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## Learning from Recruitment Challenges: Barriers to Diagnosis, Treatment, and Research Participation for Latinos with Symptoms of Alzheimer's Disease

**Caroline Rosenthal Gelman, Ph.D.**

Silver School of Social Work, New York University, 1 Washington Square N New York, NY 10012  
USA

### Abstract

This paper discusses barriers to diagnosis and treatment of Alzheimer's disease (AD) and concomitantly to participation in AD research as elicited from 29 potential Latino participants who ultimately did not enroll in a study evaluating a caregiver intervention. Nearly half of all individuals contacting the researcher about the intervention study failed to meet criteria stipulating an existing AD diagnosis. Barriers to obtaining a diagnosis include lack of knowledge about AD, perceptions of memory loss as normal aging, and structural barriers to accessing care. A quarter of caregivers contacting the researcher felt too overwhelmed to participate.

Many of these barriers have been previously identified as challenges to treatment, suggesting this is not just a methodological research problem but inextricably tied to larger issues of AD knowledge and service accessibility. Engaging Latino communities equitably in the assessment of needs and the process of addressing them, thus ensuring the validity and applicability of the research and findings, is important both for increasing this group's participation in relevant studies and for addressing existing health disparities.

### Introduction

Latinos constitute the fastest growing subpopulation among the aged in the United States. They are predicted to increase from 2 million in 2000 to over 13 million by 2050 (Federal Interagency Forum, 2000, p. 4). Accompanying this tremendous growth will be a dramatic increase in the number of older Latinos suffering from Alzheimer's disease (AD) and related dementias—from under 200,000 to as many as 1.3 million by 2050 (Alzheimer's Association, 2004). According to projections, Hispanics will be disproportionately represented in the older age groups most at risk for AD through the next five decades (Valle & Lee, 2002). Latino elders may be at greater risk for AD than the population as a whole—and at as much as twice the risk as Caucasians—because of the prevalence of several known or suspected risk factors for AD such as low levels of education, and greater prevalence of vascular diseases in this group (Alzheimer's Association, 2004; Tang et al., 1998).

Caring for someone with AD can create a tremendous burden for families (Pinquart & Sörensen, 2003). Latino family caregivers face special challenges, including significant social service needs, and may be particularly affected by caregiving (Gallagher-Thompson, et al., 2000; Janevic & Connell, 2001; Polich & Gallagher-Thompson, 1997). Thus, researching the experiences and service needs of Latinos diagnosed with AD and their family caregivers is becoming increasingly important.

However, the difficulties of recruiting and retaining minority older adults in research, particularly in the area of dementia, are well documented (Arean, Alvidrez, Nery, Estes, & Linkins, 2003; Arean & Gallagher-Thompson, 1996; Levkoff & Sanchez, 2003; Nichols et al., 2004; Olin, Dagerman, Fox, Bowers, & Schneider, 2002; UyBico, Pavel, & Gross, 2007). An inability to recruit minority older adults in AD research studies, and Latinos are no exception, limits our understanding of the impact of this disease on these populations and of how best to treat and support patients and caregivers, and thus must be addressed.

This paper describes the barriers to research participation encountered by 29 individuals who contacted the author about enrollment in a study evaluating a supportive intervention for Latino family caregivers of patients with AD. Nineteen potential participants lacked an existing AD diagnosis for their relative because of normalization of AD symptoms as natural parts of aging, lack of information about AD and available resources, and structural barriers to diagnostic services. Because diagnosis was an inclusion criterion, these individuals could not enroll in the study. Ten additional caregivers expressing initial interest reported a sense of caregiving burden so large that even a no-cost, home-based intervention intended to provide support was perceived as onerous, and ultimately they did not enroll in the intervention study.

These reasons for non-participation in the research seem significant precisely because many have been previously identified in the literature, most often as barriers to treatment rather than research participation, for AD family caregivers in general, and for minority populations in particular. What is compelling is hearing of these barriers in the subjects' own words, and being reminded that despite our knowledge of these limitations, they continue to exist in both research and treatment spheres and must be forcefully addressed. We need to better understand the specific ways these barriers manifest and are experienced by Latino caregivers, in order to partner with these communities in providing relevant and accessible general education and outreach regarding AD, and appropriate medical and psychosocial services to patients and families. Such efforts are crucial for reaching this underserved population, and also for identifying and thus creating a larger pool of potential participants to engage in research protocols that may ultimately benefit this community.

