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A Text Message Intervention to Support Latino Dementia Family Caregivers (CuidaTEXT): Feasibility study

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Abstract

Objectives: To test the feasibility, acceptability, and preliminary efficacy of *CuidaTEXT:* a bidirectional text message intervention to support Latino dementia family caregivers.

Methods: *CuidaTEXT* is a six-month, bilingual intervention tailored to caregiver needs (e.g., education, problem-solving, resources). We used convenience sampling and reached 31 potential participants via clinics, registries, community promotion, and online advertising. We enrolled 24 Latino caregivers in a one-arm trial and assessed feasibility, acceptability, and preliminary efficacy within six months.

Results: None of the participants unsubscribed from *CuidaTEXT* and 83.3% completed the follow up survey. Most participants (85.7%) reported reading most text messages thoroughly. All participants reported being very or extremely satisfied with the intervention. Participants reported that *CuidaTEXT* helped a lot (vs not at all, a little, or somehow) in caring for their care recipient (71.4%; n=15), for themselves (66.7%; n=14), and understanding more about dementia (85.7%; n=18). Compared to baseline, at six months caregiver behavioral symptom distress (0–60) decreased from 19.8 to 12.0 and depression (0–30) from 8.8 to 5.4 ($p<0.05$).

Conclusions: *CuidaTEXT* demonstrated high levels of feasibility, acceptability, and preliminary efficacy among Latino caregivers.

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Ethical Principles: The authors affirm having followed professional ethical guidelines in preparing this work. These guidelines include obtaining informed consent from human participants, maintaining ethical treatment and respect for the rights of human or animal participants, and ensuring the privacy of participants and their data, such as ensuring that individual participants cannot be identified in reported results or from publicly available original or archival data.

Clinical implications: *CuidaTEXT's* feasibility and potential for widespread implementation holds promise in supporting Latino caregivers of people with dementia.

Keywords

Latinos; mHealth; dementia; caregiving

Introduction

Support for family caregivers of individuals with dementia (IWDs) is a key component of the US National Alzheimer's Project Act (U.S. Department of Health & Human Services, 2016). Latino caregivers' physical and mental health is disproportionally impacted by caregiving (Liu et al., 2021). The reasons for these disparities are poorly understood (Liu et al., 2021), although research shows that Latinos provide more intense and longer caregiving (National Alliance for Caregiving and AARP, 2020) partly due to family values (Campos et al., 2014). In addition, Latino caregivers face multiple intersecting barriers to health including lower incomes and access to education (Mitrani et al., 2008; Sörensen & Pinquart, 2005), which compound stresses associated with caregiving. As with other forms of mental illness, stigma around dementia is prevalent in Latino populations and further compounds caregiving (Montoro-Rodríguez et al., 2009). Many Latinos lack generational experience with social support programs and may fear accessing such, particularly if they have had discriminatory experiences or if any of their family members are undocumented (Cleaveland & Ihara, 2012). Despite their high interest in caregiver support (Perales et al., 2018), Latinos experience disparities accessing it (Monahan et al., 1992; Scharlach et al., 2008).

Family caregiver support interventions have shown efficacy in improving health outcomes (Walter & Pinquart, 2020) but most have been designed for non-Latino Whites, and results usually do not generalize to other groups potentially due to linguistic, cultural, and contextual reasons (Gilmore-Bykovskyi et al., 2018; Gitlin et al., 2015; Pendergrass et al., 2015). There is a crucial need for targeted caregiver support interventions among Latinos. This need is in line with the National Institute on Aging's call to address health disparities in aging research (National Institute on Aging, 2018).

To address Latinos' caregiving disparities, we developed *CuidaTEXT* (a Spanish play on words for self-care and texting) (Perales-Puchalt, Acosta-Rullan, et al., 2021). *CuidaTEXT* is to our knowledge the first text message intervention for caregiver support of individuals with dementia (IWDs) among Latinos or any other ethnic group. Short Message Service (SMS) text messaging is a well-suited modality to deliver caregiver support for Latinos given its universal use. SMS text messaging is integrated in all cellphones by default, is easy to use, and does not require home broadband. Nearly all Latino adults own a cellphone with texting capabilities, outpacing other groups (Grossman et al., 2018; Kajiyama et al., 2018; Pew Research Center, 2021; Waller et al., 2017). Most Latinos use their cellphone to send and receive text messages, which contrasts with their low use of their cellphone to access apps, email, and the internet (Duggan, 2013). Research shows that text messaging is engaging among Latinos, convenient, low cost, private, and scalable (Cartujano-Barrera et al., 2020; Guerriero et al., 2013; Hall et al., 2015; Pew Research Center, 2021; Schilling et al., 2013; Zurovac et al., 2012).

The potential of text message interventions among Latinos contrasts with synchronous interventions or interventions that largely rely on apps, computers, or internet broadband, as these may widen disparities among Latinos due to disproportionately lower access (Atske & Perrin, 2021; Katz et al., 2022). The present study aimed to test the feasibility, acceptability, and preliminary efficacy of *CuidaTEXT* among Latino family caregivers of IWDs. This development corresponds to Stage 1b of the NIH Stage Model for Behavioral Intervention Development (feasibility testing) (Onken et al., 2014).

Methods

This study used a one-arm pre-post-intervention trial design with assessments conducted at baseline and six months. We recruited caregiver participants from June to August 2021 from our center's clinic, research registries formed in the past five years (Perales-Puchalt, 2020; Perales-Puchalt et al., 2020; Perales et al., 2018), community promotion (newspaper ads, presentations), and advertisements in national organization registries and websites. All participants were enrolled over a 20-day period during the month of August 2021. Participants were eligible if they spoke Spanish or English, were 18 or older, identified as Latino, owned a cellphone with a flat fee, and reported being able to read and write. To be eligible, participants also had to provide hands-on care for a relative with a clinical or research dementia diagnosis who also scored two or higher in the AD8 proxy-administered cognitive screener (Galvin et al., 2005; Pardo et al., 2013). In our previous research, advisory board members suggested that if two or more people cared for a single IWD, they were included in the study, as this approach could reduce burden and increase social support (Perales-Puchalt, Acosta-Rullan, et al., 2021). For this reason, we allowed more than one caregiver participant per IWD. All study procedures were approved by the Institutional Review Board of the University of Kansas Medical Center (STUDY00144478). All participants gave written informed consent.

