

**DePaul University  
School for New Learning  
Advance Project**

**Empower the Latino Community:  
Improve Alzheimer's Outreach**

**Focus Area: Leadership in Public  
Healthcare and Wellness**



**F-11: Can design and produce a significant product that gives evidence of advanced competence.**

**F-12: Understands principles and processes of Leadership in Public Health and Wellness, and can create a specialized outreach best practices guide for not-for-profit Alzheimer's organizations to identify and develop services for the Latino informal caregiver.**

**Spring 2014**

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### **Family is First**

According to the U.S. Census, “the number of Americans, aged 65 and older, in 2050 is projected to be 88.5 million, more than double its projected population of 40.2 million in 2010” (Vincent, et al 1). The surge in growth of the older population will present many challenges for lawmakers and healthcare services; as a result, “these demographic changes affect the nation’s public health” (Hopkins 377). Hopkins points out an estimated 5.2 million older Americans have Alzheimer’s disease, and the incidence rates are projected to double by 2050 (Hopkins 377).

In the United States, Latinos are the fastest growing older adult group. It is projected that by 2050 the life expectancy of Latinos will increase to 87 years of age. In the United States, the Latino aging population is expected to be the nation’s fastest growing minority population. As the U.S. Latino population ages, a growing number of families will be impacted by Alzheimer’s disease.

Alzheimer’s has impacted our family twice; first, my father’s sister, my aunt, was diagnosed with an advance stage of Alzheimer’s over five years ago due to lack of health insurance and her inability to seek medical attention. Currently, my aunt does not recognize her own family and needs a caregiver. The changes of seniors developing Alzheimer’s disease doubles about every five years after age 65, and after age 85 the risk reaches nearly 50 percent (U.S. Administration of Aging and The National Alliance for Hispanic Health 1).

Two years ago, my father, a retired steel worker began exhibiting strange behavior at the age of seventy-three. I remember, my mother telling me that he was coming home from the grocery store saying he needed to return because he didn’t pay the bill or owed monies. My father has always been very responsible and not paying his bills was unheard of. When I talked to him, he seemed confused and not himself. I immediately made an appointment with his

primary doctor. The doctor gave him a cognitive test and diagnosed him with Alzheimer's. At the time, I didn't even tell my father because I was not convinced. I had so many questions. His primary doctor mentioned an Alzheimer's specialist for a second opinion. My father's English is limited, so when the specialist asked me to translate and tell my father that he had Alzheimer's, my immediate response was I couldn't tell him. How could I explain this to him when I didn't understand it myself? I don't remember ever getting any culture sensitive materials in Spanish. I didn't get information or resources for additional help to understand the disease and treatment. According to the U.S. Administration of Aging and The National Alliance for Hispanic Health, Latinos often face language and cultural barriers as they navigate the health and social service systems. There is a lack of culturally proficient services and few long-term care facilities geared toward Latinos (1).

Culturally, as a Latina daughter, I was not going to give my father this news because I needed to protect him. In fact, I have to agree with the U.S. Administration of Aging and The National Alliance for Hispanic Health that family relationships are at the heart of Latino culture and there is an expectation that children will take care of their parents in old age (13). I remember being more upset than my father. I asked myself, what will my father think of this diagnose or how will he react? The little he understands about this disease is that Alzheimer's is a mental illness and stigma in the Latino culture. In fact, beliefs about memory loss and lack of knowledge about Alzheimer's in the Latino community delay prompt diagnosis (Rosenthal Gelman 185). The drive home seemed endless, until my father said, "I know, I'm sick, I have what your aunt has, and I know there is no cure. But, the medication is going to slow the progression of this disease, right?" I was naive to think that he did not understand the doctor. I fought back the tears because I knew my father was stronger than I thought. Somehow, I knew

he was going to be alright!

My father was fortunate because he has health insurance through his retirement pension plan. Having access to healthcare insurance allowed him to seek medical attention, and he was diagnosed at an early stage of Alzheimer's. Not to mention, his health insurance has allowed him to purchase his medication at a lower cost. More importantly, my father has loving family interested in his care and well-being. Although, as Latino caregivers, we would benefit from guidance and understanding of Alzheimer's disease; formal support services awareness, caregiving training, educational programs and formal support resources to best care for our love ones afflicted with this disease.

## **Section 1: RESEARCH STRUCTURE**

### **Rationale**

The U.S. Census Bureau projects the Latino population aged 65 years and older is projected to grow from 2.9 million to 17.5 million, a more than six-fold increase (Vincent, et al 6). Seniors age 65 years and older will compose 20% of the population in 2030 with an increase percentage of minority elders (Neary and Mahoney 163; Vincent, et al 4).

The Alzheimer's Association reports, as the Latino population ages, a growing number of Latino families will be impacted by Alzheimer's disease—a degenerative condition that causes memory loss, challenging behavior problems, and severe functional limitations (Novak, et al 2). As a result of functional limitations, a person with Alzheimer's requires a range of health care services. A person may require memory prompts and regular visits by family and friends in the early stages of Alzheimer's disease. In the late stage of Alzheimer's disease, a person requires constant supervision, support and hands-on care.

Many seniors with Alzheimer's disease are in nursing homes, but the majority of Latinos

with the disease live in the community where their families provide a majority of care (U.S. Administration of Aging 3; Novak, et al 4). According to recent research, Latino families underutilize formal caregiver services (Neary and Mahoney 165). This presents numerous challenges for their families and primary caregiver. At the same time, “many Latino families are not aware of Alzheimer’s disease, the demand on caregivers, or the variety of resources available in their community” (Rosenthal 181). The National Alliance for Health reports caregivers fail to receive current Alzheimer’s information (The National Alliance for Hispanic Health 7).