## Literature Review

The literature examining AD research recruitment and retention challenges for minority populations has, naturally, tended to focus on how to increase participation. Thus, one area of study has been the description or comparison of different recruitment strategies such as social marketing, community outreach, and health system referrals to reach potential participants (see, for example, Gallagher-Thompson et al., 2004, 2006; Nichols et al., 2004).

Another area of exploration has been the identification of particular barriers and enablers to recruitment and retention among minority groups, from both researchers' and participants' perspectives (Connell, Shaw, Holmes, & Foster, 2001; Hinton, Guo, Hillygus, & Levkoff, 2000). Valle (2005) has synthesized much of this literature into a best practices model for culturally-attuned recruitment, retention and adherence of ethnically diverse participants in AD research protocols.

There has been some recognition of the parallel issues arising in both research and practice with minority populations. In discussing his model, Valle notes that “attracting ethnically diverse group members and retaining them within existing health resources have become evermore essential concerns of both the research and practice communities” (2005, p. 261). In describing major barriers to recruitment of Latinos into research studies, Gallagher-Thompson and colleagues (2003) also mention that “because intervention research with dementia family caregivers is one way to deliver actual clinical services...there is less of a real distinction between barriers to service utilization versus barriers to research participation” (p. 46).

However, overall, little has been written about the linkages between service use and research recruitment and how the difficulties experienced in recruiting minority older adults and their caregivers may be instructive regarding the very problems often being studied in these research efforts. Such problems include structural and cultural barriers that minority older adults and their families experience in obtaining a diagnosis and treatment, which preclude them from meeting common study eligibility criteria of an existing diagnosis or of being in settings where they can have the opportunity to learn about and participate in relevant research protocols. Thus, some of the reasons why minority patients and their caregivers have been found to underutilize formal assessment and treatment services (Burnette, 1999; Ortiz & Fitten, 2000; Richardson, 1992; Starrett et al., 1990) are likely to be the same issues impeding their participation in research trials. Understanding and addressing such fundamental barriers may result not just in the much-needed increase of ethnically diverse aging populations in research, but also in their improved use of diagnostic and intervention services which will, in turn, ideally be informed by data garnered in these research efforts.

## **Design and Methods**

### **Sample and Data Collection**

The 29 respondents described in this paper originally contacted the author in response to fliers seeking Latino family caregivers of patients with AD interested in participating in the evaluation of a supportive intervention. However, for a variety of reasons, which are the subject of the present paper, these 29 individuals were not enrolled in the intervention study.

The recruitment strategy for the larger study focused on outreach to community service agencies and other important neighborhood institutions such as churches and beauty parlors (Gallagher-Thompson, Solano, Coon, & Arean, 2003). Barrier-reducing approaches such as having a bilingual, bicultural principal investigator (author of this paper) and research assistant were adopted. The author is a Ph.D.-level social work professor with nearly two decades of experience working with Latino populations. As such, the author was interested

in assessing the impact of an intervention demonstrating positive outcomes with primarily non-Hispanic White caregivers on Latino caregivers. The author has a background in anthropology and training in qualitative research methodology. Thus, as part of a mixed methods approach in the larger intervention study, systematic records of all contacts and reasons for non-participation were kept.

Five out of the total of 44 people who contacted the researcher about the intervention study did not identify as Latinos and were referred to appropriate services and research protocols. Of the remaining 39 contacts, only 10 were ultimately enrolled in the intervention study. The data presented here are based on the conversations with the 29 contacts who did not join the study, 19 of whom did not meet study criteria of an existing AD diagnosis, and 10 who felt overwhelmed at the prospect of participating. Because of the preliminary nature of these contacts assessing study eligibility, only minimal sociodemographic information was obtained from most respondents. This information, including gender, relationship to care recipient, primary language, and country of origin, is presented in Table 1.

### Data Analysis

Notes from contacts to establish study eligibility were translated when necessary and analyzed for core concepts using a categorical-content approach to narrative analysis (Leiblich, Tuval-Mashiach, & Zilber, 1998). Employing this approach, the researcher read and re-read each individual respondent's material as it was gathered, identifying, classifying and categorizing basic meanings and creating larger categories and themes. The initial open codes and more abstract themes from each individual interview were also compared across respondents for areas of agreement and difference in an iterative process. A trained research assistant coded a subset of interviews to establish interrater reliability.

