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Latino Caregivers of Relatives with Alzheimer's Disease

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ABSTRACT. This review of the literature discusses the experience of Latinos who provide care to a family member with Alzheimer's Disease and Related Disorders (ADRD). This discussion is imperative in light of the present demographic changes and in light of current findings suggesting that the risk for dementia is significantly higher for Hispanic elderly. All studies reviewed reported that the ADRD Latino caregiver is most likely to be a female caring for her parents or her parents-in-law. Despite the relatively low availability of informal support and the high levels of depression among ADRD Latino caregivers, most studies reported that ADRD Latino caregivers underutilize formal services. The major implications of the present review are that a heterogeneous perspective of the Latino community should be adopted by taking into consideration within group differences. In addition, systematic study of outreach and therapeutic interventions aimed specifically towards ADRD Latino caregivers is recommended. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2001 by The Haworth Press, Inc. All rights reserved.]*

KEYWORDS. Alzheimer's Disease and Related Disorder (ADRD), dementia, caregiving, Latinos, Hispanics

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INTRODUCTION

The fact that families provide the majority of care to family members with ADRD seems to be universal. Yet, in the United States caregiving has been researched mainly from a Caucasian (European-American) perspective with little attention to the role that socio-cultural factors play in the caregiving experience. The few studies that have addressed socio-cultural variables as significant factors in the experience of caregivers reported conflicting results, leading to the inevitable conclusion that more research needs to be done in order to fully understand the experience of caregiving and its impact on the individual (Aranda and Knight, 1997; Gallagher-Thompson et al., 2000; Kane, 2000).

According to the US Bureau of Census, 32.8 million Latinos resided in the United States in 2000, representing 12% of the population. The Latino population in the United States is a diverse group that can be of any race. Of the Latino population 39.1% are foreign born. The origin of the majority of Latinos in the United States is Mexico (66.1%), followed by people from Central and South America (14.5%), Puerto Rico (9%), and Cuba (4%). In 2000, only 5.3% of Latinos were 65 or older comparing to 14% of White non-Hispanic. It has been estimated, however, that the number of elders will reach 9.2% of all Latinos in 2050. The Latino population as a whole was less likely to have graduated from high school relative to non-Hispanic White. However, variations in level of education existed within the Latino community. Cubans were more likely to obtain a high school education (73%) or a Bachelor's degree (23%) than Mexicans were (51%, 6.9%, respectively). In addition, Latinos as a group were more likely than non-Hispanic Whites to live in poverty, to be unemployed, and to earn less money for their work (Therrien and Ramirez, 2000).

CHARACTERISTICS OF INFORMAL SUPPORT

Informal support is most often used in the care of Latinos with Alzheimer's Disease and Related Disorders (ARDR). The gender of the relatives is the most important characteristic in determining the caregiving role. All studies reviewed reported that the ADRD Latino caregiver is most likely to be a female caring for her parents or her parents-in-law (Cox and Monk, 1996; Cox and Monk, 1993; Harwood et al., 2000; Cox and Monk, 1990; Harwood et al., 1998; Henderson and Gutierrez-Mayka, 1992; Polich and Gallagher-Thompson, 1997). According to Cox and Monk (1993), daughters are most likely to be primary caregivers, followed by spouses, and lastly by sons. Similarly, Henderson and Gutierrez-Mayka (1992) reported that if blood-related females

are unavailable to provide personal care, daughters-in-law are more likely to provide such care than biological sons do. Sons, on the other hand, are more likely to help with financial management. ADRD White non-Hispanic and Black caregivers are also most likely to be females. However, in contrast to the choice of daughters as primary caregivers in the Latino community, Cox and Monk (1996) reported that ADRD Black caregivers are more likely to be from the extended family and Kosloski, Montgomery, and Karner (1999) reported that White non-Hispanic caregivers are more likely to be spouses than daughters.