Procedures

The research team explained the general characteristics of the study to potential participants over the phone or via secure videoconference. Those willing to participate were screened for eligibility. If eligible, the research team asked caregiver participants to sign an online informed consent and scheduled a phone call or videoconference to complete the baseline assessment. All participants who completed the baseline assessments were considered enrolled in the study and immediately began to receive *CuidaTEXT's* text messages. Six months after the baseline assessments, the research team messaged participants notifying them of their intention to call them and schedule the follow-up assessment, which took place within a two-week window.

Intervention

CuidaTEXT is a bilingual, six-month intervention tailored to caregiver needs via SMS text messages. *CuidaTEXT* is bidirectional, as participants receive scheduled text messages, but they can also text to receive on-demand messages. An in-depth description of the intervention and its development has been previously reported (Perales-Puchalt, Acosta-Rullan, et al., 2021). The intervention was designed from the beginning with and for Latino caregivers with the support of a team including bicultural, bilingual researchers, and informed by the Stress Process Framework and Social Cognitive Theory (Bandura, 1986; Pearlin et al., 1990). These messages include the identification of barriers to desired behaviors (e.g., problem solving, relaxation techniques, or exercising), setting of realistic goals, encouragement of gradual practice to increase healthy behaviors, integration of testimonials and videos to promote vicarious learning, integration of praise, social support, and education to increase dementia knowledge. *CuidaTEXT* includes 1–3 scheduled daily automatic messages (n=244 over six months) about logistics, dementia education, self-care, social support, end-of-life care, care of the person with dementia, behavioral symptoms, and problem-solving strategies. Participants can also text two types of messages to receive on-demand assistance via: 1) up to 783 keyword-driven text messages providing on-demand help for the above topics; 2) live chat interaction with a coach from the research team for further help upon request. Before enrollment, staff mail participants a 19-page reference booklet summarizing the purpose and functions of the intervention.

CuidaTEXT targets Latino caregivers as follows: First, Latinos can interact with *CuidaTEXT* anywhere and at any time, which addresses Latino transportation barriers (Anderson, 2016) and incompatibilities such as being ‘sandwich generation’ caregivers (S. Rote et al., 2019; Weber-Raley, 2019). Second, *CuidaTEXT* automatic messaging might be more cost-efficient than other caregiver interventions, as it relies little on workforce, which addresses Latino caregivers’ disproportionate financial strain (Gallagher-Thompson et al., 2003; S. M. Rote et al., 2019). Third, *CuidaTEXT* is available in English and Spanish and uses simple language, which addresses language and literacy barriers (Alonzo, 2020; US Census Bureau, 2016). Fourth, *CuidaTEXT* includes substantial content on family support and is deployed to caregivers’ private cellphones, which addresses Latino caregivers’ shared family caregiving roles and dementia stigma (Alzheimer’s Association, 2021; Apesoa-Varano et al., 2015).

Assessment

The research team collected information from three sources: baseline survey, six-month follow-up survey, and metrics of text message interactions. Pre-intervention survey socio-demographic information included the caregivers’ age, gender, race, US region of residence, and marital and medical insurance status. Acculturation information included the caregiver’s country of birth and primary language (Spanish, English, both, and other). Technological information included whether caregivers had previously registered in another text message notification service (e.g., bank or clinic notifications). Caregiving characteristics included the caregiver’s relationship to the IWD. Care recipients’ characteristics included the IWD’s age, gender, ethnicity, diagnosis, medical insurance status, and AD8 cognitive screening score (Galvin et al., 2005; Pardo et al., 2013).

Outcomes included feasibility, acceptability, and preliminary efficacy:

1. Feasibility outcomes were based on previous text message health research (Abroms et al., 2015; Cartujano-Barrera et al., 2020) and included the duration of recruitment and enrollment (study recruitment and enrollment feasibility), percentage of potential participants who opted into *CuidaTEXT* (intervention enrollment feasibility), percentage of participants who completed the follow-up survey (retention feasibility), percentage of enrolled participants who completed all outcome assessments (assessment feasibility), percentage of participants who sent 0 (no interaction), 1–9 (low interaction), 10–49 (intermediate interaction), 50–99 (high interaction), or more than 100 messages (very high interaction), mean percentage of text messages that were sent via keywords, percentage of participants who unsubscribed from *CuidaTEXT* by texting the keyword STOP, and percentage of participants who reported ‘I read through the text messages thoroughly most times’ in the follow-up survey as opposed to ‘I took only a short look at the text messages most times’, or ‘I did not read the text messages most times’ (engagement feasibility). The follow-up survey also included a free-response question asking whether participants experienced any technical problems (intervention delivery feasibility).

2. Acceptability outcomes were based on previous text message health research (Abroms et al., 2015; Cartujano-Barrera et al., 2020) and were all collected in the follow-up survey. These outcomes included nine four-point Likert scale questions on satisfaction with *CuidaTEXT* and its components (Not at All-Extremely). Three additional four-point Likert scale questions asked about their perceived helpfulness of *CuidaTEXT* in: caring for the IWD, caring for themselves, and enhancing their understanding of dementia (Not at All-A Lot). Each question had a slot for comments, which the interviewer recorded. The survey also included the System Usability Scale, which asks about their experience with *CuidaTEXT* (Sauro, 2011). The System Usability Scale is a valid and reliable 10-item questionnaire Likert scale (1–5). According to the developers of the scale, scores above 68 out of 100 indicate higher levels of usability.

3. Preliminary efficacy outcomes included scales administered at baseline and follow-up (Table 1). Most of these scales were validated in the US Latino Spanish-speaking population. For those that were not, we used either Spanish-speaking versions from other countries, or we translated them using standard procedures (World Health Organization, 2022).

