The Burden of Alzheimer's Disease on Cultural Integrity: Prevalence and Incidence of Alzheimer's Disease within the Latino Health Paradox

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Abstract

In the past two decades there have been large expansions in the research of Alzheimer's Disease (AD) in order to understand the mechanistic pathway of the progressively neurodegenerative disease as well as to develop viable method to treat the fatal disease because there is currently no absolute cure that can stop the deterioration in cognitive function. Even more significant is the influence of the Alzheimer's Association to drive research focused on understanding the epidemiology of the prevalence, incidence and survival frequency of AD across ethnic and culturally diverse populations in order to develop functionally successful prevention programs and community services (Alzheimer's Association, 2008). This is particularly in part to the organizations announcement that on the topic of culture, race or ethnicity the differences in AD that are observed must be due to environmental as well as cultural factors and corresponding experiences. Thus, there is a need to review research which has focused on shedding light on how AD may interact with the Latino Health Paradox.

Introduction

The behavioral symptoms and cognitive decline that were once associated with the normal process of aging are being put into question and becoming more associated with chronic mental disorders such as Alzheimer's Disease (AD) (Tyas, Snowdon, Desrosiers, Riley, & Markesbery, 2007). There is also a developing area of research that has implicated the potential for vascular risk factors to function as co-morbidities as well as modulators of the pre-clinical symptoms and the onset of AD (Snowdon, D. A., Greiner, L. H., Mortimer, J. A., Riley, K. P., Greiner, P. A., & Markesbery, W. R., 1997). As a neurodegenerative disease of interest, AD poses a great risk for the aging population and is becoming more ethnically relevant as the Hispanic elderly population continues to grow rapidly with the prospective of accounting for 20% of the elderly population by 2020 (Brookmeyer, R., Gray, S., & Kawas, C., 1998).

The concerns for the Latino community have become more critical since the completion of the Hispanic Health and Nutrition Examination Survey which was analyzed and used to frame an epidemiological phenomenon known as the Latino Health Paradox (Markides & Coreil, 1986; Morales, Lara, Kington, Valdez, & Escarce, 2002). It is characterized by the finding that Hispanics in low-socioeconomic status (low-SES) have a much better health outcome that is comparable to their more affluent white equivalent rather than other ethnicities of similar low-SES. This has been found to be maintained across important health indicators as life-expectancy, mortality from heart disease, infant mortality, mortality from types of cancer and other measures of functional health. The initial reaction may indicate that Hispanics are doing well but there is still the need to take into account the psychosocial factors that encompass their culture because these protective factors may not last the test of time and they may not be so easily translated to later generations in the U.S.

The observed elevated risk factors for poor health outcome and the persistence of significant barriers in health care access for Latinos residing in the United States in light of the Latino health paradox are enough to motivate concern to understand the cultural factors that account for good health outcome in some public health domains. The following literature review is designed to address research that has studied Latinos (interchangeable with Hispanic for this review) in the context of AD and the Latino Health Paradox in order to identify the extent to which research has been done in the following areas of immediate concern:

1. The incidence and mortality of Latinos who develop AD and cultural perceptions of the mental health disorder.
2. AD and the implication for diabetes, as a prevalent vascular risk factor among the Latino population
3. The investigation of psychosocial stressors and coping mechanism that may assist in preventing development of AD.
4. Is there evidence for the concern in the development of culturally-competent educational services that function to promote preventative steps in the development of AD among the Latino community?

The present expectation is that AD is of significant concern to the scientific research field and there is representation of Latinos in on-going studies relating to health outcome. There is also the belief that community services and outreach programs are beneficial in the treatment and support in caring for elderly Latinos with AD. However, the social awareness of AD and the distribution of knowledge on the disease may not be so accessible to ethnic groups and presents a major failure in preventative medicine.

Ethnic Epidemiology of Alzheimer's Disease

On the topic of the incidence of AD and how it pertains to Latinos, Helzner, Scarmeas, Cosentino, Tang, Schupf, and Stern (2008) address this concern in a population-based longitudinal study in the wake of estimates of AD survival ranging from 3 to 9 years post-diagnosis. This study is unique in the sense that it looked at populations that started dementia-free in order to follow the progression of incident disease in a non-bias manner to accurately estimate mortality and survival. They focused on a multiethnic population that was collected in the Washington Heights Inwood Columbia Aging Project (WHICAP) which consisted of two population-based cohorts of Medicare enrollees pertaining to Northern Manhattan.

