other stress-relieving activities were recommended such as gaming, music, recipe-sharing, videos for managing stress, and information on coping with COVID-19: "Space to add some music… I do love classical music" (P2G1).

- They also described the need for multiple lengths of time for mindfulness: “timing for both long and short” (P4G4), and a sleep meditation, “like a night meditation” (P1G4).
- For the resource list, caregivers described wanting tailored resources specific to their states, work situation, and/or caregiving needs: “having it more where you can actually look for your particular state, because each state kind of offers different benefits” (P2G4).
- Caregivers wanted more connection with other caregivers for “a community to share problems” (P2G2), and receive advice, “it would be nice, knowing that there are other people like me, too, and we could share useful info and advice” (P3G5).

Step Two

After app revisions were made (outlined in Table 3), a subsample (n=3) completed usability testing and included two women and one man. Qualitative findings are outlined for each step below and in Table 3.

Worked Well

Participants described the app as user-friendly, cool, and not overwhelming. Two of three participants felt that the Spanish translation worked well. One participant described the app as being helpful when they were stressed.

Did Not Work Well or Was Confusing

For one participant, switching to Spanish did not work. Participants noted a few glitches such as the stress log or journal not working on some days, the meditation not working while in sleep mode, and the speech-to-text for journaling not working well within the app. One participant described the privacy policy for the app as being unclear.

Features Participants Liked

Participants again described liking most dimensions of the app, including the meditation length and variety, the resource variety, having a daily stress log, and the use of the journal for reflection on the day.

Features Participants Disliked or Felt Were Missing

Participants recommended having more space for journaling, having the ability to edit journals, having longer meditation options, and more activities to help with relaxation.

Table 2: App/intervention changes

Changes After Focus Group Findings

● Spanish translation
● Caregiver support plan
● Flexibility with journaling content and amount
● Varied mindfulness options
● Resource section
  ○ Caregiving, culture, faith
  ○ Physical care tips
  ○ Caregiver support groups
  ○ State-by-state resources

Changes After Usability Testing

• App functionality issues were addressed
Future Changes
● Skill-based videos ● Podcast-like caregiver interviews ● Self-care videos ● App tailoring with activities connected to stress rating scale ● Education on cloud sharing for medication information, calendar management, and the use of a shared calendar

Table 3: Qualitative findings

Wireframe Focus Group Findings	
Category	Subcategory
Features Participants Liked	● Stress rating scale is helpful to understand mental health ● Multiple mindfulness options (recording, step-by-step guide) and flexibility to use throughout the day ● Journaling prompts for challenges and good things, may help with therapy ● Journal and mindfulness pages are simple and not overwhelming ● Like the integrated resources including employment-focused information
Features Participants Disliked	● Do not want to do a long journal on difficult days or to have the journal be mandatory
Recommended Additions	● Better tracking system over time for stress and journaling ● Rewards and personalized notifications within app ● Track stages/needs of person they care for including medications/healthcare appointments and have more educational information on caregiving skills ● Be able to click how they feel under journaling as an alternative to writing (both positive/negative emotion) ● More flexibility with timing of activities ● Include a sleep meditation. ● Include resources that are state specific, include more information about financial needs, and address diverse employment experiences ● More social options within the app to connect to other caregivers and receive answers to questions about unique needs ● Other stress-relieving activities like gaming, music, in-app chatting,

	recipe-sharing, coping with COVID-19, videos on managing stress, or other caregiver-preferred activities ● Connect stress rating to app activities, like what to do with high stress levels. ● Recommend multiple lengths of time for mindfulness (short, medium, long)
Usability Interviews	
Worked Well	● User friendly ● Thought it was cool ● Not overwhelming ● Spanish translation ● App was helpful when stressed
Did Not Work Well or Confusing	● Switching to Spanish in App ● Some days the stress log and journal did not work ● Phone going into sleep mode and meditation would stop playing ● Privacy policy unclear ● Speech to text did not work well
Features Participants Liked	● Meditation–different meditations were useful, liked short length ● Resources ● Daily stress log ● Journaling was a nice way to look back at the day
Features Participants Disliked or Felt Were Missing	● Not enough space for journaling ● Would like to go back to journals and edit ● Would like longer meditation options ● More activities to help with relaxation