My focus area is Leadership in Public Health and Wellness; therefore, my attention is focused on educating the Latino family and caregivers to recognize Alzheimer’s and offering outreach recommendations to reduce the barriers to formal services utilization. Based on the compilation of literature, I will attempt to make the connection between the inability of current non-profit Alzheimer’s outreach and services programs to sufficiently meet the needs of Latino families and Latino informal caregivers.

In 2010, the Alzheimer’s Association’s *Alzheimer’s Disease Facts and Figures* reported that studies were beginning to uncover the impact of Alzheimer’s disease among Latinos (Alzheimer’s Association). Recent reports, such as the *Latino Age Wave* and the Alzheimer’s Association’s *2014 Alzheimer’s Disease Facts and Figures* along with the journal of applied gerontology article, “An Inquiry Into Latino Caregivers' Experience Caring for Older Adults With Alzheimer's Disease and Related Dementias” have indicated Latinos are currently at higher risk for Alzheimer’s than non-Latino Whites (Borrayo, et al 487). *The New York Times* reported Latinos are not genetically more predisposed to Alzheimer’s. However, there are factors linked to their low income and cultural dislocation that can put Latinos are at a greater risk for dementia

and other diseases, such as diabetes, obesity, cardiovascular disease, stroke and possibly hypertension (Belluck A1). As a result, the projected growth of the aging Latino population and their increased risk for Alzheimer's suggests older Latinos will be in greater need of care due to the progressive deterioration of their physical functions (487). Therefore, my research study is feasible based on current data indicating an increase in the aging Latino population and an exploration "to understand how to serve the Latino families and primary caregivers" (Neary and Mahoney163). At the same time, my advance project contributions will provide a better understanding of the cultural factors, barriers to seek care and needs of the Latino families and caregivers.

### **Problem statement**

The problem is that current not-for-profit Alzheimer's best practices for outreach and service programs are not targeting the Latino informal caregivers, commonly the children, siblings, spouses who provide the care and support of an Alzheimer's family member.

### **Hypothesis**

This advance project is based on the following hypotheses:

- Currently, the Latino informal caregiver in the U.S. is not seeking formal support services.
- Effective not-for-profit Alzheimer's best practices for outreach and service programs exist in U.S. communities.
- Current effective not-for-profit Alzheimer's best practices for outreach and service programs can be used as a model for other and new Alzheimer's outreach and service programs.

## Advanced Project Goals

In this project, I will:

- Review existing literature on Alzheimer's disease affecting the Latino aging population.
- Review existing literature on the Latino informal caregiver in the U.S.
- Identify the factors that influence the utilization of formal support services by Latino informal caregiver caring for a family member with Alzheimer Disease.
- Review existing literature on current Alzheimer's outreach and service programs as means of educating the Latino informal caregiver.
- Design an *Alzheimer's Outreach Best Practices Guide for the Latino Community*.

These best practices are the final objective of my Advanced Project that I hope will equip Latino families, non-profit Alzheimer's organizations, community leaders, health professionals, not-for-profit beginners, who offer healthcare services to the aging Alzheimer's Latino population and their primary caregivers with recommendations to reduce the barriers to care and increase the utilization of formal services. I plan to design an Alzheimer's Outreach Best Practices Guide for the Latino Community because "many Latino families are not aware of Alzheimer's disease, the demand on caregivers, or the variety of resources available in their community" (Rosenthal 181).

My decision to create an Alzheimer's Outreach Best Practices Guide is to promote wellness and support services for the Latino informal caregiver. Overall, the goal for my artifact is to offer recommendations for not-for-profit Alzheimer's organizations serving the Latino community: develop advance knowledge and understanding of Alzheimer's disease; provide formal support services awareness; offer caregiving training, educational programs and formal support resources and encourage the replication of outreach and service programs throughout



Alzheimer's organizations.

### **Limitation of the Study**

This advance project will focus on analyzing current issues of Alzheimer's best practices for outreach and service programs for Latinos in the United States. This project will not focus on Alzheimer's best practices for outreach of other cultures and races.

### **Research Methodology**

This study is based on data collected through two research methods. The first body of information is collected through a literature review that consists of reviewing past and current literature on Alzheimer's best practices for outreach in the U.S. communities. The second source of information is my own experience and personal reflections. Specifically, this data is based on the Alzheimer's experiences of my own father and family experience.

## **SECTION 2: LITERATURE REVIEW**

### **Hispanic or Latino**

Hispanic and Latino are frequently used interchangeably and refer to a heterogeneous group that share Spanish as a common language. Latino has become an inclusive term that is used by people of Latino or Hispanic descent to empower themselves in political arenas, humanities, and literature (Torres 386). This study uses the term Latino rather than the term Hispanic because not every Hispanic is a Latino, or a person of a Latin American country that is fluent in Spanish.

### **Latinos a Diverse Minority Group**

The Latino population in the United States is a diverse group with 39.1% of the population being foreign born. The majority of Latinos originate from Mexico (66.1%),

followed by people of Central and South America (14.5%), Puerto Rico (9%) and Cuba (4%) (Ayalon and Huyck 94). Latinos from these regions differ in many ways, such as reason(s) for immigration to the United States, length of residency, socioeconomic status and current educational attainment (D. Gallagher-Thompson, et al 47). In spite of these differences, Latinos overall share several important cultural foundations: language, religious preference, values, and foods (47).

