Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer's disease and related dementias

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Abstract

Purpose—To identify the information and communication needs of Hispanic family caregivers for individuals with Alzheimer's Disease and Related Dementias (ADRD) and the manner in which online tools may meet those needs.

Methods—We conducted 11 participatory design sessions with 10 English- and 14 Spanish-speaking urban-dwelling Hispanic family caregivers and gathered data using a survey, collage

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assemblage, and audio and video recordings. Four investigators analyzed transcripts of audio recordings with a coding framework informed by several conceptual models.

Results—Participants had an average age of 59.7 years, were mostly female (79.2%), and had cared for a family member with ADRD for an average of 6.5 years. All participants accessed the Internet at least once a week with 75% daily. Most used the Internet to look up health information. All participants reported caregiver attributes including awareness of the disease symptoms or behaviors. The majority reported information needs/tasks (91.7%), communication needs/tasks (87.5%), and need for online tools (79.2%).

Conclusion—Hispanic caregivers of individuals with ADRD reported key information and communication needs/tasks. Only Spanish-speaking participants reported Internet and technology use deficits suggesting the requirement for further technology support. Data show a need for online tools to meet the needs of caregivers.

Keywords

Information needs; communication needs; caregiver; self-management; Alzheimer's disease and related dementias

Introduction

Although there are varying definitions, dementia can be defined as "the clinical syndrome of mental life characterized by the substantial global decline in cognitive function that is not attributable to alteration in consciousness".[1] It is characterized by a decline in the memory, language, and skills that enable a person to function in everyday life.[2] Alzheimer's disease is the brain disorder that is the most common cause of sporadic dementia accounting for 60–80% of cases, followed by vascular dementia. Sporadic dementias are increasingly recognized as being heterogeneous (e.g., Alzheimer's with a vascular contribution) and are recently referred to as Alzheimer's Disease and Related Dementias (ADRD).[3] An estimated 9.4 million Americans and 46.8 million people globally are affected by ADRD, a number that is expected to double every 20 years.[4] The estimated worldwide cost of ADRD is U.S. $818 billion.[4]

In the United States, it is estimated that there are at least 17.7 million caregivers of someone age 65 and older who has a significant impairment.[5] When compared to non-caregivers, individuals caring for a family member have higher levels of depression and anxiety[6,7] as well as numerous physical health consequences including increased risk of stroke.[8,9] The care of individuals with ADRD is challenging.[10–12] They require constant supervision and care, which risks caregivers' psychological, physical, and financial health.[13–16] A recent systematic review documented the relationship between care burden and caregiver factors in ADRD and reported that those who had poor psychological health, poor perceived well-being, high depressive symptoms, poor religious coping skills, poor family functioning, poor self-sufficiency for symptom management and high anxiety experienced a greater burden from caregiving.[17]

There is limited research specific to Hispanics who are a rapidly growing population in the United States and are disproportionately affected by ADRD and related caregiving burdens[18]

compared to Non-Hispanic Whites (NHW).[2,19,20] Findings from a 2011 nationwide telephone survey conducted by the Alzheimer's Association highlight Hispanic caregivers' unique characteristics. They are younger than NHW and Non-Hispanic Blacks (NHB), less likely to be married than NHW, more likely to have children than NHW and Asian-Americans (AA), more likely to make <$50,000 annually than NHW and AA, and more likely to need help balancing work and family and finding personal time than NHW.[13] Other studies show that Hispanics experience more strain and receive less social support than other racial/ethnic groups, despite extensive social networks, and that less acculturated Hispanic caregivers experience more depression.[21–24] The extent of this disparity is unclear but there are many negative health consequences for this group as they are likely to receive their diagnosis later on and may not have the same access to treatments.[25] Moreover, caregivers of individuals with ADRD have disproportionately bad health outcomes and it is recognized that the health of caregivers suffers as a result of their caregiving activities.[26] In addition, Hispanic caregivers are more depressed than other racial/ethnic groups, but the interplay of risk and protective factors is poorly understood[27] and mixed results from small studies have not clarified the association between social support and caregiver depression in Hispanics. [23,24] Moreover, Hispanics tend to have distinct attitudes towards caregiving, such as feeling guiltier with nursing home placement and may treat caregiving more as a family affair compared with NHW. This is consistent with the concept of "familism," which may result in less delegation of caregiving responsibilities to formal caregivers.[28]

The need to support caregivers of individuals with ADRD is of growing importance and supportive strategies for the caregiver or the care-recipient appear to be effective in improving the well-being for both.[29,30] A systematic review of 43 studies related to caregivers of those with ADRD concluded that there was strong evidence that (1) multicomponent psychoeducational interventions improve caregiver quality of life, confidence, and self-efficacy and reduce burden; (2) cognitive reframing reduces caregiver psychological distress (e.g., anxiety, depression); and (3) communication skills training improves caregiver skill as well as quality of life for individuals with ADRD.[31]

The effect of technology-enabled interventions including online tools, in general, was addressed in a systematic review of 65 studies which concluded that more than 95% of the studies reported significant improvements in the caregiver outcomes (e.g., psychological health, knowledge/skills/patient management, social support, coping/problem solving, and provider communication) and that caregivers were satisfied and comfortable with the technologies.[32] In particular, technology-based caregiver interventions can improve decision confidence, reduce emotional strain, improve spousal relationship conflict, decrease activity restriction, increase self-efficacy, and decrease burden.[29,33,34]

The most promising interventions for caregivers are based on computer networks, interactive telephonic and video platforms, and the Internet to provide direct caregiver support and are culturally tailored to the specific population for which they are intended.[35,36] The earliest computer-based intervention used computer networks to provide information, communication, and decision-support.[37,38] Researchers have also used a computer-mediated interactive voice response system integrated with a voicemail system for monitoring and counseling; in-home support groups; expert support; and activity/caregiver respite

conversations.[39] The Internet has also been used to make available disease-specific information, private email, question-and-answer forums, video-conferencing support interventions, and telephone access to information about caregiving issues.[40,41] Internet-based health information management systems (HIMS) can assist caregivers to manage their health-care services encounters and execute healthy behaviors for themselves and a family member with ADRD. However, there is no Internet-based support system that is widely available to support the increasing number of Hispanic caregivers, whether they are predominantly English or Spanish speaking.