Discussion

In this study, we sought to integrate community- and user-informed design into our adaptation of an mHealth stress and well-being intervention for Latinx Millennial family caregivers. The original intervention was developed for the general Millennial caregiver population. Significant differences we noted in the needs and preferences between groups were the inclusion of other stress-relieving activities beyond mindfulness and journaling, having an option not to journal and just indicate their emotions, and having tailored employment and financial resources for their specific situations and locations that extended the resources already embedded in the app.[7,8,10] Like the general Millennial users, the Latinx users identified the need for social engagement and community.[7,10]

This two-step process of adapting and refining an mHealth app-delivered intervention for Latinx millennial family caregivers revealed the need to expand resources, such as state- and community-focused resources that address financial and employment needs. Religious and cultural information, state resources, and support groups were added to the resource list to address the need for more resources and social connection. A caregiver support plan, informed by safety plans for individuals at risk for suicide,[20] was created. The mHealth app and intervention were also translated into Spanish to address language access.[21]

We recognize that gaps remain regarding the desire for community and having resources that are tailored to the individual. This might call for a layered intervention approach that leverages mHealth and in-person or virtual and individual or group-based caregiver coaching to address these additional needs.[22] This might also require AI solutions to pull in comprehensive, tailored, and location-based resources such as the PaidLeave.AI platform developed by Moms First.[23]

While mHealth interventions have the benefit of being accessible and time-limited,[24] which works well for the Millennial caregiver population,[25] they often do not solve larger systems issues such as resource access, social isolation, navigation, and advocacy that can help this group of Latinx caregivers who are already navigating systems-level barriers and power structures.[26, 27] This calls for upstream interventions that were largely outside the scope of this study but could be considered for future intervention iterations as findings and resources expand. This tightrope of addressing user feedback while not overstretching resources is a well-acknowledged challenge in product development and technology-based interventions.[28] A strength of this specific study is ensuring that stakeholder needs are addressed and shared decision-making is occurring.[13]

Considerations for changes in the future include leveraging podcast delivery methods to share caregiver stories and skill-based and self-care content. The podcast platform is widely used by Millennials and has been found to support health outcomes such as behavior change and social interaction.[29,30] For Latinx individuals specifically, the podcast platform is a growing medium for this group.[31] Caregivers have anecdotally, and in formal reports, expressed the desire for a one-stop shop platform that addresses financial/employment, educational, navigation, shared care, and self-care needs.[32] Further iterations could explore the feasibility of these options. One danger is the platform becoming unwieldy, difficult to use, and less reflective of stakeholder reported needs, thereby violating the principles of simplicity and shared decision-making. Therefore, continued stakeholder feedback will be required.[12,13]

Despite noted gaps in our app-based intervention currently, we believe there are important future opportunities to address Latinx Millennial family caregiver well-being. The population interviewed in this study is in early- and middle-adulthood, a critical life phase for adult development; they experience health disparities related to systems level issues in insurance, health care access, and economic opportunities; and they are navigating caregiving while also balancing work, family, and other social responsibilities.[1,2,4,5] Thus, their risks for long-term health consequences related to family caregiving are high, and there continues to be a gap in interventions tailored to this specific group.[6] It is important to intervene early with this population to address these health consequences that may influence their life trajectories. With our app-based intervention, we hope to meet caregivers where they are in an accessible format to support their well-being.

Limitations

Our study had important limitations that should be considered in interpreting our findings. First, we had an overrepresentation of female Latinx Millennial family caregivers. In the Latinx population, the gender split is almost even.[2] Due to our emphasis on a user-informed process, this over-representation of women could have affected our findings and subsequent intervention and app adaptations. We also used a disease-agnostic approach, which means that our intervention and app were not tailored to a specific disease process that these caregivers were supporting. Further iterations could address more tailored applications for disease-related issues.

Conclusions

With our user-informed process, we adapted a stress and well-being intervention for Latinx

Millennial family caregivers. During this process, we noted the difficulty of aligning the study purposes and resources with stakeholder feedback. We acknowledge that user-informed design is an ongoing and iterative process, which requires balancing the needs of stakeholders and the feasibility of recommended adaptations. We anticipate ongoing intervention and mHealth app adaptations that address more stakeholder-identified needs, more thoroughly address the need for social connection, and are individually tailored.

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Conflicts of Interest: The authors declare no conflicts of interest.

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