### **Two Significant Demographic Changes**

In the United States, two significant demographic changes contribute to the growing numbers of people with Alzheimer's in the Latino population. First, the natural aging process appears to be a strong risk factor for Alzheimer's disease. The U.S. Census Bureau reports the number of elderly Hispanics is expected to climb to 8 million by 2050 and those age 85 and older representing the fastest growing segment of the elderly population (U.S. Administration of Aging and The National Alliance for Hispanic Health 1). The Alzheimer's Association estimates that by age 65, one out of every ten persons develops Alzheimer's disease. As the incidence of Alzheimer's rapidly increases the numbers of those affected by the disease will more than double by the year 2050 (Alzheimer's Association 1).

Secondly, the Latino population is remarkably increasing in the United States. The Pew Hispanic Center reports, "The 2000 census marked the Hispanic population at 35.3 million people, an increase of 58% over 1990" (2). In addition, the Latino population will increase fifty-eight percent resulting in over 47 million Latinos by the end of this decade and 60 million by year 2020 (Pew Research Center Project 2).

Furthermore, one out of every four Americans will be of Latino descent by year 2050 (Vincent, et al 5). The combination of these two demographic changes is significant because

according to the 2000 census, Latinos are both the fastest growing minority population and the fastest growing group of sixty-five years of age and older (Pew Research Center Project 2). Due to the increase of Latino aging population and the startling incidence of Alzheimer's disease, it is imperative that professionals "understand how to serve the Latino families and primary caregivers" (Neary and Mahoney 163).

### **Understanding Alzheimer's**

M.P. Aranda confirms that over the past two decades, Alzheimer's disease has gained such attention and is recognized as a major public health problem in both developed and developing countries (116). Alzheimer's is the most common type of dementia notes the *2013 Alzheimer's Disease Facts and Figures Report* (Alzheimer's Association). Dementia is an umbrella term describing a variety of diseases and conditions that develops when nerve cells in the brain (called neurons), die or no longer function normally (Alzheimer's Association 8). The disease deteriorates the brain over a course of time and it slowly affects the intellectual functioning of the brain, eventually resulting in major thinking and physical impairments as well as changes in personality (Alzheimer's Association 12).

### **Disease Process**

Normally, as we age there is some forgetfulness, but the symptoms of Alzheimer's diseases are more than simple absentmindedness. The most common symptom pattern begins with a gradually worsening ability to remember new information. This occurs when neurons in the brain begin to die, and malfunctions occur that involve the forming of new memories. As neurons in other parts of the brain malfunction and die, individuals experience other difficulties. As the disease progresses, individuals not only lose their memory, but their ability to learn, reason, make judgments, communicate, and carry out daily activities (Alzheimer's Association

12).

For instance, individuals with Alzheimer's disease might get lost in their own neighborhood or forget how to make a phone call (12). Over time, these individuals experience changes in personality and behavior, and gradually become anxious, suspicious, and irritable. In late stages of the disease, they need help with daily activities, namely eating, dressing, and bathing. Regrettably, Alzheimer's disease is an irreversible condition and ultimately fatal (Alzheimer's Association 12).

### **Aging Latinos with Alzheimer's**

The Alzheimer's Association projects 1.3 million Latinos will have Alzheimer's by the year 2050, and more than 200,000 are already living with the disease today (54). Furthermore, the Latino community seems to have a higher rate of vascular disease, diabetes, high blood pressure and high cholesterol that promotes a higher risk of developing Alzheimer's (2). Overall, Latinos face a greater risk of the disease because unlike the general population, Latinos are living longer and growing in numbers (2). Alzheimer's impacts the Latino family and primary caregiver due to the individual's debilitating progression of memory disorders that requires assistance with daily living routines.

### **Caregiving**

A 2004 report published by the National Alliance for Caregiving in collaboration with AARP defines caregiving as the assistance with one or more personal care activities, such as bathing and dressing (3). At the same time, caregiving activities can include assistance with other daily living activities; for example, balancing a checkbook, paying bills and driving family members to medical appointments (Alzheimer's Association and the National Alliance for Caregiving 4). Caregiving is typically between spouses or between parents and adult children

(7).

In the United States, a typical caregiver is a married, 46 years-old female, has some college experience and spends an average of twenty hours or more per week providing unpaid care to someone 50 or older (National Alliance for Caregiving (20). Some of these caregivers of people with Alzheimer's have children living at home. These caregivers are called the "Sandwich Generation" because they find themselves squeezed between the caregiving for their children and their elderly parents or other elder family members (Alzheimer's Association 28).

The National Alliance for Caregiving report identifies two types of caregivers: formal and informal. Formal caregivers are trained at a home health agency or other organizations that have related education and are paid for their services (53). These caregivers are nursing aides, nurses, housekeepers and comprise the formal caregiver services (Alzheimer's Association 41).

The *2013 Alzheimer's Disease Facts and Figures* reports 11 million Americans provide unpaid care for a person with Alzheimer's disease" (23). The report mentions, in 2012, unpaid caregivers or informal caregivers provided an estimated 17.5 billion hours of unpaid care to recipients with Alzheimer's disease. This number represents an average of 21.9 hours of care services per caregiver per week, or 1,139 hours of care services per caregiver per year (34).

### **Latino Caregiver**

The most predominant form of care given to Latinos with Alzheimer's disease is through the use of informal support or care provided by a family member (Ayalon and Huyck 94). A 2008 Evercare and National Alliance for Caregiving study indicates one-third of Latino households have at least one family caregiver resulting in approximately eight million Latino caregivers in the United States (23). The study also points out eighty-four percent of Latino

caregivers believe that their role is an expectation with their upbringing. Seventy percent think that it would bring shame on their family not to accept a caregiving role versus sixty percent of non-Latinos (11).