In terms of informing user-centered design of technology-based information and communication interventions, Steiner et al. and Wackerbarth and Johnson among others have specifically looked at information needs of family caregivers of individuals with ADRD.[42,43] However, little is known about the information and communication needs of Hispanic family caregivers for individuals with ADRD or the manner in which online tools may meet those needs.[44]

Tools that support the information and communication needs of Hispanic caregivers may be especially needed for caregivers of individuals with ADRD living in the community (i.e., non-institutional care) because of the high demands of caring for a person with this disease. [45] Technology-enabled interventions offer the potential to make care more user-centered by increasing engagement and supporting self-management of care.[46,47] However, this is dependent upon designing tools that are easy to use and can meet the needs of the user. Participatory design methods enable the design of appropriate tools to meet ADRD caregiver's needs.[48]

We applied participatory design methods to develop a Family Health Information Management System (FHIMS) aimed at supporting the self-management of the ADRD caregivers and for their care recipient as part of the New York City Hispanic Dementia Caregiver Research Program (NHiRP), funded by the U.S. National Institutes of Health (R01NR014430). As part of a set of participatory design activities to inform the design of the FHIMS for Hispanic ADRD caregivers, the objective of this study was to identify (1) caregiver attributes that may influence the use of FHIMS, (2) caregiver information and communication needs and tasks, and (3) caregiver perceptions of online tools to meet those needs.

Methods

Setting and participants

We conducted the study at the Columbia Community Partnership for Health center and the School of Nursing at Columbia University Medical Center (CUMC), both located in Washington Heights, New York City, after approval by the CUMC institutional review board. We used purposive sampling to identify potential participants from those already enrolled in the NHiRP caregiver registry who agreed to participate in future studies and were computer/Internet users. Participants were required to meet the following criteria to enroll in NHiRP: adults (between the ages of 18 and 90), self-identifying as Hispanic, and as a caregiver of a family member or significant other diagnosed with ADRD who reported at

least one memory/cognition and one daily functioning symptom. To facilitate future contact, the caregiver had to live in New York City for 12 months following enrollment and have one relative or close friend also living in the New York City Metropolitan Area (New York, New Jersey, Connecticut). Additionally, they had to be physically able to provide care and could not have a diagnosis of depression with psychotic features, suicidal ideation or attempt in the past 5 years. Zip codes were used to obtain a list of potential participant closest to the research location to reduce participant burden.

The study coordinator received a list of 76 potentially eligible participants and their contact information. The coordinator called potential participants (up to three attempts) and explained the study in detail. Of those contacted, 20 could not be reached, 26 declined to participate, 30 were scheduled for participatory design sessions, and 24 participated (10 English- and 14 Spanish-speakers) in design sessions. Participants received $35 in compensation for time and transportation.

Data collection

We based our data collection methods on a user-centered distributed information design framework, which recommends multiple levels of analysis, including user, functional, task, and representational analysis.[49] The findings of this study are part of the user analysis. Although the analysis in this study is only based on one component of the data collected (i.e., the audio recordings), we describe the full data collection process to provide the context for the analysis. Participatory design sessions, using an innovative approach reported elsewhere,[48] were conducted with English- and Spanish-speaking caregivers. In brief, this method is an iterative process where study participants are the experts and teachers whereas the investigators become the learners. We conducted 11 design sessions, 5 in English and 6 in Spanish. At the start of each design session, caregivers completed a questionnaire about their personal characteristics and computer/Internet use. Between one and four caregivers participated in each of the 90-min design sessions. Three members of the research team participated in each design session.

After a thorough explanation of study procedures, individuals agreed to participate in the study by signing a consent form. A bilingual member of the research team described the overall study goals and activities of the session and informed caregivers that the focus of the design session was on them, as users of the Internet, and how they manage their own health and healthcare while managing the health and healthcare of their family member with ADRD.

In order to contextualize the purpose of the design sessions, we presented an example of an Internet-based HIMS to participants at the beginning of each session. Afterwards, we asked participants to complete a series of questions related to their Internet use, on-line health information seeking, and interest in using an Internet-based HIMS. Then, we engaged participants in two design activities. The goal of the activities was to elicit information from caregivers about their personal health and health-care experiences as well as those of their family member with ADRD.

First, participants constructed a collage to represent how they might manage their health and health-care experiences and those of their family member with ADRD using a FHIMS. We provided 51 phrases (in English or Spanish) and 81 images representing the experience of caregiving based on previous focus group discussions with caregivers, as well as, possible functionalities that the online system might contain.[50] Participants had 20 min to complete their collage.

For the second activity, we asked participants to describe their collages and why they felt the images, words, and phrases that they selected were important. Participants were encouraged to share stories that they had represented in the collage. During this reflection period, we probed about the selection and meaning of images/words; the location, proximity, and relationship of words/images; the relative importance of images/words; and, the order and/or logic of the collage. Each participant had 10 min for this activity.

The members of the research team debriefed immediately after each design session to note participants' unique and shared experiences. Design sessions were audio and video recorded. The audio recordings were professionally transcribed and then verified by a bilingual research team member (MG). These transcripts provided the data used in this study.

Data analysis

We first analyzed the questionnaire data using descriptive statistics. We performed a directed content analysis on the transcripts in the language of the design session by applying a structured coding framework, which was developed by integrating concepts from Coiera's Model of Communication Task-Information Task Continuum[51] and a health-care adaptation[52,53] of Krikelas' Typology of Supplemental Information Seeking Behavior[54] as well as adding concepts related to caregiver attributes. Key concepts integrated from the Coiera framework included information needs/tasks, communication needs/tasks, online tools to meet information, and communication needs/tasks. Other concepts to define information need and tasks came from the health-care adaptation of the Krikelas' model[54] were domain information, logistical information, and patient-specific clinical information. Communication needs/tasks were categorized by the communication partners (e.g., caregiver to patient, caregiver to health-care professional). Information and communication needs/tasks were further categorized as being for care recipient or for caregiver (i.e., self). Caregiver attributes included awareness of disease symptoms, or behaviors; management ability or deficit; and Internet or technology use ability or deficit. We tested and refined the coding framework before analyzing the transcripts. The complete coding scheme is available upon request for the authors.

Transcripts were independently coded using NVivo 10 and 11 software. Three members of the research team coded English transcripts (SB, SS, SI) and four bilingual team members coded Spanish transcripts (NS, MG, SS, SI). We met at various points throughout the coding process to ensure that we were interpreting and applying the framework in the same way, and to resolve discrepancies between coders by discussing until consensus was achieved. We translated exemplar Spanish quotes to English after coding for final presentation.