Analysis

We used descriptive statistics to summarize baseline characteristics of caregivers and IWDs. We also used descriptive statistics to summarize quantitative feasibility and acceptability outcomes. We summarized acceptability comments and reported the most frequent ones. Regarding preliminary efficacy, we used paired-samples t-tests to assess change from pre- to post-intervention, as all scores were normally distributed. To explore potential mechanisms, we calculated Pearson correlations to analyze between-outcome associations among those outcomes that changed statistically. We used SPSS v20.0 for all calculations (IBM Corp., 2013). The significance level was set at $p < 0.05$.

Results

We screened 31 potential caregiver participants. Among those, 24 participants caring for 21 IWDs were enrolled in the study. The reasons for screen failure included no longer being able to participate (n=6) and a lack of diagnosis (n=1). Participants were recruited from a memory clinic (n=5), research registries (n=6), community promotion (n=5), and advertisements in national registries and websites (n=8). Of the 21 IWDs, 19 had one participating caregiver, one had two caregivers participating and one had three caregivers participating. Given that most IWDs had one participating caregiver, we report the findings of all participants individually. Ancillary analyses with only one participant per IWD (the first one to be enrolled) show similar results (Appendix 1).

Table 2 shows the participants' characteristics at baseline for the total sample, as well as those who completed the follow-up survey and those who did not. Fourteen participants (58.4%) were caregivers of care recipients with late onset Alzheimer's dementia, five with dementia of unspecified etiology (20.8%), three with vascular dementia (12.6%), one with early onset Alzheimer's dementia, and one with early onset Alzheimer's dementia and frontotemporal dementia. Caregiver participants' mean age was 52.6 years and ranged from 26 to 81. Twenty (83.3%) were women and 13 (54.2%) were married or had a partner. Ten participants were born in the USA (41.7%), six in Mexico (25.0%), and eight (33.3%) in another Latin American country. Those not born in the USA had been in the USA for an average of 23.2 years, ranging from 3.0 to 50.0. Eleven (45.8%) chose to receive *CuidaTEXT* messages in Spanish. Most participants (n=18; 75.0%) were the adult children of an IWD.

Among the 21 IWDs, the average age was 74.9 and ranged from 52.0 to 89.0. Thirteen were women (61.9%) and six (28.6%) had no medical insurance. No baseline caregiver or IWD characteristics were statistically different between those who completed the follow-up assessment and those who did not, except for self-rated health, which was better among completers (mean=2.5) than non-completers (mean=2.0; p=0.014).

Table 3 shows the feasibility and acceptability outcomes.

Recruitment was completed in 61 days and enrollment in 20 days. Among the 24 enrolled caregiver participants, all enrolled (received the initial *CuidaTEXT* message) without any technical issues such as *CuidaTEXT* messages being blocked by the phone carrier, 21 (87.5%) completed at least the acceptability questions of the follow-up survey, and 20 (83.3%) completed the whole survey including the efficacy outcomes. The reason for one participant's incomplete follow-up survey was due to the death of the participant's IWD during the intervention (unrelated to their participation). We did not collect the efficacy information for this participant because it would not reflect the effect of the intervention. Among the 24 enrolled participants, 13 (54.2%) sent 50 or more text messages (high/very high interaction), and 44.1% of the text messages they sent were keywords

(44.1%; SD=30.6). No participant unsubscribed from the intervention. Among the 21 participants who responded to the follow-up survey, 18 reported reading most messages thoroughly (85.7%) and two (9.5%) reported experiencing mild technical issues. One reported sometimes having no internet to see videos that were part of the intervention referred content, and the other reported losing their text message history after they fixed their phone after a technical issue. All participants were very or extremely satisfied with *CuidaTEXT* and most were very or extremely satisfied with its different features. For example, 90.4% (n=19) were very or extremely satisfied with the number of text messages received per day and 85.0% (n=17) were very or extremely satisfied with *CuidaTEXT's* duration. Participants reported that *CuidaTEXT* helped a lot (vs not at all, a little, or somehow) in caring for their care recipient (71.4%; n=15), for themselves (66.7%; n=14), and understanding more about dementia (85.7%; n=18). The System Usability Scale mean score was 95.8 (SD=9.7), which is above the high usability threshold of 68.

Caregiver participants' free-response comments highlighted the helpfulness of *CuidaTEXT* in caring for themselves and their IWD. Participants reported that *CuidaTEXT* improved their dementia understanding/knowledge, perspective/attitudes, skills, and access to resources. For example, a participant reported 'I learned how to deal with day-to-day situations, and that my loved one's challenging behaviors are part of the disease'. *CuidaTEXT* provided a constant feeling of being supported, nudges, or reminders for self-care and validation of their own caregiving actions. Participants reported 'I felt supported knowing that someone was there for me', 'The program reminded me to take care of myself', and 'The messages reinforced my efforts'. The text messaging modality was more manageable than websites and other formats, as it provided daily and on-demand 'pills of information'. While most participants did not have their relatives enroll in the intervention due to lack of feasibility (e.g., living far away, too busy), some forwarded *CuidaTEXT* content to them. For example, a participant reported 'I shared several text messages with my children. They don't live in our state'. Participants described the content of *CuidaTEXT* as reliable with diverse, practical, and useful information using clear language that is easy to access and digest. For example, a participant reported 'I liked that messages were in Spanish and reliable'.

Table 4 shows the preliminary efficacy of *CuidaTEXT* on caregivers' assessments of the IWDs and themselves. The caregivers' ratings of their IWD's functional dependence as measured by the FAQ did not change from pre- to post-intervention. Most outcomes followed a trend of improvement. The following outcomes improved in a statistically significant way from pre- to post-intervention ($p<0.05$): IWDs' behavioral symptom severity (NPI-Q-D) and caregivers' behavioral symptom distress (NPI-Q-D), competence (PCS), dementia knowledge (EEDS) problem-focused coping (COPE-28), depression (CES-D-10), and positive affect (SPANE-P).