These findings suggest that similar gender role characteristics exist in all three cultural groups. In all three groups women are expected to provide informal care to an ADRD patient and are assigned the role of the primary caretaker, especially when personal care is involved. However, the familial relationship of the female to the care receiver varies across the different cultural groups.

Familism, the strong feelings of reciprocity and solidarity among family members, is said to be an important value that guides the caregiving role among Mexican-Americans (John, Resediz, and Devargas, 1997). However, research suggests that the amount of support provided to the primary caregivers by other family members in the Latino community is lower than would be expected based on the value of familism. According to Cox and Monk (1993), most Latino caregivers reported lack of strong informal assistance and were unable to identify informal support that could have taken their role if needed. The feeling that the care receiver relied solely on them for assistance intensified sense of burden. Similarly, Levkoff, Levy, and Flynn Weitzman (1999) reported that Puerto Rican caregivers often perceived having insufficient informal support and that both Puerto Rican and African-American caregivers expressed their desire to have greater familial involvement. Polich and Gallagher-Thompson (1997) reported that although Hispanic caregivers were able to identify on average 1.5 family members who assisted in caregiving tasks, the primary caretaker took responsibilities for most of the caregiving tasks and received only little assistance from other family members. In contrast, Cox and Monk (1990) reported that both Black and Hispanic caregivers stated that they had enough confidants, with whom they could discuss their experience as caregivers. They also found that more Hispanics than Blacks were able to identify someone who could have provided indefinite care for a relative if they were unable to do so.

EXPECTATIONS AND USE OF FORMAL CARE

Research suggests low levels of formal service utilization in the Latino community (Hinton and Levkoff, 1999; Henderson, Gutierrez-Mayka, Garcia,

and Boyd, 1993). Various factors have been offered as barriers to formal service utilization, including language barriers, health beliefs that promote informal care and alternative care, financial limitations, insensitivity to cultural factors in formal settings, the stigma of ADRD, and lack of knowledge about the available services and about Alzheimer's disease (Parra and Espino, 1992; Gallagher-Thompson et al., 1997).

Norms related to caregiving are likely to influence formal service use. Levkoff et al. (1999) conducted a retrospective qualitative study of four ethnic groups of ADRD caregivers: African-Americans, Irish-Americans, Puerto Ricans, and Chinese-Americans. The norm of "caring for our own" was expressed by all four groups. All four groups of caregivers associated ethnicity and religion as reasons for not admitting a relative to a nursing home. Despite religious involvement, neither Puerto Ricans nor Irish-Americans accessed services through religious facilities. Puerto Rican caregivers identified language as an additional barrier to service utilization and expressed a preference to services provided in the Spanish language by local Latino organizations. Cox and Monk (1990) examined the experience of 31 Black and 19 Hispanic dementia caregivers by conducting two structured interviews at a 4-to-6 month interval. As expected, both groups relied more heavily on informal than on formal care. Unlike Black caregivers, Hispanic caregivers considered the use of professional services as an improper fulfillment of their caregiving role.

Age and level of acculturation are also associated with formal service use. Research suggests that the older generation is more likely to access formal services through the younger generation (Henderson and Gutierrez-Mayka, 1992). This finding could be due to several reasons. The younger generation is likely to have more information about available services, a better proficiency of the English language, and may more easily acknowledge the possible benefits associated with formal services.

The Latino culture associates different etiological explanations with Alzheimer's disease. Some of the explanations are more likely than others to hamper formal service utilization among Latino caregivers. The etiological explanation provided to Alzheimer's symptomatology is likely to be related to the previous reputation of the patient (Gallagher-Thompson et al., 2000). Gallagher-Thompson et al. (2000) suggested that oftentimes the family is likely to deny the severity of the illness and to ignore the symptoms, stating that the Alzheimer's patient has always been religious. In other cases, dementia can be seen as a punishment from God, especially if the person has a history of disrupted behavior. Kosloski et al. (1999) found that relative to White non-Hispanic and Black caregivers, Hispanic caregivers were the least likely to describe the elder as having a diagnosis of Alzheimer's disease. Henderson and Gutierrez-Mayka (1992) reported that the resemblance of Alzheimer's