Results

Participant characteristics

The average age of participants was 59.7 years (SD = ±7.67) and most were female (n = 19, 79.2%) (Table 1). Participants reported caring for their mother (n = 14), significant other (n = 6), mother and father (n = 3), mother and significant other (n = 1), mother and grandmother (n = 1), and aunt (n = 1). All caregivers were Hispanic and two-thirds indicated that Spanish was the primary language spoken in their homes. Of participants, 25% were married while more than half (n = 13, 54%) were divorced. All but one participant had completed all or some high school and 41.7% indicated they had a degree beyond high school. Participants had been caring for their family member for a mean of 6.5 years (SD = ±4.7). The majority (n = 17, 70.8%) reported accessing the Internet at home while the rest accessed it either at work (n = 4, 16.7%) or in another location.

All participants accessed the Internet at least once a week with 75% accessing it at least daily. Most (70.8%) reported that they and/or someone in their family use the Internet to look up health or medical information. Fewer indicated that they had either participated in an online support group (n = 5, 20.8%) or had used email or the Internet to communicate with their doctor or doctor's office (n = 4, 16.7%). A quarter reported that they had used a website where they could get, keep, or update their health information.

Content analysis

Main coding categories were caregiver attributes, communication needs or tasks, information needs or tasks, and online tools. Figure 1 indicates the higher level codes reported by participants and the transcripts in which each of those higher codes appears. All participants reported abilities and deficits related to awareness of the disease symptoms or behaviors, their management, and Internet or technology use i.e., caregiver attributes. The majority of participants reported communication needs or tasks and information needs or tasks (87.5% and 91.7%, respectively) while fewer reported specific online tools needs (79.2%).

Caregiver attributes: abilities and deficits related to awareness of disease symptoms or behaviors and their management

Table 2 displays quotes about caregiver awareness of disease symptoms or behaviors and accompanying management ability or deficit. Participants recognized sleeplessness, confusion, and cognitive changes as disease symptoms or behaviors. Not knowing how to effectively care for their family member with ADRD and needing reassurance about what to do was a common theme. For example, many caregivers described having several medications to manage and being uncertain about how to respond to dementia symptoms or behavior changes such as, when to "give more medication" versus when to "leave alone."

Caregivers also described how the disease symptoms and behaviors of their care recipient influenced their ability to take care of their own health. Caregivers described seeking professional help, trying to fit in exercise, keeping a schedule to manage their care recipient and their own health-care needs as ways to respond to stress due to the ADRD-related

behaviors. A recognized self-management deficit was not being able to focus on their own needs. Participants indicated an understanding of healthy behaviors such as the need for exercise, healthy eating, to address mental health issues/concerns and manage their appointments as well as those of their care recipient. They reported facing numerous barriers that prevent them from completing these tasks, such as limited time to focus on themselves, need to continuously monitor care recipient or financial challenges due to illness burden.

Caregiver attributes: abilities or deficits related to internet or technology use

Table 3 presents caregivers' descriptions of their Internet or technology use ability or deficits. Examples provided by at least one caregiver included the ability to access e-mail for communication with providers or other health-care professionals, receive appointment reminders either through e-mail or text, locate patient records online using an iPhone, access virtual support groups, locate medical information online, as well as verify appointments online. Spanish-speaking participants predominantly reported Internet or technology deficits. For example, one participant compared his relationship to computers as "the computer and the prehistoric man." Others indicated feeling distant from the Internet and computers and identified wanting to learn more about computers, i.e., how to access the Internet or e-mails. One participant also indicated that a HIMS could help him to learn more about the computer.

Information needs and tasks

Caregivers identified domain, logistical, and patient-specific information needs and tasks for both the care recipient and for themselves (Table 4). In terms of the domain category for the care recipient, this included information about dementia; for example, "when my dad was diagnosed, I was so confused." Another participant indicated needing more information about her mother's medications, "it was a question of if I was not going to make a mistake and give her one medicine instead of the other." Health insurance was a key area of logistical information needs with one caregiver saying, "….there are so many insurances, so many plans, and so much stuff out there." Many participants reported that they had had problems either finding or managing the health insurance for their family member with dementia. In regards to the care recipient's clinical data, identified information needs and tasks included those related to health status, medication, interactions with food or other medication, side effects of medication, and laboratory results and their interpretation. One participant requested a collection of information organized visually stating that "a graph of collected health data to show you tendency is very important."

The domain information needs and tasks that caregivers identified for themselves were related to self-management, for example how to exercise, eat healthier foods, and learn more about their medications. Information related to health insurance was an example of a logistical information need. As one Spanish-speaking participant said, "I need help because insurances of Medicare are very complicated and many times I know that I read one thing and afterwards, I read another and I still don't understand and it is important." Examples of patient-specific clinical information needed by caregivers included better understanding of blood sugar and interactions among their medications.

Communication needs and tasks

The critical need for an overall communication plan was identified by a Spanish-speaking participant who stated, "it is very important to have a, a plan with everyone that is around the patient; the family, the doctor, the social worker, the caregivers and the family members themselves." Participants also identified communication needs related to particular groups (Table 5). Communication needs and tasks with other caregivers included teaching family members what to do for the care recipient, sharing experiences, and learning from other caregivers as well as from a community. Participants reported a need for learning how to better communicate with the care recipient including how to recognize their care recipients' mood and how to respond to awkward comments that they may make. Caregivers also need to be able to communicate with health-care team members to figure out what actions to take in certain situations and to understand the care recipient's health status. Caregivers reported many communication needs and challenges with support staff, such as home health aides. There were a number of communication needs between caregivers and other family members, such as how to ask for assistance, to discuss caring for other family members aside from the care recipient with dementia, and to share information regarding the progress of the care recipient both within the United States and to relatives living abroad. Having a mobile phone was an important tool for this communication. Communication needs and tasks not classified in the above categories included communication in a broader context of society through the Internet to understand Alzheimer's disease and the ability to communicate directly with support staff at the Alzheimer's Association. Communicating with a priest during particularly difficult times helped one participant to feel calmer, more reassured, and recognize that the caregiving work was supported by her faith and physical presence in the church was not required to worship. Communicating with a larger community, such as through Facebook, and seeking help from others to stay strong despite new language, country, and limited time was also a mentioned need.