Table 5 shows the correlations between preliminary efficacy outcomes. The reduction of IWDs' behavioral symptom severity was only associated with reductions in caregiver behavioral symptom distress ($r=0.864$). The reduction in caregiver strain was associated with an increase in caregiver competence ($r=-0.532$) and a reduction in caregiver unmet needs ($r=0.457$). Increases in caregiver competence were associated with increases in caregiver dementia knowledge (r=0.521) and reductions in depression (r=0.516). In addition to strain, reductions in caregiver unmet needs were associated with increases in dementia knowledge (r=−0.536) and reductions in depression (r=0.735). The only additional statistically significant association was that increases in dementia knowledge were associated with decreases in depression (r=−608; p<0.05 for all reported correlations).

Discussion

This study aimed to test the feasibility, acceptability, and preliminary efficacy of *CuidaTEXT*, a text message intervention to support Latino dementia family caregivers of IWDs. To the best of our knowledge, this is the first caregiver support intervention that relies largely on text messages to deliver its content. This is also one of the few caregiver support interventions purposefully developed to address common linguistic, cultural, and contextual barriers that Latino caregivers experience (Gilmore-Bykovskyi et al., 2018; Gitlin et al., 2015; Pendergrass et al., 2015). We used several survey questions, validated scales, and metrics to assess outcomes during six months among 24 Latino caregivers. Overall, results show that the *CuidaTEXT* study design and intervention are highly feasible, caregiver participants are highly satisfied with the intervention, and the intervention leads to improved outcomes of caregivers and IWDs. These findings are important given that Latino dementia caregivers experience disproportionate levels of physical and mental health issues (Liu et al., 2021) and experience disparities accessing caregiving support (Monahan et al., 1992; Scharlach et al., 2008).

Latinos are rarely included in caregiver support intervention research and are often thought of as ‘hard to reach’ populations (Gilmore-Bykovskyi et al., 2018; Gitlin et al., 2015; Pendergrass et al., 2015). This exclusion raises questions about the generalizability of evidence-based interventions among Latinos and potentially widens the gap between those for whom interventions were developed and those who were not included (Butler et al., 2020; Gitlin et al., 2015; Pendergrass et al., 2015). Our findings suggest that centering the development of an intervention on Latinos can lead to quick enrollment and high retention rates, usability, levels of intervention engagement, and satisfaction. For example, our caregiver advisory board informed *CuidaTEXT’s* low frequency of daily automatic messages, while allowing for on-demand assistance via keywords and live chat messages (Perales-Puchalt et al., 2022). These informed features likely resulted in no participants unsubscribing, 90.4% reporting high to very high satisfaction with the number of messages received daily, and 85.7% reading most messages. These findings contrast with a one-month Israeli text message smoking cessation intervention, which resulted in 34.2% of participants unsubscribing, 63.3% reporting satisfaction with the number of messages received daily, and 75% reporting reading most messages (Abroms et al., 2015). *CuidaTEXT’s* Latino caregiver informed features also likely led to a 100% high satisfaction with keyword functionalities and high text message interaction levels in line with previous text message interventions with Latinos (Cartujano-Barrera et al., 2020). *CuidaTEXT* provides caregivers with remote and asynchronous ways to receive support, increasing their access to support services. Remote assessments also increase the feasibility of the study design, making it more valuable among Latino caregivers, who disproportionately experience time constraints

(Areán & Gallagher-Thompson, 1996; Gallagher-Thompson et al., 2003; S. Rote et al., 2019; Weber-Raley, 2019) and transportation barriers (Anderson, 2016).

CuidaTEXT resulted in decreased levels of caregiver's perceived behavioral symptom severity among IWDs, and caregivers' distress, strain, and depression, among other outcomes after six months. Improvements in these outcomes took place during the COVID-19 pandemic, when there is evidence of worsening of these outcomes (Gedde et al., 2022). During this time, some tele-psychological support to caregivers (IWD or caregiver-focused) did not show improvements from baseline to 28- and 32-week follow-up assessments (Rotondo et al., 2021). The preliminary efficacy of *CuidaTEXT* is comparable to in-person interventions with the additional benefit that it is less workforce-intensive and can be delivered remotely and almost fully automatically. Our analyses showed a 40.0% decrease in the average number of caregiver unmet caregiver needs and a 19.5% reduction in feelings of caregiver strain. These results are in line with the effectiveness of the Reducing Disability in Alzheimer's Disease intervention, one of the few evidence-based interventions that have been implemented in the community (Menne et al., 2014; Perales-Puchalt, Barton, et al., 2021). *CuidaTEXT* led to average behavioral symptom severity score reductions of 4.4 points and behavioral symptom distress reductions of 7.8 points, which is more than the 2.8 and 3.1 points reported respectively to be considered a minimally clinically significant difference using the same scale (Mao et al., 2015). Other studies using the same depression scale found that control group participants reported average reductions of 0.2, 0.2, and 0.7 after five or six months (Czaja et al., 2013; Finkel et al., 2007; Martindale-Adams et al., 2013). This difference is smaller than the average 3.4 difference found in our study, which is the equivalent of one depressive symptom over 5–7 days or three depressive symptoms over 1–2 days in the last week. In fact, this reduction in depressive symptoms is comparable or bigger than the reductions reported by caregivers receiving the active caregiver support intervention in those controlled trials (Czaja et al., 2013; Finkel et al., 2007; Martindale-Adams et al., 2013). *CuidaTEXT* also led to increases in positive affect, which is an important outcome that has been rarely included in clinical trials, likely due to the prevailing deficit focus of biomedical research (de Manincor et al., 2016; Espejo et al., 2020).