### Conceptual Framework

We selected a data analytic methodology without a predefined theoretical framework in order to read the material openly to see what emerged. However, once the material was categorized, it became clear that two widely used conceptual models, Andersen's revised Behavioral Model of Health Services Use (1995) and Pescosolido's Social Organization Strategy (1992), provide useful and complementary ways of understanding how the themes generated ultimately result in Latinos' underrepresentation in AD patient and caregiver research trials and concomitantly in reduced use of AD diagnostic and treatment services. Health services utilization frameworks, including Andersen's model, have been previously used to predict willingness to participate in clinical research trials (Brown & Topcu, 2003).

Reacting to an individual, rational approach to medical decision-making, Pescosolido (1992) offers a model embedded in social interaction in which an individual's social networks provide the mechanism through which the person learns about, makes meaning of, and attempts to deal with a problem, which itself is conceptualized not as an individual phenomena, but a "shock" to the entire network (p. 1105). This seems a particularly apt model for AD, in which the very nature of the condition may impede the individual from recognizing a difficulty and it is his or her larger social network which must identify a problem and decide if and how to respond.

Andersen's Behavioral Model of Health Utilization (1995), used extensively to understand the use of health services, has been revised in an acknowledgement of criticism that earlier versions of the model did not sufficiently consider social networks and other broader societal and health policy contexts. The revised model suggests that use of health services (and in this case also those services offered through intervention research) is based on a person's predisposition to use services, predicated on characteristics such as age, gender, ethnicity and health beliefs, personal and community factors such as financial resources and available health facilities enabling or impeding their use, and a perceived or evaluated need for care. These population characteristics are embedded in the larger context of a specific health care system and external environment and lead to certain health behaviors in the form of personal health practices and health service utilization. These, in turn, influence health outcomes, which recursively affect subsequent predisposing factors, perceived need, and health behavior. In a manner compatible with Pescosolido's model, social relationships are enabling resources that can either facilitate or impede service use. After presenting and illustrating the themes generated, we return to these conceptual frameworks in our discussion.

## Results

Analysis of the transcribed conversations with the 29 contacts who were not enrolled in the intervention study are instructive regarding the difficulties Latinos with possible AD and their families face in pursuing and receiving adequate diagnosis and treatment, and the pressures their family caregivers experience in the caregiving role. Given that this is an under-identified and stressed group, it is not surprising that recruiting and retaining this population for research protocols has proven challenging. The four core themes found are illustrated with quotes selected for their representativeness of these respondents' experiences.

### Delays in Diagnosing Alzheimer's Disease

Timely diagnosis of AD maximizes treatment options, including opportunities to participate in research protocols. However, over half of the potential participants in the intervention study had yet to have their family member assessed for memory problems or other conditions such as depression that might cause such symptoms, despite what were described as long-standing and significant memory loss, confusion, and behavioral changes. Three primary reasons for delay in evaluation were: (1) a perception of symptoms as normal aspects of aging (reported by 9 respondents), (2) lack of information about AD and diagnostic and treatment services (reported by 6 respondents), and (3) financial, language, transportation and immigration status barriers which 7 respondents perceived as precluding access to diagnosis and treatment.

**Beliefs about Normal Aging**—Nine people spoke of the confusion, memory loss and disorientation described in the recruitment fliers and which they reported their loved ones experiencing as being normal aspects of aging. Several of these people approached the researcher as the fliers were being posted to ask whether such conditions were in fact considered problematic. Comments included:

“He's just forgetting things, like will happen to all of us, right?” “He is just a little *chocho* [addled]; you know how old people get.” “She's fine. It's natural to be a little bit slow and confused once you get to be her age. How do you think we will be when we're that age?” “To me this is totally normal. All the old people I know start behaving like this. How does one know if it is normal or this problem you are discussing [in the flier]?”