Online tools

Table 6 provides exemplars of quotes for online information and communication tools. Online tools may be useful to coordinate with family members, schedule and keep track of appointments and medications, hold conference calls, and participate in support groups. For self, caregivers needed communication tools to quickly find important phone numbers, e-mail follow-ups, schedule their own health-care appointments along with those of the care recipient, and tools to minimize time searching for needed information. Online communication tools that could be used to ask questions or locate self-help information, access how-to videos (e.g., how to safely move a patient), link with other caregivers, identify drug–food and drug–drug interactions, online medical records, and information about disease were also identified as tools that would be useful. Being able to identify and decide between insurance plans was a common issue mentioned by participants. Online tools that would be useful for the patient with dementia included seeing medical records online, calendar reminders for appointments and medications, personalized resources for Medicare, missing person alerts, and ability to access immunization records.

Discussion

The purpose of this study was to identify Hispanic caregivers' information and communication needs and perceptions of how online tools could meet those needs. This is a critically important area for application development because ADRD is a major global public health problem with consequences to both the care recipient and the caregiver.[26,55] Assessing caregivers' needs and preferences are recognized as important first steps to establish an effective intervention.[5] A recent report, *Families Caring for an Aging America*, examined the needs of family caregivers of older adults and recommended policies to address their needs.[5] A leading recommendation was to change the focus from patient-centered care to person- and family-centered care thereby emphasizing the importance of the caregiver's role in the health of the care recipient and for the optimization of the caregivers' health to maintain that role. Successful interventions identified in this report included education and skills training, counseling, self-care promotion, relaxation training, respite programs, care management, and personal counseling. The need for such interventions was reflected in the information and communication needs identified in our study and some are amenable to online tools such as those identified in the 2015 systematic review of technology-enabled caregiver interventions.[32]

Awareness of behaviors and symptoms and associated self-management abilities/deficits

Participants in this study were aware that behaviors and symptoms of ADRD included sleeplessness, confusion, and cognitive changes; however, they reported not necessarily knowing how to appropriately handle these situations. Similarly, in a study by Wackerbarth et al., caregivers identified dealing with behavior changes, such as forgetfulness/confusion, repeating questions/actions, losing, hiding, or taking things, and a loss of sense of time.[43] Having the information but not knowing how to process or use it was another concern of our participants. Similar to findings in our study, family caregivers of older adults have commonly reported learning by trial and error and fear of making mistakes.[5] Disease symptoms and behaviors of the care recipient also led to challenges to caregivers' self-care management abilities due to stress despite knowing what they needed to do to improve their own health. Wackerbarth et al. found caregivers prioritized the support needed for the care recipient, such as emotional support and understanding their feelings over finding support for themselves.[43] Barriers to caregiver self-care management, such as lack of time to complete necessary tasks, limited financial resources, anxiety, and depressive symptoms among others, have also been reported.[9,56,57]

Technology use and perceived abilities/deficits

Most participants in our study reported accessing the Internet several times per day and using it to look up health or medical-related information. However, few participants (16.7%) reported having used e-mail to communicate with their doctor or had used websites to get, keep, or update health information in the past year (25%). Participants who chose to participate in Spanish-speaking design sessions indicated that they have more problems with using technology than their English-speaking counterparts (Table 3). That most of our participants are able to and actively use technology for health management is consistent with findings from other national reports.[58,59] In a 2013 Pew Research Center report, being a

caregiver seemed to change how people pursued health information both on- and offline.[58] Caregivers were heavier technology users compared to other adults in all categories of health activities, such as gathering health information online, consulting online reviews of drugs and for diagnosis, and getting information, care, or support from others. A 2016 AARP representative study of 1028 U.S. caregivers found that they tended to be technologically literate, comfortable with using a variety of devices, and were already using technology to support their caregiving.[59] In addition, online health-related activities were high; however, less than 60% of caregivers with Internet access indicated that online resources were helpful to their ability to provide care and support for the person in their care. In our study, few reported participating in an online support group for people with similar health issue or having used websites where they could store, organize, or update their health information. Lastly, although the desire to communicate with doctors/professionals/pharmacies via e-mail was a reoccurring theme in the transcripts, very few ($n = 4$) had ever actually done so.

Information needs and tasks

Too much information may be overwhelming to caregivers. Therefore, it is important to identify specific information needs. Participants in this study reported key information needs regarding an ADRD diagnosis, its treatment, management of behavior changes, and disease progression, as well as logistics surrounding access to care and insurance coverage for care recipients and for themselves. They indicated being highly concerned and unsure of health-care coverage to meet the needs of their family member with ADRD, such as finding and managing health insurance coverage and comprehension of complex forms and materials. Although complex health insurances were significant issues for participants in this study, this was the least endorsed issue for caregivers in the 2016 AARP report.[59] Consistent with our findings, Wackerbarth et al. identified essential information needs of family caregivers as information pertaining to diagnosis and treatment, legal and financial issues, and dealing with behavior changes.[43] These topics were rated as more important than receiving general information. Specifically, information detailing health plan coverage and how to find the best care plan were rated the highest for importance. Although Wackerbarth and Johnson assessed findings based on population characteristics (e.g., male vs. female, rural vs. urban), caregivers in that study were primarily White females and the authors did not evaluate needs based on language preference or Latino/Hispanic ethnicity.[43] Steiner et al. asked caregivers to select their top 10 information needs from a predetermined list of 48 items[42] and found that caregivers needed more information on managing their own stress. Our study participants identified numerous information needs and tasks for the caregiver whereas the Steiner et al. found that caregivers consistently identified needs for the patient they cared for. Like Steiner et al., we found that our participants need more information on how to manage and care appropriately for the individual with ADRD.[42]

Communication needs and tasks

Participants in this study expressed difficulty communicating with family members, health-care providers, and in-home attendants. These communication difficulties are not unique to our participants. Communication with family members was also reported as a top need by caregivers in the aforementioned AARP report.[59] Our cohort described a particular need to communicate with family members abroad, such as with those living in the Dominican

Republic. Also congruent with other studies,[60,61] communication with the person with ADRD was reported to be difficult, especially as the illness progressed. Of the communication tasks that participants identified as being the most important, being able to ask questions at all times, day or night, of a health-care provider would bring caregivers more certainty that they are appropriately caring for their care recipient. That our participants expressed numerous unmet communication needs and tasks is similar to other studies that have found that caregivers of those with ADRD struggle to communicate with other family members, health-care professionals, and/or the person who they are caring for. [61,62] Additionally, unmet communication needs have been identified among caregivers of adults with other chronic conditions.[63] One additional challenge faced by the Hispanic caregiving population may be language barriers as many of our participants were predominantly Spanish-speaking. This may make it more difficult to reach out to health-care providers or other caregivers to seek information or support. Additionally, the health literacy level of information given to caregivers may be too high to effectively meet their needs, especially if they are older adults,[64] thus limiting the effectiveness of the communication. These considerations should be taken into account when designing online communication tools for caregivers so that future systems can effectively meet the extensive communication needs of users.