Participants' comments, preliminary efficacy outcomes and correlations gave insight into potential mechanisms of the intervention. For example, caregiver participants reported that *CuidaTEXT* helped improve their understanding of dementia, attitudes, skills for caregiving, and access to resources. These comments were corroborated by improvements in dementia knowledge, competence, and problem-related coping and reductions in caregiver unmet needs. In the current study, caregiver dementia knowledge correlated with caregiver competence and unmet needs. Knowledge is an important component to build self-efficacy, which is in line with social cognitive theory, one of the principles that informed *CuidaTEXT (Bandura, 1986).* Knowledge derived from *CuidaTEXT's* messages about how to care for themselves, the IWD, and how to find resources in the community may have addressed critical caregiver needs. Changes in dementia knowledge, competence, problem-related coping, and caregiver unmet needs were correlated with changes in caregiver depression and strain. *CuidaTEXT* might reduce caregiver depression and strain by improving dementia knowledge and competence, and by reducing their unmet needs.

These mechanisms are in line with the secondary intrapsychic strains-outcomes path from the Stress Process Framework that was used to inform *CuidaTEXT* (Pearlin et al., 1990). The high correlation between decreases in behavioral symptoms of IWDs and caregiver behavioral symptom distress suggests that *CuidaTEXT's* caregiving strategies helped reduce behavioral symptoms, which in turn reduced the distress generated by these. The Stress Process Framework also supports this primary stressors-outcomes path (Pearlin et al., 1990). Caregivers' frequent comments about *CuidaTEXT* providing a constant source of support did not have a corresponding increase in the social support scale. However, the ISEL-12 focuses on family and friends, and it likely does not reflect the support participants received from *CuidaTEXT*. Future studies should use a social support scale that better reflects this source of support.

This study has some limitations. The pre-post design with no control group prevents our ability to infer causal relationships between the intervention and observed outcomes. We were unable to maintain contact for follow-up with three participants, who might have had a more negative feedback and outcomes than the participants who completed the follow-up assessments. The small sample size and its convenience sampling may reduce the generalizability of these findings. The average level of functional dependence of IWDs was relatively high, which raises the question of whether *CuidaTEXT* would achieve such strong outcomes among samples with a lower level of dependence. Our sample had a distribution that was similar to the US Latino caregiver population in terms of language and medical insurance status. However, despite men's low participation in dementia caregiving, their distribution in our study (16%) was smaller than the Latino caregiving population (26%), likely due to Latino men's previously reported lower participation in research (National Alliance for Caregiving, 2008). Given the nature of the study, neither the participants, the assessment staff nor the data analyst were blinded, which could have biased the results. The current study did not analyze the content of text messages sent by caregivers. The content analysis is out of the scope of this manuscript and will be reported in a future manuscript using mixed-methods.

This study has implications for public health, clinical practice, and research. *CuidaTEXT* has high potential for implementation, given the universal accessibility of SMS text messaging and its reliance on technology rather than workforce, which potentially makes it more cost-effective and sustainable. The positive feasibility and acceptability findings in this study highlight the importance for intervention developers to design interventions with implementation in mind from the beginning of the intervention and use user-centered design for their future success (Gaugler et al., 2021; International Organization for Standardization, 2018). The next logical step for *CuidaTEXT* is an efficacy randomized controlled trial, which corresponds with Stage 2 of the NIH Stage Model for Behavioral Intervention Development (Onken et al., 2014). If successful, *CuidaTEXT* could be easily implemented in clinics and community organizations by having the caregivers send a text message to enroll or by having staff enter their phone numbers and names on a website. A future Stage 2 trial should also aim to assess mechanisms of action. Our current study suggests some mechanisms that can be tested in that future study. Despite the encouragement from our advisory board to recruit more than one caregiver per IWD due to Latinos' family distribution of caregiving tasks (Perales-Puchalt, Acosta-Rullan, et al., 2021), most participants decided to participate on their own. Future studies should explore how to increase engagement of other family members, although our participants have already provided a valid solution: forwarding the messages they consider important to their families. Given its many advantages (e.g., on-request tailoring, available anywhere and at any time, low dependence on workforce) future studies could explore the feasibility of *CuidaTEXT* in other populations in the US and elsewhere, including rural areas and low- and middle-income countries.

Conclusion

This study tested the feasibility, acceptability, and preliminary efficacy of *CuidaTEXT*, the first tailored text message intervention specifically designed to support dementia family caregivers in the Latino community. This study design was feasible in this underserved population, and the intervention showed high levels of usability, engagement, and satisfaction, as well as a promising increase in important clinical caregiver-reported outcomes. These positive findings and the potential for widespread implementation, support *CuidaTEXT* as an ideal intervention to eliminate caregiver dementia disparities among Latinos, which is a key goal of the National Institute on Aging (Goal F) (National Institute on Aging, 2018), and the National Plan to Address Alzheimer's Disease (Strategy 2H) (U.S. Department of Health & Human Services, 2020).

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Biographies

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Edward F. Ellerbeck, MD: Dr. Ellerbeck is a Professor of Population Health and the Director of the Clinical and Translational Research Education Center at the University of Kansas Medical Center. He has over 25 years of experience in measuring and improving the quality of medical care, particularly in underserved rural and minority communities. His area of interest is in the development of system changes to enhance prevention and treatment of chronic diseases.

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Amber Watts, PhD: Dr. Watts is an Associate Professor of Clinical Psychology at University of Kansas and Research Fellow of the KU Alzheimer's Disease Center. Her doctoral degree is in Gerontology and she conducts biopsychosocial research and behavioral interventions on preventable risk factors for cognitive decline and Alzheimer's disease.

Kristine Williams, RN, PhD, FNP-BC, FGSA, FAAN E: Dr. Williams is a nurse gerontologist and the E. Jean Hill Professor at the University of Kansas School of Nursing.

Her research tests interventions designed to improve the quality of life of people with ADRD and their families.

