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Exploring the Barriers of Latino Caregivers of Persons with Alzheimer's and the Underutilization of Services

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EXPLORING THE BARRIERS OF LATINO CAREGIVERS OF PERSONS WITH
ALZHEIMER'S AND THE UNDERUTILIZATION OF SERVICES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Kimberly May Holton

June 2017

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ABSTRACT

The purpose of this study is to explore the barriers Latino family caregivers of persons with Alzheimer's may experience, and evaluate methods to increase the utilization of these services among the population. The researcher conducted face-face interviews with staff members that have observed the underutilization and provide feedback on method on reaching this particular population. The results of the interviews were transcribed to written form, and then analyzed to identify and label themes. The following four major themes emerged. These themes were: 1) culture 2) language barriers 3) fear 4) lack of knowledge of diagnosis. The potential impact of this study is to find ways to reach out to the Latino population, and provide accurate viable information and services to this particular population. This will continue to further the outreach in social work practice for the Latino population.

ACKNOWLEDGEMENTS

I would like to thank Dr. Armando Barragan for his availability, support, and patience. I would like to thank Inland Caregiver Resource Center staff for taking time out of their busy schedules to help with the interviews. I also want to thank all the professors that taught me so much over the past three years, and of course the cohort that went above and beyond to help each other get through many tough times.

Most importantly I want to thank my friends and family for the continuous support over the past three years. My husband and children have been very patient and understanding as I took them on this roller-coaster ride with me. I am forever grateful for their continuous support and love. I am truly blessed

DEDICATION

I dedicate this project to my hard-working mom who never gave up on me no matter what. She watched me grow into a beautiful person and when she knew I was ready to let go, she let go and joined our father in heaven.

I love you mom.

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CHAPTER ONE

INTRODUCTION

Problem Statement

There are approximately 50.5 million Hispanics that currently reside in the United States (U.S. Census Bureau, 2010). Individuals of Hispanic origin are about 1.5 more times more likely to develop Alzheimer's disease than individuals of white origin. One of the major unrecognized public health issues in the Hispanic Community is Alzheimer's disease and other dementias. Thus, creating opportunities for Latinos to overcome cultural barriers to obtain services to reduce the burden is extremely significant. Consequently, the strong Latino cultural commitment to the family can cause an extreme amount of strain on the caregiver.

Some obstacles Latino family caregivers often encounter are language barriers, cultural barriers, and discrimination in effort to seek services (Valle, 1998). There are various agencies that are in the process of outreach to the Latino community, in hopes to recruit caregivers in receiving services to enhance quality of life. Social workers and people in the helping field are able and capable of reaching out to this community and educating the population on what services are available to the family caregivers, thus reducing stress and burnout of Latino caregivers.

The purpose of the social work profession is to improve the well being of vulnerable and oppressed individuals and communities (NASW, 2010). It is the

responsibility of social workers and people of the helping profession to educate, assist, and offer the Latino community knowledge about services that are available to them to help improve their overall health.

Substantial research has shown that individuals that care for their loved ones with dementia have a higher risk of psychological and health related problems. Some of problems they may encounter are higher levels of burden, stress, and symptoms of depression (Pinquart & Sorenen, 2003). There have also been other studies concerning the burden of Latino family caregivers of persons with Alzheimer's and self-care. However, there are few studies conducted regarding the self-care of caregivers, and the under-utilization of services that are available to the caregivers.

Social workers have an integral part in assisting family caregivers of older adults through several avenues in the health care systems. This includes mental health and long-term care. The social work profession is built on strengths based, person-in-environment perspective. This allows for the social workers to advocate for and support family caregivers of older adults. It is designed to help the public understand the role of a professional social workers as they aid in supporting family caregivers (NASW, 2010). As social workers, it is our responsibility to advocate for our clients and provide resources that are available. Latino caregivers of people with Alzheimer's would be more open to utilizing services if they knew what was available to them.