Online tools

During the design sessions, participants mentioned tools that could facilitate caregiving. The tool most commonly identified as needed by caregivers is one that enables and enhances communication with health-care providers at any time they needed to seek out reassurance about their decision-making related to ongoing ADRD care. Similarly, the AARP reports that "peace of mind is what caregivers want most".[59] Further, online communication tools could enable more effective interactions between caregivers and their friends and/or family members regardless of geographic distance. Caregivers also reported a need for a tool to facilitate connections with other family caregivers. In addition, caregivers suggested that how-to-videos made available online could provide valuable knowledge and support for learning new caregiving tasks.

There are additional tools that could be made available to caregivers based on the caregiving needs and tasks identified in this study. For example, caregivers commonly mentioned concerns with accessing high-quality information and sorting through large amounts of information. A curated library of evidence-based caregiving knowledge and practices could be compiled to effectively address caregivers' information needs. Caregivers also indicated that online tools that could be included in an online health management system might incorporate ways to manage clinical data such as having access to their complete medical records online. Specific clinical information that would be the most useful to access would be medication records including date of refills, etc. and having access to immunization records. Additionally, a tool that compiled lists of information such as of available types of insurance as well as the benefits or drawbacks of different insurance companies or plans would facilitate caregiver's ability to decide which one to choose. In addition, a number of people mentioned being concerned about medication interactions, suggesting that a tool that allows them to enter or self-report their medications to check for potential interactions

would be useful. This is similar to the findings from the 2016 AARP report on caregivers' technology needs as they identified that caregivers would like tools that help with medication refills, delivery, and adherence.[59] Also, many participants indicated that they have a calendar system to help them manage both their appointments and the appointments of their family member with ADRD. An online calendar tool that caregivers could interact with could provide a more efficient way to manage two sets of appointments, appointment alerts, and medication reminders.

Significance and strengths

This study is significant primarily because of its focus on Hispanic caregivers of individuals with ADRD. The study addressed the limited research assessing the nuanced needs of this particularly vulnerable group of caregivers and fills existing gaps in the literature. For instance, the 2016 AARP study[59] included a large cohort of U.S. caregivers; however, the authors acknowledged having a lower than expected response rate from Hispanic caregivers.

The findings from our research are also significant given the changing landscape of access to information and communication resources in the United States. The Internet access gap is quickly becoming non-existent between white and ethnic minority populations. While some differences in access persist, these become significantly less marked when demographic factors (including language proficiency) are taken into account.[65] In 2016, 88% of White non-Hispanic, 85% of Black non-Hispanic, and 88% of Hispanic (English- and Spanish-speaking) adults over the age of 18 reported using the Internet.[66] Currently, Internet adoption is being driven by factors such as age, income, education, and geographic residence.[66] Similarly, more than 8 in 10 caregivers (86%) have access to the Internet[67] and of those, 88% look online for health information, including looking up medical treatments, hospital ratings, and end-of-life decisions. Vulnerable populations such as the elderly, frequent users of health care services, and family caregivers may be principal beneficiaries of health information systems.[68]

The strengths of this study include the implementation of a user-centered study design to collect data and rigorous methods to analyze participants' information. Participatory design sessions with English- and Spanish-speaking caregivers and a bilingual team for data collection is an innovative approach that accounts for potential ethnic and cultural differences with standardized guide for participatory sessions, member checking during sessions, and peer debriefing after sessions. Additionally, we implemented a theory-based coding framework, used multiple coders for each transcript, and coded and analyzed the transcripts in language of the session.

Limitations

The main limitation of this study is the self-selection (volunteer) bias of participants, who were individuals who had agreed to participate in further research as part of their enrollment in NHiRP. As such, they may either have heightened needs, have more time available to participate in research, be better educated or more healthy, and be more able and willing to discuss caregiving that those who don't frequently participate in research. Further limitations of the study are a limited sample size, relatively high participant education level, and that the

study was conducted in one location. The 24 participants had a relatively high level of education; almost all had at least a high school education. In addition, 75% reported using the Internet on a daily basis. However, this education level and frequency of Internet use of caregivers was consistent with other national studies.[58,59] As such, information or communication needs and tasks may have been missed for those who were with less education or had limited ability to access online resources (not computer/Internet users). Furthermore, the majority of participants lived in Northern Manhattan, an urban enclave in New York City. As a result, the information and communication needs of Hispanic caregivers living in nonurban areas were not captured in this study.

Conclusions

ADRD is a major issue globally as evidenced by the growing number of diagnosed individuals needing continuous and advanced supportive care. Hispanics are a population with growing rates of ADRD and related caregiving burden, yet researchers do not have an in-depth understanding of their information and communication needs. Family caregivers provide the majority of care for people with ADRD; therefore, understanding their information and communication needs and considering how to provide convenient online tools to meet those needs are essential. In our study, key information and communication needs of Hispanic caregivers were identified and can be used to inform the development of appropriate tools to meet those needs. Caregiver burden is extensive and some aspects may be alleviated with tools that meet their specific information and communication needs. Data support the need for a FHIMS. Our findings may be useful to others designing systems to support ADRD caregivers.

Summary table

What is already known about the topic?

● Hispanics are a rapidly growing population who are disproportionately living with Alzheimer's Disease and Related Dementias (ADRD), and related caregiving burdens, compared to Non-Hispanic Whites

● Caregivers of individuals living with ADRD have disproportionately bad health outcomes and it is recognized that the health of caregivers suffers as a result of their caregiving activities

● Little is known about Hispanic caregiver information and communication needs

What this study added to our knowledge?