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Data availability statement:

None

Appendix 1.: Ancillary analysis: Preliminary efficacy outcomes comparing pre- and post-intervention scores; including only the first participant from each IWD-cluster

		Baseline		**Follow up**		
Person with dementia	**N**	**M**	**SD**	**M**	**SD**	**P-Value**
FAQ dependence (0–30)	17	24.9	5.1	25.9	5.4	0.386
NPI-Q Severity (0–36)	17	16.6	8.4	12.1	9.5	**0.010**
Caregiver	17					
NPI-Q Distress (0–60)	17	21.0	14.2	12.2	12.8	**0.001**
Caregiver Strain Index (0–26)	17	13.8	5.5	11.1	6.5	**0.011**
ZBI Burden (0–24)	17	10.6	5.2	9.3	6.4	0.265
PCS Competence (0–4)	17	2.1	0.7	2.6	0.7	**0.001**
Positive aspects of caregiving (9–45)	17	33.2	8.3	34.9	7.8	0.310
Unmet needs (0–34)	17	15.4	9.1	8.9	7.3	**0.001**
EEDS dementia knowledge (0–14)	18	10.1	1.7	11.1	1.5	**0.024**
ISEL-12 appraisal support (4–16)	17	12.7	3.1	14.1	2.3	**0.021**
ISEL-12 belonging support (4–16)	17	12.2	3.4	12.6	2.9	0.624
ISEL-12 tangible support (4–16)	17	12.6	2.7	13.0	3.3	0.623
COPE 28 problem focused (8–32)	17	21.5	5.9	24.5	5.1	0.074
COPE 28 emotion focused (12–48)	17	31.1	5.2	32.9	6.2	0.180
COPE 28 avoidant focused (8–32)	17	13.3	3.3	12.4	3.2	0.200
CES-D-10 depression (0–30)	17	8.6	4.2	5.2	4.4	**0.016**
SPANE-Positive affect (6–30)	17	22.1	5.1	25.1	3.5	**0.003**
SPANE-Negative affect (6–30)	17	13.0	3.1	11.6	3.1	0.134
Perceived health (1–4)	17	2.4	0.9	2.4	0.7	0.999

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Clinical Implications

- Latino family caregivers of individuals with dementia face many barriers to caregiver support access that may be alleviated through culturally tailored text message interventions.
- *CuidaTEXT*, a text message intervention for family caregiver support, has high feasibility, acceptability, and preliminary efficacy and has potential for widespread implementation.

Table 1.

Preliminary efficacy scales included in the current feasibility study at baseline and follow up at six months.

Name of scale and acronym	**Description**
Functional Activities Questionnaire (FAQ) (Acevedo et al., 2009; Pfeffer et al., 1982)	This is a 10-item questionnaire completed by the caregiver as a proxy respondent for the care recipient to monitor changes in instrumental activities of daily living over time (e.g., preparing balanced meals, or following the news). Each item is rated with six response options: Dependent (3 points), Requires Assistance (2 points), Has Difficulty but Does By Self (1 point), Normal (0 points), Never Did but Could Do Now (0 points), and Never Did And Would Have Difficulty Now (1 point). Total scores range from 0 to 30 with higher scores indicating higher dependence. This outcome assessed dementia progression and was not expected to improve.
Behavioral symptom severity (NPI-Q) (Acevedo et al., 2009; Kaufer et al., 2000)	The NPI-Q is a clinical instrument for evaluating psychopathology in dementia with two scales, care recipient severity (NPI-Q-S) and caregiver distress (NPI-Q-D). If any of the 12 neuropsychiatric symptoms are present in the last month (e.g., depression, repeating), caregivers rate the level of severity for the IWDs on a 3-point scale (Mild–Severe). An overall severity summary score is calculated by adding the severity scores of all items. For any present symptom, caregivers also rate their own distress on a 6-point scale (Not Distressing at All-Extreme or Very Severe Distress). An overall distress summary score is calculated by adding the distress scores of all items. Higher scores indicate higher severity and distress.
Caregiver strain (Modified Caregiver Strain Index; CSI) (Thornton & Travis, 2003)	The CSI is a 13-item screener that measures caregiver strain. For each of the items (e.g., caregiving is inconvenient), the caregiver can respond either No (0), Yes Sometimes (1), or Yes on a Regular Basis (2). The total score is the sum of all item scores. Higher scores indicate higher strain.
Caregiver burden (Zarit Burden Interview-6; ZBI-6) (Higginson et al., 2010)	The ZBI-6 measures caregiver burden (e.g., having enough time to yourself). Each of the six items of the ZBI-6 is a statement the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). An overall burden summary score is calculated by adding the scores of all items, and higher scores indicate higher burden.
Caregiving competence (Preparedness for Caregiving Scale; PCS) (Carter et al., 1998; Gutierrez-Baena & Romero-Grimaldi, 2021)	The PCS is a self-rated instrument that consists of eight items that ask caregivers how well prepared they believe they are for multiple domains of caregiving (e.g., caring for care recipient’s physical needs). Responses are rated on a 5-point Likert scale with scores ranging from 0 (Not at All Prepared) to 4 (Very Well Prepared). The scale is scored by calculating the mean of all items answered with a total score range of 0 to 4. The higher the score the more prepared the caregiver feels for caregiving.
Positive aspects of caregiving (Positive aspects of caregiving scale; PAC) (Tarlow et al., 2004).	This scale was designed to measure psychosocial benefits of caregiving among family caregivers (e.g., feeling more useful). The PAC has nine statements and caregivers rate their level of agreement with those statements ranging from 1 (Disagree A Lot) to 5 (Agree A Lot). An overall score can be obtained by adding their item scores. Higher scores indicate more perceived positive benefits.
Unmet needs (Measure of Unmet Needs; UN) (Gaugler et al., 2004)	The UN is a 34-item survey for caregivers that requires 0 (No) or 1 (Yes) answers regarding additional assistance with categories such as activities of daily living, dementia symptoms, and social support. A total score can be obtained by summing all 34 items. The higher the score, the higher the number of unmet needs the caregiver reports having.
Dementia knowledge (Epidemiology/Etiology Disease Scale; EEDS) (Connell & Holmes, 1996; Roberts & Connell, 2000)	The EEDS is a 14-item True/False questionnaire about dementia. An example of a question includes ‘There is no cure for Alzheimer’s disease (True)’. Correct answers are scored one point each and a total score is calculated by adding the 14 items. The higher the score, the higher the dementia knowledge.
Social support (Interpersonal Support Evaluation List; ISEL-12) (Merz et al., 2014)	The ISEL-12 is a 12-item measure of perceptions of social support. This questionnaire has three different subscales designed to measure dimensions of perceived social support: Appraisal support (e.g., someone to share private worries with), belonging support (e.g., being invited to do things), and tangible support (e.g., finding help with daily chores). Each dimension is measured by 4 items on a 4-point scale ranging from ‘Definitely True’ to ‘Definitely False’. Higher scores indicate higher perceived support.
Coping (Coping Orientation to Problems Experienced Inventory; COPE-28) (Carver, 1997; Perczek et al., 2000)	The COPE-28 is a 28 item self-report questionnaire designed to measure effective and ineffective ways to cope with caregiving. The scale is rated using a 4-point Likert scale ranging from 1 (I Haven’t Been Doing This at All) to 4 (I Have Been Doing This A Lot). Subscales include problem-focused coping (e.g., taking action to improve the situation), emotion-focused coping (e.g., getting emotional support), and avoidant coping (e.g., not believing the situation is real). High scores indicate caregiver participants use that strategy more often. Higher scores in problem-focused coping and lower avoidant coping are typically indicative of positive outcomes.