Some family members had been experiencing increasing difficulties for as long as four years. For all respondents the problems, as described by the family member, appeared to the researcher to go well beyond an expectable and normal decline in functioning and warranted further evaluation. For these respondents, however—even those describing years-long and increasing loss of memory, confusion, and disorientation—these changes still fit a normative conceptualization of aging. Because this was considered expectable and common, no thought had been given to evaluation of it as a condition that might be amenable to intervention, until their exposure to this study's flier.

**Lack of Information about AD and Diagnostic and Intervention Services—**Six respondents considered the changes they were witnessing in their loved one to be indicative of a problem, but because they lacked knowledge about AD, they did not know what the condition might be or where to turn for adequate specialized help.

We use Dr. Flores right here in the neighborhood. He's one of us, so I feel comfortable with him, but now I wonder about his training. Maybe it's not as good in the Dominican Republic, because I kept taking my husband there and telling Dr. Flores that I'm worried about him, there's something wrong, he's just not himself. But he kept saying I was worrying too much and just prescribed some vitamins.

In addition to creating confusion and worry for family members, and delaying diagnosis and treatment, lack of education about AD also creates conflict within families regarding whether something should be done and, if so, what. One respondent remarked:

I think God sent you here [a beauty parlor where I had been allowed to post a flier] to help me. My mother has all those things [memory loss, confusion, behavioral changes] and I know there is something wrong but my sisters and brothers disagree and are saying she's fine. But none of us really knows anything about this. I didn't know what to do, but this [the flier] is a sign.

This lack of knowledge about AD was echoed by another respondent, who half-jokingly wondered if his mother was going crazy.

It's very strange, because sometimes one notices lots of problems in her – she doesn't remember things, it's almost like she can't locate herself, she doesn't know what to do – and other times everything is normal and I feel like I am the one going crazy. [Do you think she has a mental illness?] I don't know. [Pause] No. [Pause] If she is going crazy, it's in a really strange way.

One woman whose husband had been diagnosed with AD described a lack of knowledge and understanding about the condition and its treatment within the extended family.

There was conflict in our family about what to do. I was thinking it was a medical problem and we needed a doctor. His son didn't see him enough to notice the changes, so he said it was just his father getting old. His sister said he had been hexed and I needed to take him to Ecuador for a cleansing. To this day she won't accept that he has Alzheimer's and it is a medical condition and she is angry with me for not having him treated the way she thinks he needs to be – by a *curandero* [folk healer].

The importance and value of providing adequate education about AD through relevant and accessible means was illustrated by another person's experience:

I think we had all noticed that she was changing and something wasn't quite right, but we didn't know what it was, or what to do, where to take her. Honestly, I was just praying she'd get better. But then I saw a show on Cristina [a Spanish-language talk show] – she's very good – and it sounded exactly like my mother. And they said what one should do and gave the information right there on the program. It was the Alzheimer's Association number and I called and they told me where I could go sort of near my house where they spoke Spanish, because my mother only speaks Spanish. And we went. And she was diagnosed.

**Structural Barriers to Diagnosis and Treatment**—Seven respondents viewed the changes they witnessed in their loved ones as worrisome, but due to financial, linguistic, transportation or immigration status barriers perceived themselves to be unable to access services.

Everyone in the family kept saying it was normal, she had always been forgetful and it was to be expected as you got older, but I knew something bad was happening. I just didn't know where to take her because we don't have papers, so who would help us and how would we pay for it?

#### **Another potential participant recalled**

I thought, please God, don't let it be this *demencia* that they call it. So partly, if the truth be told, I don't really want to find out and partly I don't know where to go and how will I understand what they tell me. My children speak English but they are very busy with their lives and I don't want to worry them about their father.

One respondent felt fairly certain his mother had AD, and knew of the various specialized assessment centers in the city, but described the family's inability to pay for such services.

Well, of course there's something major going on with her and her doctor is telling us to take her to X Hospital for an evaluation. But we don't have insurance or Medicare, so I don't know how that would go.

Another respondent felt the diagnostic center was inaccessible due to its distance from her home and her husband's frail health.

To get there I would first need to take a bus to the subway, then transfer one time, and then walk several blocks with him. It would take probably two hours each way and I just don't think he can handle it physically. But I can't take a car service; they

want to charge me \$70 each way. And the one time we tried Access-a-Ride, they were 1 hour late to pick us up and we missed the appointment.