● Key information and communication needs of Hispanic caregivers of individuals with ADRD

● Internet and technology use deficits were identified from only Spanish-speaking participants and not Hispanics who chose to participate in the English sessions

● Important considerations for designing online interventions for Hispanic caregivers

Acknowledgments

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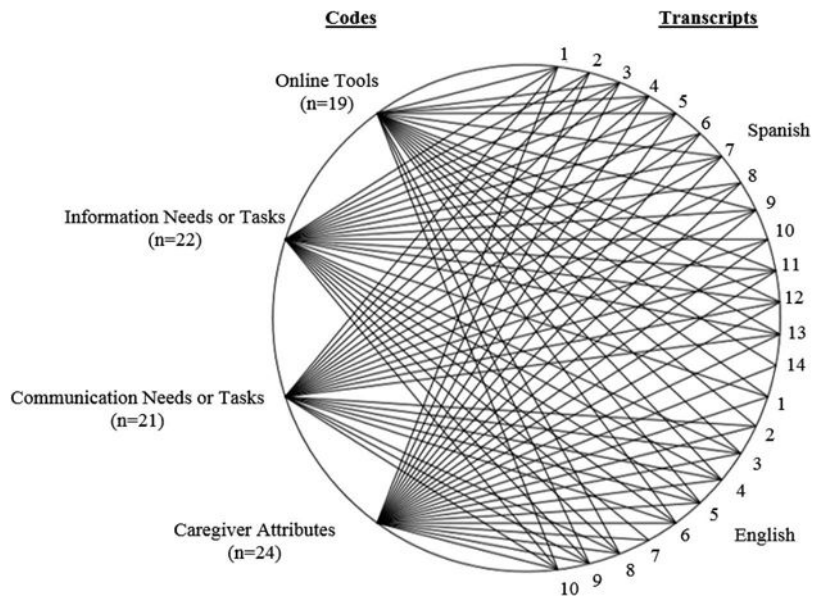
Figure 1.
Higher level codes and the transcripts ($n = 24$) in which they appear.

Table 1

Demographic and computer/internet use characteristics of participants ($N = 24$). [*]

Characteristic	
M (SD)	
Age (years)	59.7 (7.7)
Length of time caring for family member (years)	6.5 (4.7)
Time spent caregiving each week (h)	68.7 (56.6)
N (%)	
Gender	
Female	19 (79.2)
Male	5 (20.8)
Marital status	
Married	6 (25.0)
Widowed	1 (4.2)
Divorced	13 (54.2)
Separated	2 (8.3)
Never married	2 (8.3)
Race	
White	5 (20.8)
Black or African American	1 (4.2)
Mixed race	3 (12.5)
Other	10 (41.7)
Ethnicity	
Hispanic	24 (100.0)
Languages spoken	
Spanish only	11 (45.8)
English and Spanish	13 (54.2)
Primary language spoken at home	
Spanish	16 (66.7)
English	7 (29.2)
Highest level of education completed	
Eighth grade or less	1 (4.2)
All of some of high school	12 (50.0)
Degree beyond high school	10 (41.7)
Caregiver for	
Parent	16 (66.7)
Spouse	6 (25.0)
Other relative	2 (8.3)
Locations where use computer to access the Internet	
Home	17 (70.8)
Work	4 (16.7)
Friend or relative's home	1 (4.2)

Characteristic	
Other location	2 (8.33)
How often accesses the Internet	
Several times a day	13 (54.2)
Once a day	5 (20.8)
Several times a week	4 (16.7)
Once a week	2 (8.3)
How often accesses Internet outside of work on a typical day	
1 h	11 (45.8)
2–4 h	7 (29.2)
5 h	5 (20.8)
Does anyone in your family use the internet to look up health or medical information?	
Yes	17 (70.8)
No	5 (20.8)
Participated in an online support group for people with similar health issues (past 12 months)?	
Yes	5 (20.8)
No	17 (70.8)
Used e-mail or the Internet to communicate with your doctor or doctor's office (past 12 months)?	
Yes	4 (16.7)
No	18 (75.0)
Used the Internet to look up health or medical information (past 12 months)?	
Yes	17 (70.8)
No	5 (20.8)
Have you ever used websites where you can get, keep, or update your health information (past 12 months)?	
Yes	6 (25.0)
No	17 (70.8)

[*]
Sample sizes vary based on missing data.

Table 2

Caregiver attributes: awareness of disease symptoms or behaviors and management ability or deficit.

Awareness of disease symptoms or behaviors	Management ability or deficit
For care recipient	
For instance, she doesn't sleep for 24 h. She's laying in bed and she's talking, talking, talking	Am I supposed to give her more medication? Should I just leave her alone? What can I do? She seems to be agitated. Should I take her blood pressure?
I was more concerned about my mother's psychological health … I understood that they travel, so I'll always watch that	Whenever she wanted to go someplace, I took her. That's what I did … I would take her so she wouldn't disappear on me because she did one time
She goes into these little episodes where I don't know what to do.	I need to call somebody to reassure me that I'm doing the right thing. I'm giving her the right medications … I'm trying to call the doctor to ask him a thousand questions, but he's not available
For caregiver	
I sometimes feel stressed out, but I do have help at home	I do see a psychiatrist every Wednesday
The problem that I had in my house that was so huge because my mother had dementia, she loved screaming and yelling and this exasperates a person*	Therefore, I tried to do exercise early in the morning I go to the gym to get the strength to be able to fight*
…it also happens to me, it is that I forget the medicines, I give it to my mom and I forget to take mine [medicine]. You see? And it stresses me*	I have to have [it] written, all of the time written, or a calendar or the phone to remind me and also the time.…*
I also need to take care of my own appointments and my immunizations and all that. I have taken care of hers, but I know that I haven't done anything with mine	I need to focus more on what it is that I need to do on a timely basis

*
Translated from Spanish.

Table 3

Caregiver attributes: Internet or technology use and self-described ability or deficit.

Ability

It helps if I can obtain his records on the Internet. I can use my phone. I have an iPhone

Again, iPhones. You can access your e-mail for any information as far as medication

That works for me. Appointment reminder sent by e-mail or text message

But after everybody goes to sleep at night, I can go online and I can do whatever I have to do

Basically if I can get something that I can go online and maybe do a virtual support group, guess what? I'd rather do that

I'm very lucky to say that my mom's doctor is amazing. She does give me her e-mail, and I update her on what's going on

I would like those things [website functions], I would like to have a page [website] to find a doctor, see results, and program appointments [*]

Deficit

The computer and the prehistoric man, sometimes I feel like that [*]

I want to integrate a little more with the Internet, the computer, therefore in this case, I want to work with the computer instead of books or brochures [*]

With respect to technology … yes I would love it, I would love if there were a system [HIMS] would love this, learn more about the computer [*]

[*] Translated from Spanish.