Participants and Measures

Participants were randomly selected based on ethnicity (Hispanic, non-Hispanic black, non-Hispanic white) and age (range 65 to 74, and 75+). Sample consisted of 323 cases of AD for which follow-up data was available and who were dementia-free at baseline. The sample consisted of 70% women, 55% Hispanic of Caribbean ancestry and 33% African American. The longitudinal nature of the study for follow-up of participants had a mean of 4.1 (up to 12.6) years and measured for ethnicity-specific age, sex, education, and major known co-morbidities (heart disease, hypertension, diabetes, cancer and stroke). Possible or probable AD was diagnosed using established criteria and associated dementia through DSM-III revised criteria. Physical and neurological assessments were administered at baseline and subsequent follow-up periods at 18-month intervals. Mortality was determined by interviews at follow-up points and by reference to the National Death Index.

Results, Limitations and Strengths

Participants had a mean age of 87 at initiation of the study and mortality was highest among white (non-Hispanic) and mostly more years of education. Hispanics had the least years of education (5.1 years). Diabetes and hypertension were the only co-morbidities independently associated with shorter lifespan. Hispanics had the longest survival time post-diagnosis (7.9 years) compared to non-Hispanic whites (3.7 years) and African Americans (4.8 years) with no evidence for gender differences. This result was interesting since Hispanics had the highest incidence of diabetes. There are implications for coping style and family networks in the Hispanic culture functioning as protective affect to offset AD mortality.

The strengths of the study are outweighed by the limitations. The follow-up intervals may have been too long and underestimated the onset of AD. There is also no heterogeneity in the representation of the Hispanic sample. Also, there was no assessment of the cause of death of participants over the course of the study. Was it due to incident AD and any associated co-morbidities? This is important in providing validity to the diagnoses of AD in the participants at *post mortem.*

Knowledge of Alzheimer's Disease Among the Ethnic Elderly

Previous studies have demonstrated that while AD may be prevalent in ethnic groups, they are more likely to receive delayed diagnosis of AD after living with late-state symptoms and as a result seek less services focused on early intervention and treatment (Gallagher-Thompson, Aréan, Coon, Menéndez, Takagi, & Haley, 2000; Hinton, 2002). By providing access to information about AD, it would be expected that Latinos could comprehend the benefit of seeking treatment or appropriate support. There have been suggestions that even though there is a valid biomedical definition for AD, it is not surprising that ethnic minorities may rely on a

folk-based definition to explain the disease process (Dilworth-Anderson & Gibson, 2002). This is seen in studies that observed the stigma of AD associated with "a punishment from God" by members of a specific cultural context (Gallagher-Thompson et al. 2000). The study by Ayalon and Areán (2004) sought to investigate the ethnic group differences in knowledge about AD with a close-ended AD questionnaire and to identify how level of education and level of acculturation function to modulate what ethnic groups know about AD.

Participants

Participants were selected based on age (55 years or older) and fluency in either English or Spanish. The ethnic groups consisted of African Americans (n=30), Asian (n=30), Latino (n=37) and Anglo (n=96) with the inclusion of both genders for each groups. Recruitment was from four public areas of primary-care clinics in the San Francisco area.

Measures

Each ethnic group was asked to complete a 17-item, true-false questionnaire to assess knowledge of AD based on nature of the disease, consequences and the cure. Acculturation was defined as years residing in the US and years of speaking English which were self-reported during an interview along with educational level, marital status, place of birth, and age. Ethnicity was obtained from a multiple-choice question similar to the US Census.

Results

The Anglo group was significantly more knowledgeable of AD however low levels of AD knowledge were seen across all ethnic groups. The older participants across all ethnic groups were not proficient in knowledge about the prevalence, etiology, diagnosis, and financial

coverage of AD. For the Latino ethnic group, neither of the defined elements of acculturation was associated with knowledge of AD. It is possible that in old age the AD symptoms are normalized and to some extent stigmatized to the point that ethnic groups may not recognize their state of progressive mental health decline. Although this study was able to observe the relatively low levels of knowledge of AD in an ethnically diverse sample, there was neither intention nor an effort made to identify factors that could account for this deficit in the knowledge of AD, which could have benefited in the development of the expectations for an educational campaign. Also, future research should increase the sample size and employ a more comprehensive acculturation assay.