symptomatology to certain mental disorders was associated with embarrassment to the whole family and with barriers to service utilization. The stigma associated with Alzheimer's disease may generalize to the entire family, especially if problem behaviors exist. Emphasizing the organic nature of the disorder was associated with a decrease in the stigma. However, research suggests that although the bio-medical model is often employed by Latinos to explain Alzheimer's disease, familial tragedies are more likely than the bio-medical model to be identified as causing the cognitive loss (Hinton and Levkoff, 1999; Levkoff et al., 1999).

Lack of knowledge about Alzheimer's disease has also been suggested as a barrier to service utilization (Gallagher-Thompson et al., 1997). However, a recent study reported that all ethnic groups studied have misconceptions about Alzheimer's disease and that no significant differences exist between Hispanics and Whites in levels of misconception of Alzheimer's disease (Edwards, Cherry, and Peterson, 2000).

The perception of need is a major factor in determining the pattern of formal service use. Kosloski et al. (1999) suggested that the perception of need varies across different ethnic groups and therefore results in different ethnic patterns of service utilization. Cox and Monk (1990), in a six-month follow-up, found an increase in formal service use among both Black and Hispanic caregivers and a decrease in informal use, suggesting that the need for formal services increases as the availability of informal services declines. Similarly, Mintzer et al. (1992) found that relative to White non-Hispanic caregivers, Cuban-American caregivers were significantly more aware of the availability of financial services, suggesting that knowledge about available services is acquired as need arises. Kosloski et al. (1999) analyzed intake data of 2,947 Black, Hispanic, and White dementia caregivers. The perception of need was more highly associated with the use of in-home respite and meal services among Hispanic caregivers than among Black and White caregivers. In addition, for ADRD Hispanic caregivers older age of care recipient was associated with increased likelihood of formal service use.

THE CAREGIVING EXPERIENCE

Almost all studies reviewed focused on the negative aspects of caregiving. Most studies reported higher levels of depression and stress among Latino caregivers relative to other ethnic groups. Harwood et al. (1998) assessed the prevalence of depression in 184 White Hispanic and 469 White non-Hispanic caregivers of relatives with Alzheimer's disease. Greater prevalence of depression was reported by White Hispanic caregivers than by White non-His-

panic. The prevalence of depression was higher among wives and daughters than among husbands and sons in both ethnic groups. Similarly, Cox and Monk (1993) conducted structured personal interviews with 86 Hispanic caregivers of Alzheimer's patients. On average caregivers had high levels of depressive symptomatology and moderate levels of stress. They also found that caregivers that more strongly supported the norm of performing tasks for the elderly were more depressed. Polich and Gallagher-Thompson (1997) examined the role of acculturation, caregiver burden, and family support in predicting depression in 42 Hispanic females caring for a relative with ADRD. Almost half of the participants scored within the depressed range. The perceived impact of caregiving on health status and dissatisfaction with family support significantly predicted depression. Dissatisfaction with family support was significantly related to depressive symptomatology in the more bicultural group but not in the traditional group. Cox and Monk (1996) evaluated the caregiving experience of 76 African-American and 86 Hispanic caregivers. They found that ADRD Hispanic caregivers reported significantly more personal and role strain than ADRD African-American caregivers. In contrast, Mintzer et al. (1992) compared 13 ADRD Cuban-American caregivers to 15 ADRD White non-Hispanic and found no significant differences in levels of depression among caregivers. The small sample size of the latter study could account for these results.

Deterioration in health status is another indicator, used to evaluate the impact of caregiving. Cox and Monk (1996) found that only 36.8 % of the African-American caregivers and 29.4% of the Hispanic caregivers reported deterioration in their health. On the other hand, a different study by Cox and Monk (1990) found that 63% of Hispanics compared to 29% of Blacks reported change in their health condition over a period of 6 months.