Beliefs about what constitutes normal aging preclude some Latino caregivers from considering the memory loss and confusion their family member may be experiencing as a problem requiring assessment and treatment. Lack of information about AD and related disorders and where to seek specialized evaluation and treatment keeps others, who may consider their relatives' behavior problematic, from knowing where and how to get help. For others, language, immigration status, transportation, and financial barriers limit access to diagnostic and treatment services. These belief, knowledge and structural barriers to diagnosis and intervention likely also preclude this population from being aware of or being eligible to participate in relevant research.

### Caregiving Burden Restricting Participation in Research

Ten persons inquiring about the intervention study met eligibility criteria but, despite their initial interest, ultimately declined to participate. All of these caregivers were adult daughters caring for a parent and children and struggling to balance their work and family responsibilities. Participation in this no-cost intervention, despite its intended supportive nature, and the offer to meet in their homes at a convenient time, felt to them like an additional burden in their already overwhelming lives. After repeatedly offering her various times to meet, including weekends and evenings, one woman finally confided:

I know that I need this help, and I know that it would be good for me. But I just can't do it. I can't see it as anything other than yet another appointment I have to keep because of this odious disease, another obligation robbing me of my time and my privacy. My entire life is now this disease; everything is about it.

Another potential participant, caring for a parent with AD, young children, and working full-time, had a similar reaction:

I called because when I saw the poster I realized I really could use some help. This is really so difficult. But then the reality hit me that when exactly did I think I could do this [participate in the intervention]? There aren't enough hours in the day to fit it in.

That over a quarter of potential Latino respondents expressed interest in participating in an intervention meant to offer emotional and concrete support free of charge and in their choice of location and yet still perceived this as onerous alerts us to the fact that these caregivers are under enormous pressure.

### Discussion

Interviews with 29 Latino caregivers who sought information about participating in an intervention study and who ultimately did not enroll revealed that the obstacles to recruiting this population for research studies are consistent with the barriers this population experiences in regard to diagnosis and treatment of AD more generally. Many of these caregivers perceive significant memory loss and confusion to be a normal aspect of aging. Applying the Social Organization Strategy Model (Pescosolido, 1992), such beliefs will



preclude the social network from reacting and seeking care, as no difficulty is perceived. In Andersen's model (1995), this normalization of memory loss and confusion is a predisposing characteristic that reduces the likelihood that the affected person and their family will see a need to seek professional assistance. This compromises early diagnosis and intervention, limiting exposure to information on potential research studies or rendering these families ineligible for studies requiring an existing AD diagnosis.

The belief among Latinos that even significant memory loss and confusion are part of normal aging, which delays recognition and treatment of actual medical conditions, has been frequently reported in the literature (Hinton, Franz, Yeo, & Levkoff, 2005; Mahoney, Clutterbuck, Neary, & Zhan, 2005; Ortiz & Fitten, 2000). It has also been reported as a reason for delaying diagnosis in non-minority caregivers as well (Boise, Morgan, Kaye, & Camicioli, 1999). A recent study of knowledge and beliefs regarding AD among a large sample of White, Black, and Hispanic adults found that the public does not clearly distinguish between normal memory loss and AD, and this finding is particularly true of Blacks and Hispanics (Connell, Roberts, & McLaughlin, 2007).

This misperception about what constitutes normal aging is linked to a lack of information about AD and specialized diagnostic and treatment services among the Latino community at large- immediate and extended family, friends and acquaintances, and even neighborhood physicians – described by many of the respondents. Employing Pescosolido's (1992) model, such a gap in knowledge makes it difficult for the affected social network to respond. Using Andersen's (1995) model, this lack of information constitutes an impeding factor to using services.