Coping Style as a Ethnic-specific Protective Factor Against AD

The Latino Health Paradox has implications for certain protective factors being significant in promoting some of the observed positive Latino health outcomes in select clinical diseases. Also, the loss of these protective factors with increased acculturation suggests the need to study the type of psychosocial responses that are present in recently immigrated Latinos. This could help in determining the efficacy of protective factor in the Latino population to buffer against a severe mental disorder such as AD.

At least three representative investigations have shown the significance of event-specific coping research among a 1st generation immigrant sample (Padilla, Cervantes, Maldonado, & Garcia, 1987), identify dominant coping styles for stress effect on mental health in a comparison of Mexican citizens and Mexican-American samples (Farley, Galves, Dickinson, & de Jesus Diaz Perez, 2005), and categorize the specific behavioral and neuropsychiatric symptoms associated with AD in a Hispanic sample (Ortiz, Fitten, Cummings, Hwang, & Fonseca, 2006).

Event-specific Coping

The Padilla et al. (1987) investigation sought to observe the type of psychosocial stressors experience by Mexican and Central American immigrants in the context of stressors associated with immigration to the US in order to address their mental health needs. It was specifically focused on looking at general methods of behavioral coping in life domains (marriage, family life occupation, household finances) and more importantly the ethnically-specific coping and perceived stressors.

The participants consisted of 62 respondents (Mexican, n= 32; Central American, n= 30) who were recruited from high density areas of immigrant populations with equal numbers of males and females and who were living in the US for less than 10 years. The mean age was 33.8 years and 56% were married. Measurements consisted responses obtained from an in-depth open-ended stress and coping interview. The questions first asked for general stress and coping methods used by all Latinos (intra-ethnic perspective) followed by more personal perceived and experienced stressors and the coping methods used. Depression and anxiety also assessed using a symptom checklist, which like instruments were previously translated to Spanish.

The results showed that the three most significant stressors were (1) the inability to communicate in English, (2) difficulties in acquiring employment, and (3) their undocumented status in the US. Although the respondents were able to provide general and or personal coping behavioral solutions they rarely took their own advice. Their undocumented status was also increased by the stress of leaving family and friend back at country of origin (77% male concern, 93% female concern). Even in the mists of so many stressors, 40% reported that they have great concern for ensure that their children benefit from a good education. Social support through

families and friends were identified as good source buffer stressors but this study didn't explore the extent of the social network.

Active Coping Style in Mexican Americans

The study by Farley et al. (2005) investigated the lack of sufficient research on the association between stress-coping styles, stress and the health quality of life for Mexican, Mexcian-American and non-Hispanic Whites. They particularly asked if Hispanics have healthier stress-coping styles than non-Hispanics. Participants consisted of a total of 288 Hispanic and non-Hispanic White individuals recruited at a community/migrant health center in an agriculturally dominant town and asked to completed surveys to access stress, coping style and overall composite mental and physical health. Results showed that non-Hispanic Whites and Mexican-Americans were more likely to have chronic health disease such as metabolic syndrome, diabetes and heart disease compared to Mexican citizens. The Mexican citizens had high indicators for active coping styles such as positive reframing, denial and religion. There was also a trend for acculturation where Mexican-Americans and non-Hispanic Whites shared similar properties in coping style and no differences in risk factors for chronic diseases compared to Mexican sample. These results support the outcomes of the Latino Health Paradox. The limitations in the study are in the lack of sufficient data on characteristics of the participants and that results may not be applicable to an affluent population because of uniformly low-SES of sample.

Behavioral and Neuropsychiatric symptoms in Hispanics with AD

Ortiz et al. sought to characterize and compare neuropsychiatric symptoms in a sample of 367 community-dwelling Hispanics (n= 70, n=19 males, n=73 females) and non-Hipanics (n=230)

patients with AD. The average level of education in the Hispanic group was 8.12 years and with mean age of 73.0 years. Subjects were recruited from the San Fernando Valley in Southern California through two different Memory Disorder Clinic sites. It is already understood that neuropsychiatric symptoms are common in AD but the goal of the research was to observe the distribution of such symptoms among an ethnic population.

Subjects were assigned caregivers to contact daily and report behavioral symptoms. Other pertinent measures consisted of mental health as well as level of acculturation which accounted for generation, length of type in the U.S. and age at arrival in the U.S. AD and dementia were independently determined with the use of approved standard diagnostic criteria and the DSM-IV standards for dementia. Results showed low levels of education in the Hispanic subjects, 81% prevalence of low English proficiency and low US acculturation. Hispanics with AD expressed significantly more behavioral symptoms, including apathy, anxiety, irritability, depression, aberrant motor behavior and some degree of agitation. There are implications for the elderly Hispanic population to be at a greater risk of neuropsychiatric and behavioral symptoms due to the mediating effect of education level. Limitations of the study include the small size, lack of random selection of subjects and not representative of all Hispanics across U.S. There is also concern that the caregivers level of education may have influence the level risk associated with Hispanic AD subjects.