Only one study reviewed evaluated the role of positive appraisals in the caregiving experience. Harwood et al. (2000) assessed positive and negative appraisals of caregiving experience in 40 Cuban-American caregivers of Alzheimer's patients. Older caregiver age and high levels of perceived social support predicted appraised satisfaction. Length of stay in the United States, as a measure of acculturation, was not associated with positive or negative appraisals.

OUTREACH AND THERAPEUTIC INTERVENTIONS

Several articles have described outreach attempts aimed towards increasing formal service use of ADRD Latino caregivers. The present review suggests that personal contacts with potential participants and with other agencies are of major importance (Gallagher-Thompson, Moorehead, Polich, and Arguello,

1994; Henderson et al., 1993). A culturally sensitive approach that promotes the administration of services by bilingual/bicultural staff and the distribution of educational material in the Spanish language is also essential for the success of the outreach programs (Hart, Gallagher-Thompson, Davies, Diminno, and Lessin, 1996; Taussig and Trejo, 1992).

Henderson et al. (1993) described outreach efforts aimed towards extending ADRD support groups to Hispanic and African-Americans in two large urban cities in Florida. Initially, only Anglo caregivers attended the available support groups in the region. Extensive outreach was conducted by community-based liaisons, recruitment and training of indigenous volunteer support group leaders, ethnic minority media, brief educational presentations, and brochures. Within two years of implementation of the outreach program 114 primary caregivers were identified, 37 of them were Hispanic. Active recruitment through personal contacts in the community was identified as the most beneficial method for recruiting ethnic minority caregivers.

Gallagher-Thompson et al. (1994) compared four different methods of outreach directed towards the Hispanic community: contacting existing programs, mailing flyers to community agencies serving Hispanic elderly, placing public service announcements in newspapers, and placing public service announcements on local TV or radio stations. The most successful method was identified as collaboration with local service agencies serving the Hispanic community.

Hart et al. (1996) described an effort to target ethnic minority families with a demented relative in the state of California. Several ingredients were identified as detrimental for the success of the outreach program. First, strong involvement of decision-makers and center leaders in the outreach program. Second, basing the new programs on already established preliminary groundwork of the agency. Third, bilingual/bicultural staff serving as liaisons between the client population to the agency. In addition, Taussig and Trejo (1992) reported that providing brochures in Spanish without the use of complicated technical words was useful when targeting the Hispanic population.

According to our review of the literature, only one article described therapeutic interventions aimed specifically to ADRD Latino caregivers. Mitrani and Czaja (2000) described a therapeutic intervention, Structural Ecosystems Therapy (SET), which was developed by the Resources for Enhancing Caregiving Health (REACH) project for White-American and Cuban-American caregivers. The intervention evaluates family interactions and strives to decrease caregiver burden by emphasizing adaptive patterns of interaction and by changing maladaptive ones. Particular emphasis is placed on the cultural factors that characterize the family system. In the case of Cuban-Americans, attention was placed on the perception of the family and familial obligations,

on family structure, and on attitudes towards caregiving and caregiving responsibilities. The impact of the program was evaluated qualitatively by the use of case examples.

CONCLUSIONS AND RECOMMENDATIONS

The Latino population is a diverse group that originates from different geographical locations, has diverse educational and economical backgrounds, and is likely to hold diverse beliefs and values. Yet, although most researchers agree on the importance of studying within group differences, to our knowledge, no study has evaluated variations in ADRD caregiving within the Latino community.

The Latino caregiving experience for ADRD relatives has been compared mainly to Whites or to African-Americans. These are important comparison groups, yet it might be more meaningful to compare ADRD Latino caregivers to other immigrant groups. This will provide better understanding of the role of immigration status, level of acculturation, and years in the United States in the ADRD caregiving experience. It is also important to compare the ADRD Latino caregiving experience to the caregiving experience for relatives suffering from other physiological disorders. This comparison will improve the understanding of the role of stigma of ADRD in hampering formal service utilization.