Lack of accurate information among Latinos about normal aging, AD, its diagnosis, and medical and psychosocial interventions for patients and caregivers and the obvious negative impact this has on the pursuit of a diagnostic assessment, treatment and possible participation in pharmacologic and psychosocial research, has also been previously noted in the literature (Gallagher-Thompson et al., 1997, 2003; Hinton et al., 2005). This lack of information has also been cited as a barrier to diagnosis and treatment for caregivers in general (Boise et al., 1999; Wackerbarth & Johnson, 2002). Indeed, in their study comparing knowledge of AD among Anglo, Latino, Asian and African American elders, Ayalon and Arean (2004) found that low levels of knowledge regarding AD were prevalent across all groups, but Latinos and Asians demonstrated the greatest gaps. While 78% of older Anglos answered at least half of the questions correctly, only 53 % of the African Americans, 20% of the Asians, and 22% of the Latino older adults did so. Lacking this knowledge leaves many families relying on primary care doctors who often assess improperly, a situation reported by respondents in this and other studies (Neary & Mahoney, 2005). Indeed, as many as half of dementia cases may go undiagnosed in primary care settings (Boise et al., 1999). Outreach and education regarding dementing conditions among Latinos offered to both primary care providers and the Latino community might improve its recognition and subsequent treatment (Gallagher-Thompson, Haynie, Takagi, Valverde, & Thompson, 2000).

Given these findings that a general lack of information about normal aging and AD is common with caregivers in general, it is not clear to what extent this is based on culture or low levels of education often associated with minority status. Only about 51% of Latinos complete high school (U.S. Bureau of the Census, 2001) and there is comparably scant information on AD and related dementias available in Spanish (Gallagher-Thompson et al., 2003). While there is a tendency in the literature and among service providers to view these misperceptions and lack of information as related to culture, lack of education and health literacy are clearly significant and perhaps more important factors, as several studies have indicated. For example, in a study reporting greater knowledge of AD among Anglos, compared to Latino, Asian and African Americans, it was not ethnicity per se, but factors associated with it, such as level of education and English-speaking ability, that accounted for the differences found (Ayalon & Arean, 2004). A qualitative study of 11 Latino caregivers stressed that lack of knowledge, rather than cultural beliefs, influenced their initial misunderstanding of dementia symptoms (Neary & Mahoney, 2005). A third study found that, except for the increased likelihood of failing to distinguish between normal memory loss and AD among Hispanics already mentioned above, there were few differences in knowledge of AD between Whites, Blacks, and Hispanics (Connell et al., 2007). The authors note that this contrasts with the existing literature, and offer the sample's higher-than-national-average educational attainment as a potential explanation. However, another study found that ethnicity accounted for a significant portion of variation in help-seeking characteristics of Latino and Euro-American AD family caregivers even after socioeconomic variables were taken into account (Valle, Yamada, & Barrio, 2004). Thus, findings regarding whether perceptions and behaviors surrounding AD are due to cultural beliefs or to the poverty and low levels of formal education often accompanying minority status are equivocal and require further study. As noted by Hinton (2002, S51) "these two variables correlate with each other, and both powerfully influence health outcome and access to care".

An additional question to consider is the extent to which these explanatory models of what constitutes normal aging or the failure to seek further information regarding troubling symptoms might in part be masking understandable denial on the part of caregivers to avoid acknowledging a potentially painful situation. This possibility was hinted at by several respondents in the quotes above, and should be explored further in future studies. Another question for further exploration involves the extent to which Latinos conflate symptoms of AD with "craziness". While this has been reported as "common" in Latino culture (Henderson & Gutierrez-Mayka, 1992, p. 67), and the resulting stigma seen as a barrier to accessing services, only one person in this study mentioned it, and this to say they did not think the symptoms their loved one was exhibiting indicated they were "crazy". Furthermore, in a study of 30 Latinos queried regarding their perceptions of cognitive impairment and AD symptomatology, only 10% attributed such symptoms to "being crazy" (Perez, Cortes, & Mittelman, 2001).

The third set of barriers to accessing diagnosis and care presented by these respondents – structural barriers such as linguistic, transportation, and financial obstacles –in Andersen's model constitute impeding factors to service utilization, and have also been noted in the literature. In a study of over 700 patients presenting to a public hospital emergency room for

nonurgent care, Derose and Baker (2000) found that Latino patients with limited English proficiency made significantly lower use of physician services, possibly adversely affecting health outcomes. In their study of factors influencing healthcare access for older Hispanics with memory or cognitive problems, Ortiz and Fitten (2000) also report that language proficiency and economic status significantly delayed early diagnosis and treatment. Conversely, efforts to provide culturally-attuned, accessible and relevant information and services regarding AD to Latinos result in reduction of barriers to care and increased knowledge and services utilization, as reported in descriptions of targeted educational interventions and programs (see, for example, Aranda, Villa, Trejo, Ramirez, & Ranney, 2003; Valle, Yamada, & Matiella, 2006).