The same study showed Latino caregivers spend more hours a week giving care and taking on the more intensive caregiving needs, than caregivers from other ethnic groups (35). Forty-three percent of Latino caregivers live with their loved ones versus thirty-two percent of non-Latino caregivers (11). Many Latino caregivers have made major changes in their employment, from taking a leave of absence, to changing jobs, cutting back hours or stopping work entirely (49). Ultimately, many caregivers are making themselves more vulnerable to financial, health and emotional distress (59).

In 2009, the National Alliance for Caregiving, in collaboration with AARP, published *Caregiving in the U.S.A Focused Look at the Ethnicity of Those Caring for Someone Age 50 or Older*, a report that indicates Latino caregivers are females on average 43 years-old, less likely to be married than some of their counterparts, more likely to have children or grandchildren living in their household, have lower educational levels and lower annual household incomes (13). The report confirms sixty-seven percent of Latino caregivers are females versus thirty-three percent males (13).

### **Past and Current Studies Understanding the Latino Caregiver**

In 2002, authors Dilworth and Anderson wrote *20 Year Review of Issues of Race, Ethnicity and Culture Study (1980-2000)*. A narrative approach was used to review a total of fifty-nine articles and studies published between 1980 and 2000. The study focused particularly on race, ethnicity, and culture (Dilworth-Anderson, et al 237). The authors selected articles and studies that focused on informal caregiving of dependent people (Dilworth-Anderson, et al 237).

The review identifies four domains: 1) social support of the caregiver (formal and informal), 2) negative effects of caregiving on the primary caregiver, 3) coping with the stress of caregiving both on the individual and family network level, and 4) cultural effects on caregiving. The results confirmed culture affects the caregiving experience (Dilworth-Anderson, et al 238). The findings of values and norms showed evidence that Latino families use clear guidelines influencing the care of the family member and the interactions between caregivers, family members, and social institutions (Dilworth-Anderson, et al 238). Furthermore, the review indicates most researchers found cultural groups have values about reciprocity, obligation, and a sense of responsibility for providing care to older family members (Dilworth-Anderson, et al 264).

Most importantly, the review indicates Cox and Monk's 1993 study and Huttlinger's 1998 study were the only two studies conducted specifically on the influence of culture in caregiving. Both studies discovered cultural values and norms manage "familial relationships" and the care of the elderly among Latinos (Dilworth-Anderson, et al 265). These two studies revealed extended family members provide care to older relatives (265). Overall, Dilworth and Anderson use an identifiable theoretical approach for almost half (28 out of 59) of the articles and studies reviewed. The remaining studies relied primarily on empirical generalizations and provided less direction for researchers with no definite expectations about what an observation should look like (265).

In 2002, Dr. Karl Kosloski's study provided a better understanding of how the role of culture affects the use of respite services (Kosloski, et al 93). Respite services provide the family caregiver with a temporary rest from caregiving. The types of respite care are provided at home by a paid homemaker service or outside the home in a health care setting, such as adult day care

or residential facility (Alzheimer's Association). Kosloski's study confirms Latinos endorsed the "highest levels of family values and the regression of respite use on family values, but as the strength of family values increased, so did respite use" (83). Latinos chose to use respite care services because these services targeted Latinos in a manner consistent with their beliefs and family values, reported Kosloski. Moreover, these care services were specifically designed to increase "access to minorities and greater access leads to greater use" (83).

Neary and Mahoney's study in 2005 once again explores the phenomenon of dementia caregiving of the ethnically diverse group of Latino caregivers with the goal of identifying cultural influences on the caregiving experience (Neary and Mahoney 163). The study's findings concluded participants shared "culturally related beliefs about family obligations, reciprocity, and the primary of home-based care" in the decision of ongoing care management and nursing home placement (169). Caregivers in this study viewed placement of a family member in a nursing home as the last resort. At the same time, the study indicated Latino caregivers continue to maintain vigilant in their family members' care and keeping with their Latino values of family obligation if placement in a nursing ever became an option (169).

### **Barriers to formal caregiving services**

Literature reviewed for this study reveals Latino families underutilize formal caregiver services (Neary and Mahoney 165; Scharlach, et al 143; Ayalon and Huyck 95). Various factors have been determined as barriers to formal caregiver services: language barriers, health beliefs that promote informal care and alternative care, financial limitations, insensitivity to cultural factors in formal settings, the stigma of Alzheimer's and lack of knowledge about the available services and about Alzheimer's disease (Ayalon 96). In the process of this review, four major barriers were identified that prevent formal caregiver services.



First, the culture health belief barriers, some Mexican Americans believe in the health barrier of “balance” (Gallagher-Thompson, et al 213). This health barrier is a combination of spiritual faith and nutrition that says how one lives his/her life determines whether or not an illness is brought on (213). Often times, Latino families see Alzheimer’s as their “cross to bear” because “it is God’s will” (214). Another health belief barrier is the belief that their loved one’s memory impairment is caused by “nerves” and is a temporary state (214).

Second, the barrier of the lack of awareness or knowledge about the Alzheimer’s disease, and services available to Latino caregiving families may be tied to a language barrier (215). Many older Latinos speak limited English and public awareness campaigns on Alzheimer’s disease are usually delivered in English instead of Spanish (216). Consequently, caregivers fail to receive current Alzheimer’s information (U.S. Administration of Aging and The National Alliance for Hispanic Health 7).