Table 4

Caregiver information needs or tasks.

For care recipient

Domain information

It's nice to always be in a group. My sister and I went to one of the Alzheimer's classes, and we learned a lot. We even learned what type of dementia my dad has, so that helps…. Because when my dad was diagnosed, I was so confused

I had to have, you know, the time for medicines because my mom was taking a lot of medicine. It was a question of if I was not going to make a mistake and give her one medicine instead of the other [*]

I would also like an educational talk about medications and things because my mom could die because of a medication too [*]

Logistical information

It's good for people to know that there's geriatric hospitals that are family-orientated that really care

Insurance information. There's so many insurances, so many plans, and so much stuff out there. I think that's also an area that if you could be able to go to one place and look at all that, I think that's good. Instead of taking, well, no, I don't like this one, this didn't work, or whatever. Cuz I went through that too also at the beginning with all these HMO plans

I had to be vigilant of health insurance, always this, you know that medical insurances cause a lot of problems. Therefore, when I came to see if the insurance was dropped and if it hadn't, I had to struggle with that [*]

Patient-specific clinical information

I need to know certain things about what is the progress? What is going on with her?

I have binders and binders of stuff. I have one binder that's just hers that has her appointments, her—every major condition she has, the doctors that treat it, copies of a test that I asked the doctors for when we go

A graph of collected health data to show you tendency is very important. When one has a statistic and can see, "look, your A1C has gone up or down" this is very interesting, to have the knowledge, as much of your [own health] as well as for your family member [*]

For caregiver

Domain information

This would be more like a caregiver for taking care of themselves. The instructions, if you could tap on this for lifting up someone's in need of care so you that you don't hurt yourself. Obviously, taking care of yourself with exercise, diet, food. All the information labels to help you manage your medication over here

Caregiving is more than just caring for the person because you have to care for yourself. In order for you to do that, you need support and get answers to questions

I don't know how to involve him because I tell him lets dance, please me with a dance, no, no [he says] and I don't know how to get him involved to do a little exercise, so that he doesn't have another problem [*]

Logistical information

I'm constantly traveling. Never enough time. There's not enough time in the day. There's not. I need lots of help. Basically if a lot of things were more accessible online for me, cuz I'm computer savvy and I find it very helpful that the more we get, the better it is for us caregivers I mean for me personally, cuz I don't have time

I say I need help because insurances of Medicare are very complicated and many times I know that I read one thing and afterwards, I read another and I still don't understand and it is important [*]

Patient-specific clinical information

I've been having a problem with my blood sugars going insanely high which they never, ever had done, and so I'm working with my endocrinologist to work that

For example, I know how to look for mine because in the hospital, they taught me how to look for it. I know how to look for my history, my medical record. When I have my appointment, whatever happened to me, what were the results of this one, what were the results of the other one [lab test or exam]. All of this, I already know how to look for it [*]

This warning about medication interactions; … I take a lot of medication for myself [*]

[*] Translated from Spanish.

Table 5

Caregiver communication needs and tasks.

For care recipient

Caregiver to other caregivers

I have to teach my brother, since he's there a lot and my sister, and I'm like in both places, just to make sure they don't give him greasy food, although, my dad is picky

It's kinda like when we went to the first meeting that I went through the Alzheimer's Association. I met other people. We were able to interact and talk about our personal situations. It was nice to hear other people and their experience of what they were going on because it's tough

If they could send, send the update of the status of the patient to the family and the providers of medical services and maintain a constant communication with the medical team [*]

Caregiver to care recipient

[Communicating with patient is] a form of the heart to express love between, between … the patient and the caregiver there should exist an elevated level of love, if there is not love, there is not, is not efficiency [*]

When I see him very aggressive, I don't call him, I leave him in peace

…I think that he also stresses because sometimes he says to me "I am crazy," I tell him you are not crazy….

Caregiver to healthcare professionals

So I call—there's a hotline for a nurse that you can call a nurse and ask them several questions, but they don't seem to be helpful because nobody seems to want to make a judgment call when it comes to medication for a patient when the neurologist is not available because someone would tell you, "Stop the medication."

It was like pulling teeth trying to get information about my mother. I don't find that they were helping me in that sense. That was my most recent experience. Maybe it's just that one. You know what I mean? Other than that, the hospital's very helpful when I get it

I communicated with the pharmacy, I communicated with the doctor, I communicated with all of the means to be able to carry out the care of my mother [*]

I would like to have more communication with, with the doctor, more directly [*]

It didn't occur to me to call the doctor nor his clinic, nothing, because I know how they work and what did I do? I called the Association of Alzheimer's that Sunday, they were the ones who oriented me, guided me [*]

I had a lot for my mom and dad, the computer maintains my, my communication with the nurse of my mother, and her doctor because they do house visits, they informed me about everything, they text me and this way we maintain better communication

Caregiver to support staff

She's taken care of [by home aid] and I have reliable people now. I know I won't have a conflict with that because for years I had a conflict with the home attendants

I went through a huge crisis because a person [home aid] who was in my house that served my mother and they began to replace her and change her and find people and it lasted, they sent like 6 or 7 different people and the person never arrived on time, therefore it created a problem for me because it created a trust issue, I did not know who was who was going [*]

You have to be vigilant about what she eats, what she [home attendant] is giving her and fight with home attendant also, about what she is giving her [patient], how is the environment, is it clean? that she is clean [*]

…then I call her [home attendant]—is everything OK? [*]

Caregiver to family

Well, I have a 4-year-old grandson that I'm raising, and I have my 17-year-old son who doesn't really understand. Like my mom used to be so— like took care of his clothes and she still like ask him again, "Are you going to school today? Are you going to school today? Are you going to school today?" He's like, "Ah, she's going to drive me crazy." You know?