While caring for a loved one with AD has been widely recognized as distressing to any family caregiver (Pinquart & Sörensen, 2003), Latino family caregivers may face special challenges for a variety of reasons. Latino elders tend to be significantly more disabled than Whites (Jette, Crawford, & Tennstedt, 1996) and to underutilize formal services when compared to other groups (Burnette, 1999; Tennstedt, Chang, & Delgado, 1998). The latter means greater dependence on family caregivers (Haley, Han, & Henderson, 1998).

The specific way that AD presents in Latinos also potentially increases the burden on caregivers. Dementia-related behaviors such as combativeness, wandering and hallucinations, often the most troubling to caregivers, are more likely in Blacks and Latinos than Whites (Sink, Covinsky, Newcomer, & Yaffe, 2004). Furthermore, Latinos may develop Alzheimer's symptoms on average nearly seven years earlier than non-Latinos (Clark et al., 2004), making it more likely that their caregivers will be younger, with multiple familial and work roles to fulfill. Latino caregivers are indeed more likely to be younger and also caring for children under 18, in addition to being poorer, less educated, underemployed and in worse mental and physical health than Whites (Cox & Monk, 1990; NAC/AARP, 1997). These predisposing demographic and social structure characteristics shared by many of the Latino caregivers included in this study offer an explanation, via Andersen's model, for their failure to participate in the intervention. Most importantly, the persistence of these long-identified and continuing barriers to research participation—lack of knowledge about AD and available resources and services, and caregivers too overwhelmed to participate in an intervention meant to be supportive—suggests that researchers and service providers have failed to fully understand and meet the basic needs of Latino AD caregivers, preconditions fundamental to their participation in and the relevance of any subsequent research. Given this, community-based participatory research (CBPR), which involves the targeted community as equal partners in every phase of research, and to generate and use knowledge to promote change collaboratively, may hold the greatest promise in finally addressing this gap (Israel, Schulz, Parker, & Becker, 1998; Israel, Schulz, Parker, Becker, Allen, & Guzman, 2003; DePoy, Hartman & Haslett, 1999). For example, as one caregiving daughter who did participate in the intervention described her initial experience with her father:

It made it much harder at the beginning, when I was realizing that something was wrong, but I wasn't really sure what, and all the people that I asked—the people I know—didn't really know either or said that it was normal, what happens to people

when they get old. How could they know? The truth is that we need a lot more information to get out to our community, not just in Spanish, but in ways that people can understand and makes sense to them.

This caregiver is in a uniquely qualified position to inform researchers and service providers of the need for information about AD and related services and how to present it in “ways people can understand and makes sense to them.” Had a CBPR framework of inquiry been employed in this study, efforts would have likely focused first, with caregiver collaboration, on finding accessible, relevant ways of providing information on normal aging, AD, and diagnostic and treatment services to the Latino community. Subsequent research in areas such as supportive interventions for caregivers can then build on this foundation. Participants themselves provided concrete examples of successful outreach approaches such as the use of high-profile and trusted Latino television personalities to convey information. Such educational efforts would not only result in earlier diagnosis and intervention and therefore enhanced care for patients and their families, but also would create a larger pool of Latinos with AD and their families available, because of an existing diagnosis and increased access to information on research, to participate in such protocols. We have, in fact, because of our experience in this study, used a CBPR approach in partnering with a community-based agency to develop a comprehensive AD outreach and education program for Latinos and African Americans which involves participation of local service providers, patients with AD, and their family caregivers.

The themes derived from the 10 caregivers who did choose to receive the intervention did not differ significantly from those who did not. Like the latter, these intervention-receiving caregivers experienced a lack of knowledge about AD and appropriate diagnostic and treatment services, which initially compromised diagnosis and intervention. It was often only through persistence and “desperation” that families finally connected with an agency or provider that offered relevant services and information, underscoring the current lack of consistently accessible information about AD for the Latino community.