Name of scale and acronym	Description
Depressive symptoms (Center for Epidemiologic Studies Depression Scale; CES-D-10) (Cheng & Chan, 2005; González et al., 2017)	This is a 10-item, self-report rating scale that measures characteristic symptoms of depression in the past week (e.g., depression, loneliness). Each item is rated on a 4-point scale, from 0 (Rarely or None of the Time) to 3 (Most or All of the Time) with positively worded items (items 5 and 8) reverse scored. Items yield summary scores that range from 0 to 30, with higher scores indicating higher depression severity.
Affect (Scale of Positive and Negative Experience; SPANE) (Daniel-González et al., 2020; Diener et al., 2010)	The SPANE comprises 12 items, six positive (SPANE-P; e.g., positive, pleasant) and six negative experiences (SPANE-N; e.g., negative, unpleasant). Both sets of items measure three general and three specific emotions encompassing a wide range of human experiences. The instrument uses a five-point frequency rating scale ranging from 1 (Very Rarely or Never) to 5 (Very Often or Always). Total scores range from 6 to 30 with high scores indicating high positive (SPANE-P) or high negative affect (SPANE-N).
Self-perceived health (Patel et al., 2003).	This is a one-item question that is self-reported by the caregiver. The question includes a four-point Likert scale and asks ‘Overall, how would you rate your health- Excellent, Good, Fair, or Poor?’.

Table 2.

Baseline characteristics of the participants enrolled in *CuidaTEXT*

	Total (n=24)	Completers (n=21)	Non-completers (n=3)	P Value
Age in years, mean (SD)	52.6 (13.2)	53.8 (2.3)	44.0 (15.6)	0.594
Women, % (n)	83.3% (20)	81.0% (17)	100.0% (3)	0.563
Region				
Midwest, % (n)	70.8% (17)	66.7% (14)	100.0% (3)	0.494
South, % (n)	16.7% (4)	19.0% (4)	0.0% (0)	
West, % (n)	12.5% (3)	14.3% (3)	0.0% (0)	
Race, % (n)				
Other/ Hispanic/Latino, % (n)	62.5% (15)	61.9% (13)	66.7% (2)	0.854
White, % (n)	29.2% (7)	28.6% (6)	33.3% (1)	
Mixed, % (n)	8.3% (2)	9.5% (2)	0.0% (0)	
Country of birth				
US, % (n)	41.7% (10)	42.9% (9)	33.3% (1)	0.176
Mexico, % (n)	25.0% (6)	19.0% (4)	66.7% (2)	
Other, % (n)	33.3% (8)	38.1% (8)	0.0% (0)	
Years of education, m (SD)	14.7 (3.8)	14.9 (3.9)	13.0 (3.0)	0.424
Caregiver without medical insurance, % (n)	20.8% (5)	23.8% (5)	0.0% (0)	0.310
Spanish only as primary language, % (n)	41.7% (10)	42.9% (9)	33.3% (1)	0.409
Married or have a partner, % (n)	54.2% (13)	52.4% (11)	66.7% (2)	0.796
Ever signed up for text message reminders, % (n)	66.7% (16)	66.7% (14)	66.7% (2)	0.723
Relation to care recipient				
Children, % (n)	75.0% (18)	76.2% (16)	66.7% (2)	0.641
Children-in-law, % (n)	8.3% (2)	9.5% (2)	0.0% (0)	
Partner, % (n)	16.7% (4)	14.3% (3)	33.3% (1)	
Financial inadequacy (0–4), m (SD)	1.7 (1.3)	1.7 (0.3)	1.7 (0.3)	0.918
Self-rated health (0–4), m (SD)	2.4 (0.8)	2.5 (0.2)	2.0 (0.0)	**0.014**
Spirituality (1–5), m (SD)	4.5 (1.2)	4.5 (0.3)	4.7 (0.3)	0.849
Care recipients is a woman, % (n) [*]	61.9% (13)	66.7% (12)	33.3% (1)	0.316
Care recipients is a Latino, % (n) [*]	95.2% (20)	94.4% (17)	100.0% (3)	0.857
Age of care recipient, m (SD) [*]	74.9 (12.6)	76.6 (11.7)	65.0 (15.6)	0.145
Care recipient without medical insurance, % (n) [*]	28.6% (6)	27.8% (5)	33.3% (1)	0.900
AD8 total score of care recipient, m (SD) [*]	7.2 (1.3)	7.5 (0.6)	7.0 (1.0)	0.245

[*] Out of 21 care recipients; **Bold**: $p<0.05$

Table 3.