The third barrier is the lack of education about Alzheimer’s disease; many elder Latinos have little to no formal education (D. Gallagher-Thompson, et al 214; Ayalon and Huyck 97). The lack of education only increases the caregiver’s misunderstanding of the disease and adds to the caregiver’s misconception of Alzheimer’s. Latino caregivers view Alzheimer’s as a physical illness and not a mental illness (214). Mental illness in the Latino families is viewed as social stigma and embarrassment (214).

The fourth barrier are the generational differences, in Latino families there is the concept of respect, and the family is prohibited from sharing their Alzheimer’s experience with others, as to not bring further shame to the affected family member (215). Therefore, older Latino caregivers may not feel comfortable discussing their caregiving responsibilities. For instance, the term burden is not an acceptable term to many Mexican American caregivers. Older

caregivers view it's their responsibility as a strong sense of obligation towards an aging Alzheimer's relative, with the expectation that caregiving is provided at home. So, to acknowledge the experience of burden is to acknowledge complaining about being a caregiver and this is culturally inappropriate. This is unlike younger Latino caregivers, who were more likely to attend support group and discuss their experiences (D. Gallagher-Thompson, et al 47).

At the same time, norms related to caregiving are likely to influence Latino families to use formal service (Ayalon 96). Culturally defined values, norms, and roles have been identified as major determinants of the caregiving experience and are likely affecting service utilization (Scharlach, et al 135). The Latino culture value of "familism" or "family is first" is a very important culture value that guides the Latino caregiving role (Ayalon and Huyck 95). This value emphasizes an expectation that children will take care of their aging parents. "Respeto" or "respect" is another culture value among Latinos that involves showing respect to their elders (U.S. Administration of Aging and The National Alliance for Hispanic Health 8).

As a result, this value does not allow for adult children to tell their aging parents what to do. Spirituality is another important Latino culture value that plays a central role when older Latinos suffer health issues (8). This culture value makes it difficult to convince older Latinos the importance of managing their condition. Understanding Latino culture values and norms is important because culture affects the ways Latinos make decisions about caregiving (8).

### **Current Alzheimer's outreach and service programs**

Existing programs for Latino older adults need to offer care and services to this underserved population. The Little Havana Activities Center in Miami to the support services of the Spanish-Speaking Elderly Council-Raíces in Queens and Brooklyn, NY, as well as the Dementia Care Network of El Portal: Latino Alzheimer's Project in South Los Angeles are community-

based organizations offering Latino families culturally relevant, linguistically relevant, accessible, affordable and replicable projects and programs (Brown-Santiago 1). These current Alzheimer's service programs offer the means of educating Latino families and the Latino informal caregiver.

In particular, the El Portal Latino Alzheimer's Project is a dementia specific outreach and services program targeting Latino caregivers in the Los Angeles area. The program uses culturally specific outreach and services delivery strategies. More importantly, the program recently evaluated their service utilization and found that there was a reduction in barriers to care and an increase in services utilization (Aranda 116).

The El Portal Latino Alzheimer's Project, initiated in 1992, created a Dementia Care Network model that has been used by the Los Angeles Chapter. The model is a "great example of an interorganizational community-based collaborative developed to provide an array of coordinated, ethnic-sensitive services to Latino families" (Brown, Rabiner and Wiener 1). Equally important, this type of service model has shown it can be replicated with a variety of ethnic groups and works to create an ongoing change in community dynamics and service delivery (Brown, Rabiner and Wiener 1).

*Alzheimer's Disease Demonstration Grants to States Program* reports, the El Portal suggests that a number of system-level and network-level elements are needed to change the care environments in ethnic communities (Brown, Rabiner and Wiener 1).

On the system level, an intervention must have:

- An alliance of trust among the community's service organizations, forming a Dementia Care Network to address the needs of the community as a whole.
- Technical expertise on dementia care and fund-raising among the members of the Dementia Care Network.

With a Dementia Care Network in place, outreach to ethnic caregivers must:

- Respect and incorporate the cultural beliefs and language of the caregivers in the counseling process and in planning for support services.

- Approach the caregivers in ways appropriate to their level of literacy and at the institutions where they can be reached.
- Acknowledge and address the caregivers' fears of discrimination.
- Acknowledge and address limits that the poverty of many caregivers places on their ability to secure support.
- Maintain flexibility in overcoming practical barriers (3).

The El Portal Project conducts an intensive public relations and outreach campaign, including print and electronic media, marketing presentations to consumer and provider groups, and community fairs (Aranda 116). Outreach is culturally appropriate, including the development of bilingual materials in recognition of the need to educate the community about Alzheimer's disease and available services (Brown, Rabiner and Wiener 6).

### **Section 3: CONCLUSION: RECOMMENDATIONS**

Literature reviewed for this study confirms the term Latino is preferred by this inclusive diverse minority population group in the United States. As this research point out the combination of two significant demographic changes in the Latino aging population increases this population's incidence of Alzheimer's disease. The affected Latino elder's progressive physical deterioration will result eventually in the assistant of their daily living routines. The assistance of one or more personal daily living routines is defined as caregiving. Latino families will be impacted with the caregiving of a relative with Alzheimer's.

The review of past studies, specifically the study, *20 Year Review of Issues of Race, Ethnicity, and Culture Study (1980-2000)* revealed past studies focused on race, ethnicity, and culture on informal caregiving of dependent people (Dilworth-Anderson, et al 238). In essence, Dilworth-Anderson's findings confirmed culture effect the caregiving experience. The findings of these two studies indicated extended family members provide care to older relatives (Dilworth-Anderson, et al 265).