Vascular Risk Factors and Diabetes as Co-morbdities of Alzheimer's Disease

The pathway which underlies pre-clinical symptoms and onset of AD is still under dispute particularly with the finding that vascular legion have been observed in AD and may further fade the differentiation of vascular dementia and AD type dementia. Within the past

decades, the work performed by Jose Luchsinger has focused on studying the association that vascular risk factors, specifically diabetes, can have in modulating or co-existing with AD related neuropsychiatric symptoms and early onset of cognitive decline.

Aggregation Effect of Vascular Risk Factors Increase AD Risk

In a study done by Luchsinger, Reitz, Honig, Tang, Shea, and Mayeux in 2005, there was an initial interest to understand whether there may be a compounding effect of accumulating vascular risk factors on risk of developing AD. The study consisted of 1, 138 participants who were initially dementia-free at baseline (mean age = 76.2 years) and were followed for an average of 5.5 years in a longitudinal observation. Participants were from a list of Medicare recipients 65 years or older who resided in the Manhattan area. The sample was 69.8% women, 33.1% African-American, 44.4% Hispanic and 22% White. Methods for assessment included in-person interviews for general health and cognitive function, medical history, and comprehensive neurological examination.

The study measured specifically for diabetes, hypertension, heart disease and current smoking as vascular risk factor of interest at 18-month intervals. In the comparison of incident *possible* and *probable* AD, in the presence of 3 or more vascular risk factors there was a significant increase in the risk of incidence of AD. Diabetes was among the strongest risk factor and the cluster of hypertension and heart disease also showed notable increase in risk of AD onset. This suggests that the association of diabetes with AD may not be by chance and by be explained by the co-existing with other co-morbidities for an aggregation effect. However, there was no indication of AD being ethnically specific. The only limitation was that diabetes was self-reported and no sub-clinical assessment was used to verify.

Association of Depression with Vascular Risk Factors to Increase incidence of AD

On the topic of depression, there is much speculation whether it has any associations with vascular risk factors in the development of AD symptoms. With the finding that vascular risk factors have a modulating effect on AD incidence (Luchsinger et al., 2005), there is interest in seeing whether vascular and cerebrovascular risk factors (e.g. stroke) may function as the link between depression and AD. The work by Luchsinger, Honig, Tang, & Devanand (2008) was conducted with this objective in mind. The study sample consisted of 526 elderly individuals from New York City who where dementia-free at baseline and followed for a longitudinal study for 5 years. Demographic distribution of participants was 31.2% African-American, 48.3% Hispanic and 20.5% White. Measures of depression, AD and dementia were collected using established criteria and surveys. Data on vascular risk factors (same as those measured in Luchsinger et al. (2005)), stroke and ethnicity were all collected by self-report.

Among the major findings, results indicated that 114 cases among the 526 sample where individuals with incidence of AD and where older, more likely to be Hispanic, and likely to have diabetes the a person without AD. However, the association of depression and AD was not explained by a history of vascular risk factors or stroke. This has been followed by the possibility that depression may be part of AD cluster of symptoms. The significant findings of this study indicate that in this first account of community-based epidemiological investigation, depression symptoms prelude dementia in the elderly. Certain important limitations include the dependence of vascular disease and stroke data purely on self-report.

Borderline Diabetes Enough to Increase Risk of AD and Dementia

Previous research associated with linking vascular risk factors with AD incidence have focused on the dependence of the future development of the risk factors, which may not be the case for diabetes. The association of diabetes with AD is still controversial because of the previously categorized association with vascular dementia. However the events that underlie the diabetes pathway, specifically the onset of insulin resistance have been implicated with a direct effect on the brain (Yaffe, Kanaya, Lindquist, Simonsick, Harris, Shorr, & et al., 2004).