I had to call my daughter and my granddaughter who is 17, I have had to call them to help me with my mother because my mother had to stand up, [we] had to help her do everything [*]

I had to be aware of everything, therefore I got my family involved so that they could help [patient] because it was a lot for me [*]

I have always had my cell phone and it has been my battle, call the boys, call my husband, that they run downstairs, that my dad fell, or come downstairs my dad is not doing well or mom's blood sugar has dropped [*]

For caregiver

Caregiver to other caregivers

When you have the opportunity to share with a group or with people that have similar situations to yours, it is a "feedback," that is, you feed off of them and often they feed off of you and there are situations that they know how to confront better than you [*]

Caregiver to other family

I text my daughter a lot, my cousin, my daughter who lives in Texas and I call. Text, you know is the most modern there is [*]

It scares me at times to arrive at the situation of my mother, to share the information, I always share information with my family and friend, the good and the bad experience, whatever. I like to communicate with people, I feel like the core of the family [*]

I always talked and no one responded from my cousins and therefore…the whole world is busy and everything; therefore I organized three reunions, he saw me stressed, and told me, try to see if one of your children from the two of them that are here [can help], call them to see [*]

I feel more depressed because as I said there are more family and they don't, they don't collaborate [*]

Caregiver to healthcare professionals

Yes, I am with [name of social worker], they gave me six sessions, I have, I have one session left and it has helped me a lot [*]

Caregiver to other not classified (e.g., friends, neighbors, online groups)

For care recipient

…sometimes experiences arise and recommendations come from higher beings to resolve the situation and share with friends and neighbors

I ask that they help me stay strong, at times I am so, so desperate I call the priest from my church and I talk to him and I despaired a lot because, as I say, I could not go to the prayer groups and the father/priest told me, no, no, no that is your mass, that is your group and that's it, it doesn't do you any good being here glorifying the Lord and your mother falls down and he gave me many recommendations and this calmed me a little. I told him OK, very well I am calm, this is my ministry

Facebook, or whatever, a community, with different communities and this would help me a lot, more than the same job, incredible. My relationship outside of my work, where I work is good, but outside of it at outside group, including foreign groups [would help] [*]

I have had help from people because you have to stay positive and ask for help and you arrive for example, you arrive in a country, the language, the people, there are many decisions that you have to make sometime with little time [*]

[*]
Translated from Spanish.

Table 6

Online information and communication tools.

Information tools

Domain information

I think where the Internet would come in and would be a good place for me would be, I'm trying to call the doctor to ask him a thousand questions, but he's not available

How-to videos, how to detract the conversation—how to meander the conversation away from where I don't want it to go to where I do want it to go

If there were an Internet page we would look for it, we could look for everything faster on the Internet. If there were a page for caregivers, we would understand more about the patient, it would be easier to look for it there, everything much faster and I believe that we could better understand our sick patient [*]

Internet-wise I learned about grapefruit and some pills are no good so it's good to know what kind of medications you shouldn't have your— you not take or your person you're taking care of

My medical records online, I think that's awesome to be able to have access to your medication, like when was it that I had this?

Physical exercise, I would have liked these things, how to videos, they tell me meditation is good, yoga, relaxation etc. I would have liked to find out more about illnesses and ailments these things. Therefore hygiene, in the end I began to become more conscious of hygiene and I would like more email and these things via internet

In the scene of animations and videos to watch for solutions, to manage a positive registry of health and wellbeing [*]

Logistic information

…Find a physician through the Internet; whatever medical or records you would need; storage. How-to videos; people who you can call in an emergency

Online resources of Medicare… I'll tell you, I look for whatever thing I need, if Medicare doesn't work, I check there [*]

There are a lot of things to investigate on the computer, a lot, whatever you want about health … What I say is that through it [the computer], if you don't know about an insurance plan's coverage, you can inform yourself [online] you can choose doctors and plans online [*]

To send messages to a local pharmacy, interesting, one could send basically the information that one has, the status of the necessary medications and why not have rapid feedback that tells you the day the medication will expire/run out [and asks] "do you want them"? … if you have an insurance that is immediately approved, methodologically, you have to know by which date there is a deadline that you have to have the medications for this person [*]

Insurance information. There's so many insurances, so many plans, and so much stuff out there. I think that's also an area that if you could be able to go to one place and look at all that, I think that's good. Instead of taking, well, no, I don't like this one, this didn't work, or whatever. Cuz I went through that too also at the beginning with all these HMO plans

Patient-specific clinical information

Maybe in a more personalized way when they have the opportunity to see the medical record of each person [*]

Immunization records online. When was it that my mom got her pneumonia shot?

Communication tools

I chose the missing person alert because my dad, when he had to stay with my brother, he walked out. That was the worst time of our lives

I have this appointment for myself on this and this and this day, or I have a class. Can you take her?" I would e-mail my two sisters. Can you e-mail? "Can one of you?" I would try to get immediately that I know about the appointment, I'll e-mail her even if it's a month, two months. I e-mail them, "This is what's going on"

I forget a lot of things, therefore, I am always needing reminders for everything, [for example] reminders to pay my medical bills sent through emails or text message [*]

…medication reminders sent by email and text message too

Maybe a self help on line, on line you can say, Look I have this situation, what can I do? And a professional can help you and say to you, look I am going to call you right now and I am going to say to you and even if they don't respond via internet that you can call them through the internet and they can answer you on the telephone, that you can feel the communication [*]

I use a calendar. My mother has a calendar and I have a calendar. I put the appointments on the calendar

Calls, you know, [online] conference calls if I for example I have tried it with the doctors, with her regular doctor, the cardiologist and psychiatrist, we have through the Internet, I go online telephone and we have, you know…. [*]

Online support groups, communication, very important; very important with that cuz I've tried to communicate, but sometimes

—I don't know what she's hearing, but sometimes she just doesn't get it

I went online and I got an 800 number to the Alzheimer's organization hotline. She walked me through it and it calmed me down

Social workers, I highly recommend them. Even if it is on a screen it could still help. All you need to do is you have to voice what's going on in your life at the time, like you're doing now. I can appreciate that. E-mail, follow-up calls from social workers, yeah. Keep in touch

Schedule all of your appointments. I do it on a calendar. That works for me. Appointment reminder sent by e-mail or text message

Well I was thinking that more of the connection to the computers and to the systems. …Being able to be connected to everything in the world

Basically if I can get something that I can go online and maybe do a virtual support group

A system like the Internet, that reaches the home and can be accessed whenever you want, would help keep us informed and share and exchange knowledge of Alzheimer's [*]

You're a caregiver. You have no time. You have no time to go to support groups. Can you give me a support group online? I would be more than happy in my time, get on there and actually even be a part of a support group or maybe watch other support groups and see what ideas and things that I can get from that

[*] Translated from Spanish.