The review of current studies; such as, Dr. Karl Kosloski's 2002 study showed Latinos had the "highest levels of family values and chose respite care services that were consistent with their family values (Kosloski 83). Neary and Mahoney's study in 2005 explored the phenomenon of dementia caregiving of Latino caregivers, with the goal of identifying cultural influences on the caregiving experience (Neary and Mahoney 163). Their findings indicated caregivers viewed placement of a family member in a nursing home as the last resort.

Literature reviewed for this research identified various factors that have been determined as barriers to formal services (Ayalon 96). In particular, four major barriers were identified that prevent Latinos families from using formal services. This research also identified three strategies to encourage formal care services in Latino families. Lastly, El Portal Latino Alzheimer's Project in Los Angeles, California is an example of a successful program that provides culturally specific outreach and services delivery strategies. "Employing a culturally appropriate approach to promote enduring change in community dynamics and service delivery, the El Portal project has brought increased dementia services to a wide range of ethnic communities"(Brown, Rabiner and Wiener 22).

### **Recommendations**

There is lack of culturally proficient formal care services geared toward Latinos (U.S. Administration of Aging and The National Alliance for Hispanic Health 5; Ayalon and Huyck 102). The *Alzheimer's Disease Outreach to the Latino Community Report* noted a key strategy to provide culturally formal care services to Latinos families by making available culturally proficient and bilingual Alzheimer's information (5). It's essential to create and distribute bilingual resources to increase formal caregiving services and provide support to Latino families and caregivers. The bilingual resource information should include the following: respite care,

caregiving training, financial support, local elder care services, and assistance in navigating through the medical and insurance jobs.

Maria Shriver, a former journalist and first lady of California became an Alzheimer's activist after her father, Sargent Shriver, was diagnosed with the disease in 2003. In a 2010 speech, she mentioned, "We need more information out there in Spanish, and we need more people from the Latino community speaking out about the realities of Alzheimer's, so that people understand what the disease is and what they can do to deal with it" (Hernandez).

Alzheimer's disease awareness is increased in the Latino population through community outreach, education and networking; as a result, these strategies promote formal caregiving services (U.S. Administration of Aging and The National Alliance for Hispanic Health 5). For instance, the implementation of bilingual Alzheimer's programs can create family support through education and provides caregivers with informed choices about their family member long term needs.

Lastly, a strategy to promote formal caregiving services can provide Latino families and caregivers with access to local Alzheimer's services or caregiving services i.e. home health care services, home-delivered meal programs, hospice care and caregiver support programs (Herrera, et al 145). These local services have outreach staff, healthcare and social services professionals that are culturally proficient or have an understanding of the Latino culture and its role in caregiving services (5).

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DePaul University  
School for New Learning  
Advance Project Artifact

**Alzheimer's Outreach  
Best Practices Guide  
for the Latino Community**



**Spring 2014**

## Alzheimer's Outreach Best Practices Guide for the Latino Community

Advance Project Artifact

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*For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer's disease is a pain they know all too well. Alzheimer's disease burdens an increasing number of our Nation's elders and their families, and it is essential that we confront the challenge it poses to our public health. ~ President Barack Obama*



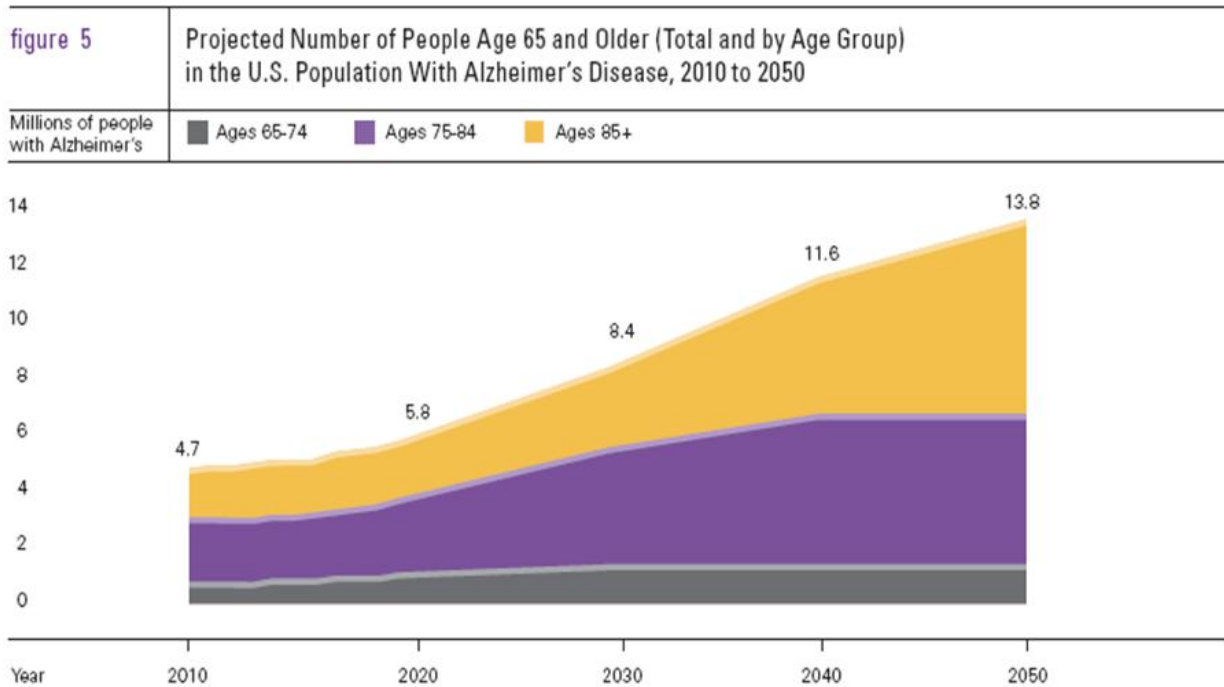
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This easy to use best practice guide is designed to equip Latino families, non-profit Alzheimer’s organizations, community leaders, and health professionals, non-for-profit beginners, who offer healthcare services to the aging Alzheimer’s Latino population and their primary caregivers with best practices to increase Alzheimer’s outreach and awareness. In addition, these best practices are being offered in attempt to reduce the barriers to care and increase the utilization of formal services.