As suggested by Connell and Gibson (1997), moving away from exploratory to confirmatory research is essential. Most studies reviewed evaluated the Latino ADRD caregiving experience without attempting to develop a theoretical basis for the findings. Research suggests that values such as Catholicism, familism, role-differentiation, interdependence, personalism, and *simpatia* are important for Mexican-Americans (for detailed discussion see John et al., 1997; Mi Lim et al, 1996). Yet, none of the studies reviewed evaluated the role of these cultural values in the ADRD Latino caregiving experience. Future research should emphasize within group comparisons, by identifying the significance of these cultural values to the different Latino groups and by identifying the impact of these values on the ADRD caregiving experience.

Most studies reported elevated levels of depression among ADRD Latino caregivers. Yet, caution should be taken when interpreting the results of the present studies since research suggests that elevated levels of depression relative to the general population exist also in Hispanic non-caregivers (Falcon and Tucker, 2000; Kessler et al., 1994). In addition, most studies have empha-

sized the subjective experience of ADRD Latino caregiving and paid little or no attention to the objective aspects of caregiving.

Elevated levels of depression in Hispanic non-caregivers imply that something other than the caregiving experience is responsible for the present findings. Racial variations in depressive symptomatology, biased measures, the form of evaluation, or even the language used during evaluation may be responsible for elevated levels of depression among Hispanics.

The Geriatric Depression Scale (GDS) and the CES-D have been frequently used in the study of depressive symptomatology of Latinos (Arena and Miranda, 1997; Golding and Aneshensel, 1989; Gatewood-Colwell, Kaczmarek, and Ames, 1989; Guarnaccia, Angel, and Worobey, 1989; Lobo, Ventura, and Marco, 1990; Mui, Burnette, and Chen, 2001; Roberts, Rhoades, and Vernon, 1990; Taussig, Henderson, and Mack, 1992). Despite their frequent use, it is important to take into consideration the possibility that the measures function differently in Anglos and Latinos. When used with Latinos, the CES-D has yielded a different factor solution from the four-factor solution previously suggested (Miller, Markides, and Black, 1997; Mui et al., 2001; Roberts et al., 1990). It was argued that despite its good internal consistency as a scale, at the item level the scale does not function similarly across different age and ethnic groups (Arena and Miranda, 1997). The use of the GDS with Latinos has been favorably supported (Lobo et al., 1990) and it has been argued that the norms of the GDS for Hispanics in the United States are comparable to those of Anglos (Taussig et al., 1992). However, Mui et al. (2001) have argued that without alterations, the GDS may not be sufficiently valid for use in groups other than Caucasian-Americans.

The form of evaluation (i.e., paper and pencil versus interview) should also be taken into consideration. Research has demonstrated that the two forms of evaluations may not be comparable when administered to elderly Latinos (Brink, 1978; Brink, 1985). Face-to-face interview may introduce the factor of demand characteristics and may be intimidating, especially if conducted by an interviewer of the majority culture (Brink, 1981). Paper and pencil administration also poses an obstacle, since it requires written competency in Spanish. The limitations of each of these techniques should be taken into consideration when conducting research with elderly Latinos.

The language of interview should also be taken into consideration. Research has shown that Hispanics interviewed in Spanish score higher on measures of depression than Hispanics interviewed in English (Mills and Henretta, 2001). Malgady and Costantino (1998) found that Hispanic-American clinicians rated depressive symptoms among Hispanics more severely than Caucasian clinicians. Severity was rated highest when the interview was conducted by bilingual interviewers, followed by Spanish, and lowest by English interviewers.