In addition, many participating caregivers were not receiving all necessary services due to the same structural obstacles such as language, financial and legal status barriers described by non-participating respondents. Furthermore, these caregivers experienced multiple biopsychosocial problems, which when paired with the barriers previously mentioned, greatly compounded their sense of caregiving burden. Adding to this stress, in contrast to the oft-repeated tenet in the literature that Latinos' value of *familismo*, “a strong identification and attachment of individuals with their families” (Sabogal et al., 1987, pp. 397–398), leads to greater actual involvement of extended family in the care of sick members and reduced caregiving burden, since providing care is expected and valued, these caregivers described overburdened extended families unable or unwilling to provide support. Thus, these caregivers can easily be described as “overwhelmed” as well. Because we had little information and contact with the overwhelmed caregivers who chose not to partake of the intervention, it is difficult to say if and how these two groups differ, except in their choice to participate. Asked in qualitative interviews about their experience of the intervention, which stresses problem-solving and enhancement of social supports in its family and group components, and provides concrete assistance through case management in its third

component, all participants described it as extremely helpful. However, a more organic approach involving Latino caregivers in the development of an intervention, perhaps with concrete problem-solving as a first component, may be more palatable to more caregivers, resulting in higher rates of participation.

## Conclusion

This study's findings that the barriers to recruiting Latino caregivers into AD research studies mirror the barriers this population experiences in accessing diagnostic and treatment services are limited by the small, non-random sample of Latinos interviewed in New York City and the recognized heterogeneity of the Latino population. In addition, encounters were generally brief, averaging 20 minutes, although some lasted as long as 75 minutes. Yet, the themes uncovered regarding the challenges Latinos face in participating in research studies have been discussed in the service utilization literature for caregivers in general and for Latino and other minority caregivers in particular. Through respondents' own words we illustrate the link between barriers to diagnosis and intervention and obstacles to research participation, and underscore that despite our knowledge of their existence, these challenges have yet to be adequately addressed. Much research, including this one, has failed to acknowledge the fundamental needs of Latino communities when it comes to AD: education about normal aging, AD, and relevant services. Thus, we offer several specific recommendations based on our experience.

The first is to use CBPR as a framework of inquiry to avoid this lack of fit between community needs and research. Involving community members in developing this study would have immediately alerted us that evaluating a supportive intervention, while important, was several steps beyond where community needs lay. That is, many families had yet to understand their loved one had AD or what the diagnostic and treatment options were, and these areas must be addressed before supportive interventions for these caregivers are truly meaningful.

A CBPR approach would likely organically lead to the second recommendation, which is, in collaboration with community stakeholders (families, patients, service providers), to assess existing educational materials aimed at Latinos pertaining to normal aging, AD, and related services for their potential utility. The Alzheimer's Association, the Alzheimer's Foundation, and the Administration on Aging are sources of such Spanish-language information. Furthermore, it may be necessary to collaboratively develop culturally-attuned, accessible and relevant additional material tailored to the unique needs of community members and primary care providers. Successful examples of educational and outreach materials involving relevant stakeholders in their development include brochures, videos and fotonovelas (graphic novels) (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Valle et al., 2006).

A third area for researchers to focus efforts on would be to evaluate the accessibility (linguistic, geographic, financial, cultural) of existing diagnostic and treatment services. There are descriptions in the literature of model programs (Aranda et al., 2003; Yeatts, Crow & Folts, 1992), and such promising strategies and models involving the communities

targeted must be evaluated and replicated as appropriate. These recommendations would increase knowledge regarding normal aging, AD, and relevant, culturally-informed diagnostic and treatment services accessible to Latinos, preconditions for reducing health disparities and for simultaneously creating a pool of Latinos interested in participating in every aspect of research, and ultimately maximally benefiting from AD research studies.

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**Table 1**  
**Sociodemographic Characteristics of All Latinos Responding to Recruitment Efforts**

	Participants in supportive intervention ( <i>N</i> = 10)	Nonparticipants ineligible due to lack of existing diagnosis ( <i>N</i> = 19)	Non participants feeling too overwhelmed to participate ( <i>N</i> = 10)	Total ( <i>N</i> = 39)
Gender				
Male	2	6	0	8
Female	8	13	10	31
Caregiver status				
Spouse	6	7	0	13
Adult child	4	12	10	26
Language				
Spanish	5	9	1	15
Bilingual	5	10	9	24
Place of origin				
Puerto Rico	4	7	6	17
Dominican Republic	2	9	4	15
South America	3	1	0	4
Mexico	0	2	0	2
Cuba	1	0	0	1