## Introduction

The number of Americans, aged 65 and older, in 2050 is projected to be 88.5 million. The number of elderly Latinos is expected to climb to 8 million by 2050 and those age 85 and older representing the fastest growing segment of the elderly. The increasing growth of elderly Latinos has significant implications for health care planning and services. As the number of elderly Latinos increases so will projected number of Alzheimer’s Disease cases as shown in Figure 5.



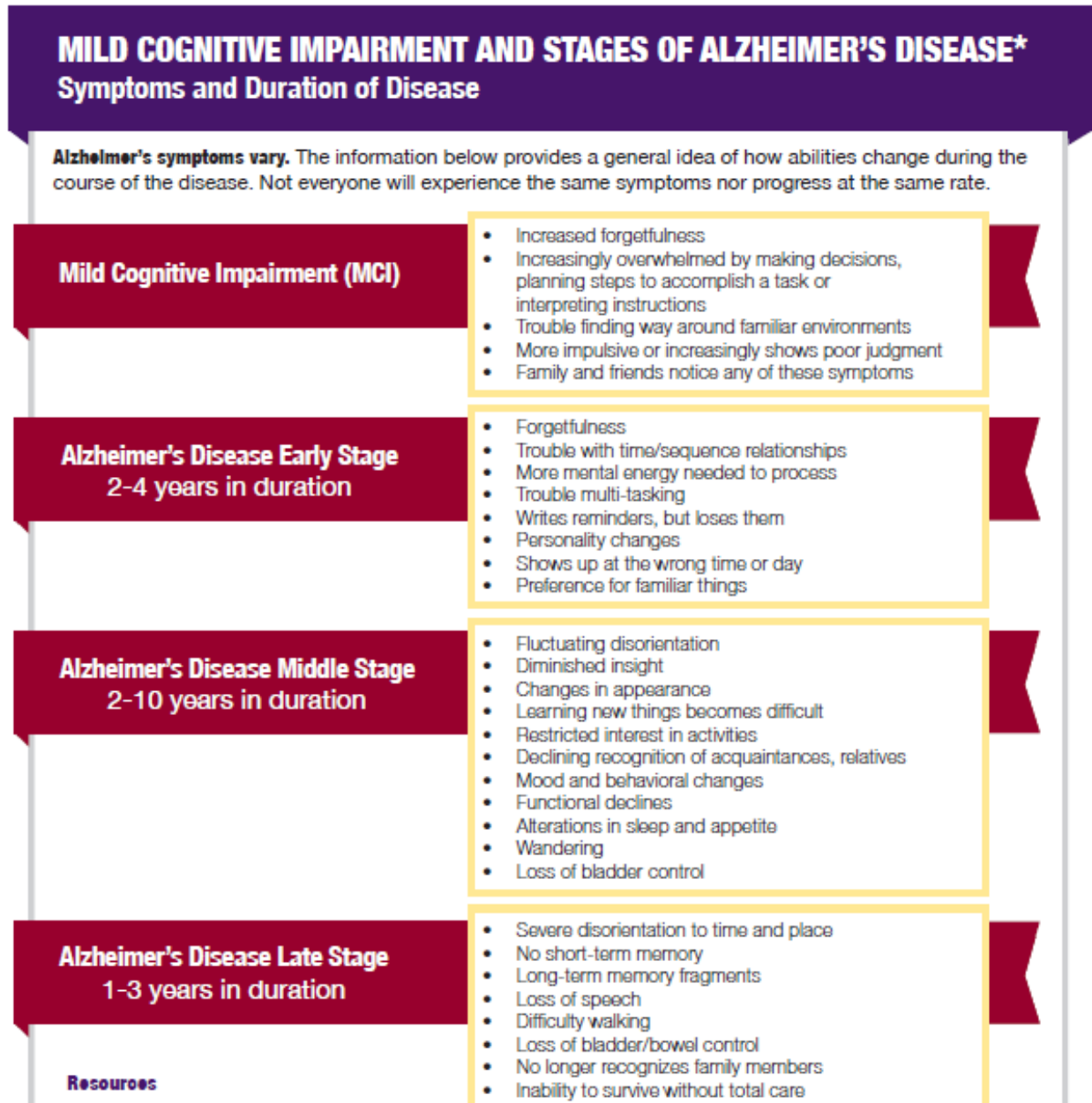
Source: (Alzheimer's Association 21)

*“...there was also wide spread agreement that more community-based organizations will either need to emerge or the ones that exist will need to expand in order to meet the needs of a growing Latino older adult population.” ~ The Latino Age Wave*

## Alzheimer's

Alzheimer's is the most common type of dementia. Dementia is an umbrella term describing a variety of diseases and conditions that develops when nerve cells in the brain (called neurons), die or no longer function normally. The disease deteriorates the brain over a course of time and it slowly affects the intellectual functioning of the brain, eventually resulting in major thinking and physical impairments as well as changes in personality as shown in Figure 6.