Purpose of the Study

The purpose of this study is to explore the barriers Latino family caregivers of persons with Alzheimer's may experience, and evaluate methods to increase the utilization of these services among the population. The researcher conducted face-face interviews with staff members that have seen the underutilization and provide feedback on method on reaching this population. The target population will be Latino Caregivers of persons with Alzheimer's, and the staff that works with the caregivers because the study is to explore their perspective on services that they may or may not be familiar with.

Social service workers that work with caregivers of persons with Alzheimer's can provide an array of services to help when the caregivers are struggling; however, the community is not always aware of the services that are readily available to them. If the researcher along with the social service workers can identify why this particular population is not utilizing services, then we can work together to reach out to them to address the issue. This study served as an effort to explore through the perception of social service workers what are the barriers Latino caregivers may have, and what do they see as ways to reach out to this population.

Significance of the Project for Social Work

This study is significant for social work practice, such that the data obtained can provide a possible technique to reach Latino family caregivers to assist with potential utilization of services that are readily available. Caregivers of

persons with Alzheimer encounter many stresses and burdens while caring for their loved ones; however, Latino family caregivers encounter many more barriers since they are unaware of the services that are available.

This study is to explore what barriers Latino caregivers encounter, and why they are not utilizing the services that are readily available in the community. The Latino population continues to increase; however, the utilization of service does not significantly increase. Latino immigrants are more likely to underutilize health care services and are more likely to receive low-quality care when the service are used (Oretega, 2015). Since the Latino population underutilizes these services, it then becomes a social problem. Underutilization of the services prevents this population from having full access to a service that can assist with coping with the stresses of being a caregiver.

Social workers that are involved with caregivers and their care receivers can assist the Latino community in accessing caregiver services for themselves and for their loved one. Social workers that work with Latino caregivers of persons with Alzheimer need to evaluate what the caregiver and care receiver need, and provide detailed resources to better help serve this specific population. In order to provide opportunities for these caregivers and lighten the social issue of underutilization of services, social workers must be mindful of the distinct needs of this population.

What are the unique barriers Latino Caregivers have in regards to obtaining services, and what ways can social workers increase the utilization of these services?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This section will provide an overview of literature regarding the barriers and the under-utilization of services among the Latino community. The literature review will cover three major factors that affect the utilization of services that are readily available to Latino caregivers. The first factor that will be discussed is Latino cultural values, and the perception of utilization of services. The second factor is the lack of education readily available for caregivers about self-care. The last factor that will be discussed is the services available. Theories guiding conceptualization will conclude this chapter.

There many ways to describe or define what a caregiver may entail, but it is commonly an individual that assists with personal care activities, such as bathing or dressing. These individuals go above and beyond to care for their loved ones. It is typically a spouse, a parent, or adult child. These caregivers also may assist with other caregiving needs such as financial support and planning. In a recent survey of more than 1,500 participants caregiving was defined as “providing care for a relative aged 50 or older to help take care of themselves” this included assistance with personal needs, household chores, arranging for services, or visiting regularly (National Alliance for Caregiving/American Association of Retired Persons, 1997).

Culture

Latino caregivers have numerous barriers in regards to seeking and receiving services. The primary barrier for the Latino community is culture differences. The caregiving experience usually is different for each culture. Different cultures have different values and norms, and this may determine if a caregiver utilizes services. Close family ties or Familism, is one of the values that has been observed in Latino families. Having a close family and caring for each other is one of the primary values of Latino culture. This has been the major motivation for Latino families as they provide care for one another (Cox & Monk, 1993). Familismo is a word used in the Latino community and refers to have a close relationships and loyalty to all the family members. Having a sense of protection, honor, respect, and support among the family members is also included in the definition of Familismo (Leon, 2008). Latino cultures differ from many other cultures in that they are more concerned with that family and less focused on individuality. Some of the advantages of being family oriented are that there is an overabundance of family support when there is a medical crisis. However, a disadvantage of this is that they are hesitant to seek services that are readily available because they prefer to rely on the family.

Familismo is associated with idea of mutual support, giving back love and support the family gave to them, and respect for the elders (Scharlach, et al. 2006). Often the younger family members care for their elders as their health begins to decline. However, research shows that Latino families that care for

their loved ones show a responsibility and respect towards elders because it is part of the family life (Ibarra, 2003). Understanding the role of Latino caregivers clarifies how difficult it can be to accept services, which can contribute to self-care, and longer healthier life.