A recent study conducted by Xu, Qiu, Winblad, and Fratiglioni (2007), pursued the theory that even the most preliminary indicators of the development of diabetes may be enough to increase the risk of dementia and AD. The longitudinal study with 3-month and 9-month time points included a cohort of 1,173 dementia- and dementia-free individuals with the criteria of 75 years or older. Measure consisted of 3 follow-up sessions to diagnose dementia and AD according to DSM-III revised criteria. Demographic characteristics such as age, education and other vascular factors were also collected at every time point in the study. Borderline diabetes was defined as a random blood plasma glucose level below diabetes. Data supports the notion that the association of elevated borderline diabetes and a ~70% increase in enhanced AD and dementia risk is significant and independent of the future onset of diabetes. The study is however limited in the decision to randomly assign a blood glucose level to define borderline diabetes and there was no effort to measure insulin level to verify diabetes.

The Dissemination of Services and Resources to Support Latinos with AD

Effective Recruitment Strategies

One of the most prevalent observations in the studies that seek to offer knowledge as well as services to the Latino population is that Latinos may not always be willing to continue in

longitudinal studies or take part in studies at all. This may be associated with their undocumented status or a case of lack of knowledge of the availability of such resources. The work done by Gallagher-Thompson, Singer, Depp, Mausbach, Cardenas, & Coon (2004) to improve the development and success of educational and mental health support and treatment has been significant in identifying which modes of recruitment are best suited for attracting the Latino population.

The sample consisted of a total of 310 caregivers (195 Latino and 105 Caucasian). Measures screened for overall participation any three forms of recruitment: non-profession (health fairs), professional (community agencies) and advertisements. Results indicated that Caucasian caregivers where more likely to be retained across all recruitment strategies. Latino caregiver only had similar retention values in the profession strategy for recruitment. Methods included either active-treatment or support by telephone. Further measures were obtained from the caregiver to account for stress levels, mental health and diagnosis of dementia. The observation that Latinos responded more to the professional method of recruitment suggest that there may be an element of trust involved in the process which must be accounted for to retain high levels of Latino involvement in studies.

El Portal Alzheimer's Project

After the consideration of the prevalence of AD and associated diabetes and dementia in the Latino elderly, it important to consider whether any significant strides have been made to provide easy access to support centers and the local community in dealing with AD to underserved Latino population. One of the most important movements to make education and treatment for prevention of AD onset has been the El Portal Alzheimer's Project which is located

in Los Angeles (Aranda, Villa,Trejo, Ramirez, & Ranney, 2003). The initial success of this project was assessed with the frequency with which 900 adults used the resources, specifically the bilingual helpline. Only 273 actually came into the clinic to receive the face-to-face in-take interview for further assessment.

Intake and referral were valuable measures in determining the efficacy of the El Portal Alzheimer's Project. 80% of the callers to the helpline where women and had a family-member with dementia. Children to young adults were more likely to call on behalf of one of their family members and speak in English. It is significant to say that 91% of the respondents reported this as their first attempt to reach the L.A. Alzheimer' Association and 54% reported no previous use of community services. Also, 64% said stated that they were unaware of these facilities. Most of the people who were admitted were women and of Latino origin. There was a 93% report of severe impairment in function of daily life of the demented family member. Those who have become frequent attendees at El Portal report high use of case management (89%), counseling (87%), information (74%), and educational training (67%). This report on the success of the El Portal Alzheimer's Project in addressing the needs of the Latino caregivers in the local community with demented relatives shows one of the most remarkable programs to decrease the barriers to sufficient and effective health access in the area of mental health.

Discussion

The following review has thoroughly reviewed only a selection of research literature which has made discoveries that have increased the awareness for the consideration of culturally-specific factors as well as the impact of psychosocial burden in the context of ethnically relevant mental health. There is evidence for the lack of knowledge of AD among the Latino population

which poses as a significant barrier to adequate health access and preventative support treatment. The Latino Health Paradox seemed to be applicable to the low incidence of Latino mortality and the increase survival time post-diagnosis which reveals the benefits of the social support and active coping strategies that Latino employ to buffer the burden of daily stressors on physical and mental health.

On several accounts, Latinos have been shown to have a greater risk of developing dementia and AD and these chronic effects are enhanced by diabetes. The body of research that has focused on defining the coping styles of Latinos has been vital in making the biomedical field more aware of more variables that have to be measured or accounted for in the context of ethnically diverse studies. The existence of El Portal Alzheimer's Project through the Alzheimer's Associations is a good indicator that influential organizations relevant to healthcare and the community are becoming vital in disseminating knowledge and advocating research on chronic mental illness. It is even more significant to recognize the emphasis for the need to take into account the fact that there is a large cultural component of availability and access to healthcare that has to be addressed to meet the needs of one of the largest ethnic minorities that is rapidly growing and in need of sufficient intervention programs and health care in old age.

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