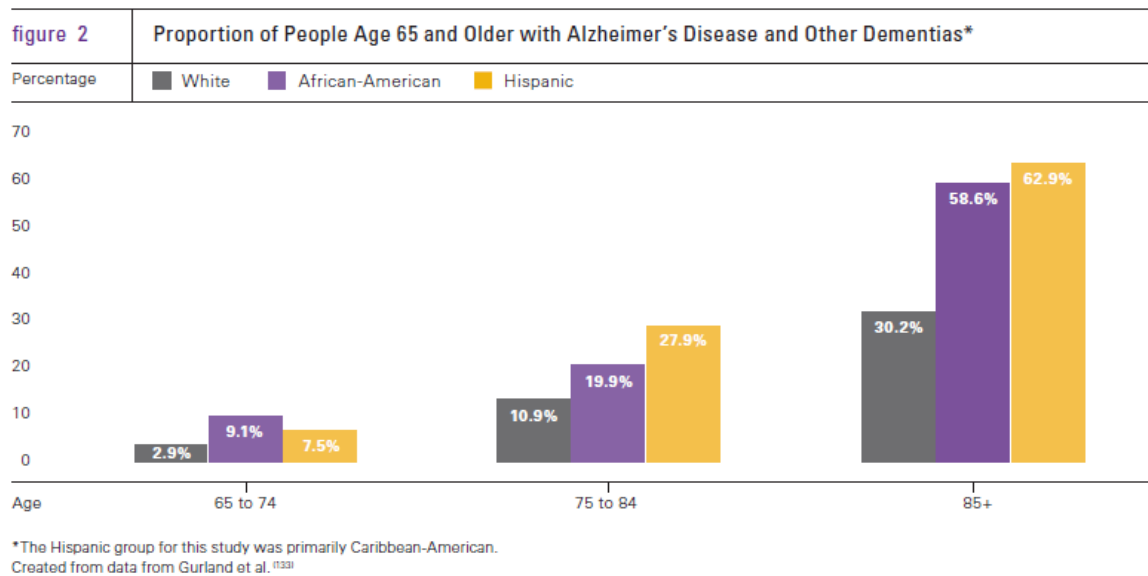
Figure 6



Source: (Act On Alzheimer's 4)

## Latinos with Alzheimer's

The Alzheimer's Association projects 1.3 million Latinos will have Alzheimer's by the year 2050, and more than 200,000 are already living with the disease today. Furthermore, the Latino community seems to have a higher rate of vascular disease, diabetes, high blood pressure and high cholesterol that promotes a higher risk of developing Alzheimer's. Overall, Latinos face a greater risk of the disease because unlike the general population, Latinos are living longer and growing in numbers as shown in figure 2.



Source: (Alzheimer's Association 18)

## Impact on the Latino Caregiver

Family is the heart of the Latino culture and there is an expectation that children will take care of their aging parents. Aging Latinos are more likely than other seniors to live with families.

- One-third of Latino households have at least one family caregiver resulting in approximately 8 million Latino caregivers in the United States.
- Eighty-four percent of Latino caregivers believe that their role is an expectation with their upbringing.
- Seventy percent think that it would bring shame on their family not to accept a caregiving role versus 60% of non-Latinos .
- Latino caregivers spend more hours a week giving care and taking on the more intensive caregiving needs, than caregivers from other ethnic groups.
- Forty-three percent of Latino caregivers live with their loved ones versus thirty-two percent of non-Latino caregivers.
- Many Latino caregivers have made major changes in their employment, from taking a leave of absence, to changing jobs, cutting back hours or stopping work entirely.
- Ultimately, many caregivers are making themselves more vulnerable to financial, health and emotional distress.

*“ The family is the most important social unit among Latinos and it plays a central role in how they care for aging relatives. According to a 2008 survey, there are an estimated 8.1 million Latino caregivers in the U.S. — 74 percent of who are female and in their early 40s.”*

*~ The Latino Age Wave*

## Understanding the Barriers

Latinos families and caregivers are not receiving Alzheimer’s information and support service they need. These barriers make it difficult for them to seek services and place a heavy burden on the family.

- Lack of knowledge of the Alzheimer’s disease.
- Limited in speaking English makes it difficult to communicate with health professionals.
- Status of citizenship impacts the accessibility to public benefits and healthcare.
- Religion influences the attitudes and behaviors of Latinos.
- No health insurance or limited health insurance
- Lack of finding culturally proficient bilingual healthcare professionals.
- Limited culturally proficient Alzheimer’s services for Latino families and caregivers.
- Shortage of culturally proficient bilingual support and information for the Latino families and caregivers.
- Lack of knowledge of available federal, state and local assistance programs, as well as health and social support services related to Alzheimer’s.

## Alzheimer’s Outreach Best Practices

Alzheimer’s Outreach Best practices provide advice and guidance for how to best serve the Latino aging population and their families; promote confidence to ask for Alzheimer’s support; and encourage participation in Alzheimer’s programs to enhance their quality of life. These best practices are based on practical considerations: culturally-appropriate, effective and replicable.

- Use culturally proficient and bilingual outreach staff that understands the Latino culture and its role in care.
- Make culturally proficient bilingual and bicultural materials available to the Latino community, caregivers, community partners and health and social service professionals.
- Train outreach staff to link Latino clients with Alzheimer’s resources and with assistance they are eligible for.
- Work with the Latino media to raise awareness about Alzheimer’s disease and dementia.
- Disseminate Alzheimer’s information through community events.
- Offer workshops and trainings for healthcare and social services professionals to educate them about Latinos and the Alzheimer’s disease.
- Partner the Latino community with existing and trusted community organizations.
- Operate Alzheimer’s programs as a means of providing culturally proficient activities, information and support for caregivers



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