Self- Care

Being a caregiver for a person with Alzheimer's disease can become extremely stressful. Research on caregivers that care for persons with Alzheimer experience tremendous burdens and strain. Often time's Latino caregivers are unfamiliar with what services is available to them to assist with taking care of themselves. Being educated on self-care is crucial toward maintaining a longer healthy lifestyle.

Research has shown that caring for a family member can increase the use of substances and depression. As a caregiver, many unexpected occurrences determine how each day turns out. The caregiver may feel that caring for their loved one exemplifies love and commitment, and can make an individual feel gratified by the work they are doing. However, caregiving can also result in fatigue, anxiety, and the sense that there are not enough resources, and this constant care can cause an extreme amount of stress. An estimated 46 to 59 percent of caregivers are clinically depressed. There are many other issues that emerge in the life of a caregiver, such as anger, frustrations, relationship issues, financial stress, and seclusion (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Rabins, Mace, & Lucas, 1982). However, these findings are focused

mainly on Caucasian caregivers. The experiences of Latino caregivers was not presented in these findings, which may be the reason behind the underutilization of service.

Maintaining activities outside of caregiving is a form of self-care. These activities may include taking care of one's own physical and mental health, seeking support from friends, church, other family members, and even support groups (Merluzzi, Philip, Vachon, & Heitzmann, 2011). Oftentimes caregivers forget to make time for themselves to continue to maintain a healthy lifestyle so they can continue providing quality care to their loved ones. Taking care of the caregiver is the most important aspect in caregiving, and often the most overlooked. A primary form of self-care for caregivers is reaching out for services. Often individuals of the Latino culture are unfamiliar with services that can be utilized in regards to self-care.

Services Available

The utilization of services by Latino caregivers is limited since they are unfamiliar with what services are available. If more outreach to the Latino community is put into action the probability of utilizing the services would increase. Several studies, as stated above, illustrate that caregivers of the Latino culture are more likely to rely on family members for support, than to seek outside care, and the elderly also typically seek less medical care than European-American, that may be experiencing similar situations. Additionally, Latino caregivers are not aware that there are medical treatments that can help

an individual that suffers from dementia which could also significantly reduce the amount of stress the caregiver may be experiencing (Harwood et al., 2000; Hinton, Haan, Geller, & Mungas, 2003).

Additional research has shown that much of non-Hispanic whites were able to utilize service due to the fact they advertised these services at various locations such as, dementia diagnostic centers, adult day care programs, and community support groups. However, it was found that Latino typically don't use the services as often as non-Hispanic whites. There are many factors for the underutilization of the services, such as, lack of knowledge about services, language barriers, and previous negative experience from the service systems (Starett, Todd, Decker, & Walters, 1989). Therefore, this has resulted in the underutilization of these services by Latino family caregivers.

Language barriers about the services available are also an issue for Latino caregivers. There has been an ongoing issue with language barriers and the information provided by agencies that offer service for Alzheimer's disease. For many Latino caregivers, their primary language is Spanish, and oftentimes Public awareness information is not accessible in Spanish (Gallagher-Thompson et al., 1996). This has resulted in inadequate distribution of information to the Spanish speaking community. This can be an issue because they do not always interpret the correct services available, and they possibly could be missing out on services that are readily available.

Theories Guiding Conceptualization

For the purpose of this study two essential theories will be used to help guide the conceptualization of the research: (1) Systems theory and (2) Ecological perspective.

First, Systems Theory is described as multiple unrelated systems which influence human behavior. According to systems theory each one of the subsystems influence each other's parts of the whole. This theory is utilized to view individuals holistically in the environment they are in, and to determine how such environment influences the systems and how they connect (Buss, Perone, & Spencer, 2011).

General systems theory will be applied to the study to understand how the interaction of Latino caregivers and the family subsystems influence the larger systems such as services that are available to caregivers of persons with Alzheimer. There are several barriers that influence the utilization of these services, such as lack of knowledge of services available, language barriers, and cultural and family beliefs.