The role of acculturation (i.e., the process of change of attitudes and behaviors as a result of an encounter with a new culture) was considered by only two of the studies reviewed. Miranda and Matheny (2000) suggested that acculturation stress is likely to result from multiple sources such as lack of coping resources, degree of acculturation, familiarity with the English language, degree of familial cohesiveness, and length of residency in the United States. Inattention to factors associated with acculturation stress among Latinos may lead to inappropriate interpretations of research findings. It is possible that the relatively consistent finding of higher levels of depression among Latinos does not reflect caregiving burden, but rather, reflects a constellation of factors related at least partially to acculturation stress.

Informal care is highly prevalent in the Latino community. Yet, all studies reviewed except one evaluated only the negative aspects associated with ADRD caregiving. Since ADRD informal care is prevalent in the Latino community, there should be made an attempt to evaluate all factors that maintain it. To date researchers have ignored the positive aspects associated with caring for an ADRD relative in the Latino community. It is possible that this line of research is guided by Caucasian-American perspective that views caregiving as a burden. This perspective may invalidate the ADRD Latino caregiving experience. It is also possible that Latinos, who seek formal services and, therefore, are being evaluated for research purposes, are distinctly different from Latinos who do not seek such services. Negative aspects of caregiving are likely to be more prominent in the former group, while positive aspects of caregiving are likely to be more prominent in the latter. Further research and exploration of positive aspects of caregiving in the Latino community is recommended.

The present review suggests that cultural norms and practices such as personalism (i.e., the tendency to trust people, rather than institutions) and the preference of the Spanish language among Latinos are major obstacles to formal service utilization. Once these obstacles are targeted outreach efforts become relatively successful. A more personal approach that utilizes liaisons in the community is likely to increase service utilization among Latinos, since it follows the value of personalism. In addition, the provision of information in Spanish by Spanish speaking professionals is an important factor in successful outreach, since it provides a more culturally sensitive intervention. It may also be beneficial to initially market formal services by emphasizing the educational component of the program. Educational groups do not threaten the norm of "providing care for our own," since they do not attempt to substitute informal care. Educational groups may assist in ameliorating the stigma associated with Alzheimer's disease and may open the door for future therapeutic interventions.

The value of familismo is likely to pose a major challenge to any program or intervention directed towards Latino caregivers. Research suggests negative stereotypes of people of Mexican descent, held both by others and internally, while the centrality of the family is one of the few positively valued characteristics (Niemann, 2001). An intervention targeting Latino caregivers should honor this norm, while intervening in the family dynamics. In particular, it is essential for the White non-Hispanic therapist to refrain from viewing interdependence as enmeshment.

The present review suggested that there is an increasing recognition of the role that socio-cultural variables play in the caregiving experience. There is also an increasing recognition of the fact that therapeutic interventions should be specifically tailored for the needs of the cultural group targeted (Gallagher-Thompson et al., 1997). Yet, none of the studies reviewed evaluated quantitatively the impact of therapeutic interventions developed specifically for ADRD Latino caregivers. The next stage in the field of ADRD Latino caregiving has to incorporate systematic evaluation of caregiving outreach and therapeutic interventions. To date there is no systematic information on the specific therapeutic needs of ADRD Latino caregivers or on the interventions that are most likely to be beneficial for this population.

Research over the past decade has demonstrated that there is no universal experience of caregiving; rather, the diversity reflects varied factors including the past relationship of the care receiver and caregiver, and the sociocultural expectations surrounding the relationship and the disease (Montgomery and Kosloski, 2000). Although there is substantial evidence that services overall can relieve some caregiver burden, it is clear that no single service is always useful. Little is known about why some services are used and have beneficial impact for some individuals and not for others. It is imperative to understand this diversity in order to deliver the most appropriate services. This is particularly important in light of the shifting cultural demographics. Nationally, the Latino population is increasing; it is predicted that by 2050 the number of older Latinos will be approximately 12.5 million (US Bureau of Census, 1996). This is also important in light of current research suggesting that the risk for dementia is significantly higher for Hispanic elderly (Gurland et al., 1999; Perkins et al., 1997).

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