Feasibility and acceptability of the *CuidaTEXT* study and intervention (n=21)

Feasibility		
Study recruitment	Recruitment duration	61 days
Study enrollment	Enrollment duration [*]	20 days
Intervention enrollment	Percentage of participants able to opt into *CuidaTEXT*[*]	100% (n=24)
Retention rate	Percentage of enrolled participants who completed the follow-up survey [*]	87.5% (n=21)
Assessment feasibility	Percentage of enrolled participants who completed the preliminary efficacy outcomes [*]	83.3% (n=20)
Intervention delivery	Percentage of participants who experienced technical issues 1) Sometimes had no internet to see videos, 2) lost text message history when phone stopped working	9.5% (n=2)
Intervention engagement	Percentage of participants who sent 0 text messages (no interaction) [*]	8.3% (n=2)
	Percentage of participants who sent 1–9 text messages (low interaction) [*]	0.0% (n=0)
	Percentage of participants who sent 10–49 text messages (intermediate interaction) [*]	37.5% (n=9)
	Percentage of participants who sent 50–99 text messages (high interaction) [*]	29.2% (n=7)
	Percentage of participants who sent more than 100 text messages (very high interaction) [*]	25.0% (n=6)
	Mean percentage text messages that were keywords	44.1% (SD=30.6)
	Percentage of participants who unsubscribed from *CuidaTEXT*[*]	0% (n=0)
	Percentage of participants who reported reading most messages thoroughly	85.7% (18)
Acceptability		
Satisfaction	Very or extremely satisfied with intervention [a]	100.0% (21)
	Very or extremely satisfied with number of texts per day [a]	90.4% (19)
	Very or extremely satisfied with keyword functionality [a]	100.0% (19)
	Very or extremely satisfied with links to videos [a]	93.8% (15)
	Very or extremely satisfied with numbers to resources [a]	75.0% (12)
	Very or extremely satisfied with links to resources [a]	95.0% (19)
	Very or extremely satisfied with length of the intervention [a]	85.0% (17)
	Very or extremely satisfied with booklet [a]	100.0% (13)
	Very or extremely satisfied with family participation [a][**]	100.0% (4)
Helpfulness	Helped a lot in caring for their care recipient [b]	71.4% (15)
	Helped a lot in caring for themselves [b]	66.7% (14)
	Helped a lot in understanding more about the disease [b]	85.7% (18)
Usability	System Usability Scale score (0–100)	95.8 (SD=9.7)

[*] Metrics calculated for all participants (n=24)

[**] Only four participants responded to this question, as all other participants enrolled alone with no other relative

[a] Very and extremely satisfied have been collapsed vs not at all and somewhat satisfied

[b] Helped a lot vs not at all, a little and somehow.

Table 4.

Preliminary efficacy outcomes comparing pre- and post-intervention scores

		Baseline		**Follow up**		
Person with dementia	**N**	**M**	**SD**	**M**	**SD**	**P-Value**
FAQ dependence (0–30)	20	24.3	5.0	25.5	5.3	0.237
NPI-Q Severity (0–36)	20	16.2	8.0	11.8	8.9	**0.004**
Caregiver						
NPI-Q Distress (0–60)	20	19.8	13.5	12.0	11.8	**0.001**
Caregiver Strain Index (0–26)	20	13.3	5.6	10.7	6.4	**0.003**
ZBI-6 Burden (0–24)	20	10.4	5.4	9.1	6.2	0.179
PCS Competence (0–4)	20	2.1	0.7	2.6	0.7	**0.000**
Positive aspects of caregiving (9–45)	20	33.0	7.7	34.4	7.6	0.344
Unmet needs (0–34)	20	15.7	8.6	9.4	6.9	**0.000**
EEDS dementia knowledge (0–14)	21	10.0	1.7	11.2	1.4	**0.005**
ISEL-12 appraisal support (4–16)	20	12.3	3.5	13.3	3.1	0.194
ISEL-12 belonging support (4–16)	20	11.9	3.4	12.3	3.0	0.577
ISEL-12 tangible support (4–16)	20	12.5	2.5	12.9	3.0	0.587
COPE 28 problem focused (8–32)	20	21.9	5.6	24.8	4.8	**0.041**
COPE 28 emotion focused (12–48)	20	30.9	4.9	32.7	5.8	0.120
COPE 28 avoidant focused (8–32)	20	13.1	3.4	12.3	3.1	0.234
CES-D-10 depression (0–30)	20	8.8	4.3	5.4	4.1	**0.008**
SPANE-Positive affect (6–30)	20	22.3	5.0	25.4	3.4	**0.001**
SPANE-Negative affect (6–30)	20	13.2	3.5	11.3	3.2	0.056
Perceived health (1–4)	20	2.5	0.8	2.5	0.7	0.999

Bold: $p<0.05$

Table 5.

Mechanistic analysis: between-preliminary efficacy outcome correlations

	NPI-Q Severity change	**NPI-Q Distress change**	**Caregiver Strain Index change**	**PCS Competence change**	**Unmet needs change**	**EEDS ADRD knowledge change**	**COPE 28 problem focused change**	**CES-D-10 depression change**	**SPANE-Positive affect change**
NPI-Q Severity change	1	-	-	-	-	-	-	-	-
NPI-Q Distress change	**0.864**	1	-	-	-	-	-	-	-
Caregiver Strain Index change	0.342	0.390	1	-	-	-	-	-	-
PCS Competence change	−0.407	−0.329	**−0.532**	1	-	-	-	-	-
Unmet needs change	0.249	0.293	**0.457**	−0.311	1	-	-	-	-
EEDS ADRD knowledge change	−0.144	−0.051	−0.373	**0.521**	**−0.536**	1	-	-	-
COPE 28 problem focused change	0.089	0.007	0.172	−0.215	0.125	−0.159	1	-	-
CES-D-10 depression change	0.356	0.240	0.281	**−0.516**	**0.735**	**−0.608**	−0.024	1	-
SPANE-Positive affect change	−0.186	−0.215	−0.391	−0.011	−0.339	0.256	−0.193	−0.295	1

Bold: $p<0.05$