From a systems' perspective, this study will explore the unique barriers within the Latino community of caregivers, and provide a better understanding of services that may be utilized for caregivers of person with Alzheimer's. Systems theory will also be used to develop a general understanding of how several systems connect and how the environment influences each other.

Second, the ecological perspective differs from systems theory, but has employed many of the concepts associated with it (Kondrat, 2015). Applying the ecological perspective in this study will help with determining the client's needs and addressing the problems they may encounter as caregivers.

Social work's interest in social networks is firmly rooted in the ecological perspective, which focuses on the correlation between the clients that are being served and the environment they are in. This method distinguishes the cause and solution of problems that individuals may encounter within society (Barth, 1986). The ecological approach has been utilized in two ways (1) building more supportive nurturing environments through various forms of environmental help (2) improving client competencies through the teaching of specific life skills (Whittaker, Schinke, & Gilchirst, 1986).

The ecological perspective will consider the effects the environment has on Latino caregivers, and how this may shape individual behavior. Furthermore, the ecological perspective may assist in providing researchers with a way to understand why Latinos do not utilize services that are readily available.

Summary

This section has explained the barriers and some reasons for the underutilization of services that are available. Also, this chapter provided an extensive amount of research and evidence to demonstrate that Latino caregivers of persons with Alzheimer's have a tremendous amount of stress and

barriers when dealing with a loved one. Finally, this chapter indicated two essential theories that will help conceptualize and guide further research.

CHAPTER THREE

METHODS

Introduction

This section will address the research methods and design that was used to determine the impact of cultural and environmental barriers on Latino caregivers of persons with Alzheimer's. This section will also provide procedures for data collection and instruments, protection of human subjects, and data analysis.

Study Design

The purpose of this study is to increase the knowledge about underutilization of services by Latino family caregivers of persons with Alzheimer's, and to explore ways to increase the utilization of these services among the population. The researcher conducted interviews with staff members that have seen the underutilization and provide feedback on method on reaching this population. The design that was utilized in this study is a qualitative research design. The qualitative design consisted of face-face interviews with staff members that have seen the underutilization of services, and provide feedback on how to reach out to this community. The researcher provided informed consent to all participants of the study as needed. The target population will be Latino Caregivers of persons with Alzheimer's, and the staff that works with the

caregivers because the study is to explore their perspective on services that they may or may not be familiar with.

The purpose of this study is to explore the barriers Latino family caregivers of persons with Alzheimer's may experience, and evaluate methods to increase the utilization of these services among the population. By examining the perceptions of current staff, case managers, family consultants and social workers, this study will aim to gain insight on how to reach out to the community to better serve the Latino community.

Sampling

Since this population is often hard to reach, nonprobability-sampling approach will be used for this study. Purposive sampling can be useful in this type of sample because it needs to reach out to the target populations quickly and where the opinions of the population can be obtained. Also, reaching out to the population allows the possibility of reaching out to others that are in the same community, and spreading the word about the study. Thus, snowball sampling was utilized.

Multiple social service workers that work with Latino family caregivers of persons with Alzheimer have agreed to participate in the interviews for this study. These participants have contact with the Latino community, and understand the need for advocacy in the aspect of outreach. There are currently 10 staff members at Inland Caregivers Resource Center that includes: Intake specialists, Social workers, marriage and family therapists, family consultants, and the

Executive Director, have agreed to participate in a survey and or interviews for the purpose of this study.

Data Collection and Instruments

This research study utilized a series of questions that were asked by the researcher to the social service workers in an interview setting (Appendix A). Questions that were asked were pertinent to the underutilization of services among Latino caregivers of persons with Alzheimer.

Procedures

The primary data that was used was from staff members and clients from Inland Caregivers Resource Center. The researcher utilized the staff that works within the Latino Caregivers community to partake in a brief interview. Intake specialists, social workers, marriage and family therapists, family consultants, and the Executive Director, all participated in the interviews for the purpose of this study.

To begin the interview, process each participant was provided with details about the purpose and procedures of the study. They were also provided with informed consent form to be signed (see Appendix B). This form was explained in detail along with the complete understanding of anonymity for the participant. The participants were also assured that he or she is not required to continue participation and if, at any time, he or she feels uncomfortable during the study,

they can withdraw without consequence. The participant was also given a demographics questionnaire for the purpose of this study (see Appendix C).

For the interview portion, each participant was asked a series of questions pertaining to the underutilization of services of Latino caregivers (see Appendix A). The interview took no more than 15 minutes. After the interview was complete the participant could ask any questions that pertain to this study unless it disclosed confidential information.

Protection of Human Subjects

The researcher completed Human Subjects Ethics Training in the Protection of Human Participants prior to beginning the research project and conducting interviews. There are no known risks at the time for participation with the study. Participants were informed that participation in the interview was voluntary, and had the option to withdraw if he or she felt uncomfortable. Participants were made aware that withdrawing from the study would not result in any consequences. The anonymity of the participants is protected and participants were instructed not to reveal any identifying information during the interview. Participants completed an informed consent prior to providing any information (see Appendix B).

Data Analysis

The current study utilized a qualitative study design to explore the barriers for Latino caregivers of persons with Alzheimer and the underutilization of

services. The study explored a small group of current social service workers and their perceptions of underutilization of services within the Latino community. The researcher conducted interviews that were recorded and then transcribed which provided pervasive themes and patterns of the participant's perception of the underutilization of services. These themes were then being categorized, sorted, and analyzed. The questionnaire portion was also analyzed for perceptions of why Latinos underutilize services that are readily available.

Summary

This chapter addressed the research methods and design that were used in order to determine the impact of cultural and environmental barriers on Latino caregivers of persons with Alzheimer's. This section also provided procedures for data collection and instruments that were used for the purpose of the study. This section also addressed, procedure, protection of human subjects, and data analysis.

CHAPTER FOUR

RESULTS

Introduction

The purpose of this study is to explore the barriers, if any, contribute to the underutilization of services of Latino family caregivers of persons with Alzheimer's. This chapter discusses the qualitative results obtained from interviews with social service workers. These interviews were recorded and then transcribed to analyze the emerging themes. This chapter will demonstrate what social service workers encounter as barriers for Latino family caregivers. The demographics of the participants will also be discussed in this chapter. These demographics consist of age, gender, race/ethnicity, level of education, religion, language preference, and language spoken.

Demographics of Participants

There were a total of 6 participants in this sample. Their ages ranged from 18-59. All the participants were female (n=6). Of the six participants, five identified as being Latino/ Hispanic (83%) while one participant identified as being Caucasian (7%). Education levels of the participants included three having Bachelor's degrees (50%), and three having Post-graduate degrees (50%).

Religion and spirituality data were included in the demographics portion of this study. Participants indicated that they were of the Christian faith and Catholic

faith. Half of the participants were of the Christian faith and the other half were of the Catholic faith.

Language preference and languages spoken other than English was also collected from the demographics portion of the study. A total of four participants (67%) stated that they prefer to speak Spanish, and the other two participants (33%) prefer to speak English. Out of the six participants, five (86%) speak another language, which was Spanish.

Table 1. Demographic Information of Participants

ID	Age	Ethnicity	Level of Education	Religion	Language Preference	Other Languages Spoken
1	18-29	Hispanic	Bachelors	Catholic	English	Spanish
2	30-39	Hispanic	Bachelors	Catholic	English	Spanish
3	30-39	Hispanic	Bachelors	Christian	Spanish	Spanish
4	50-59	Hispanic	Post-Graduate	Christian	English	Spanish
5	40-49	Hispanic	Post-Graduate	Catholic	Spanish	Spanish
6	50-59	Hispanic	Post-Graduate	Christian	English	None

Presentation of the Findings

After analyzing the data from the interviews, the following four major themes emerged. These themes were: 1) culture 2) language barriers 3) fear 4) lack of knowledge of diagnosis. This section will address each of the themes with a description from the participants during the interview process.

Culture

During the interviews, each one of the participants expressed that culture appeared to be one of the major factor for the underutilization for Latinos caregivers. Each participant observed that culture affects decisions made by Latino caregivers of persons with Alzheimer's.

Respondent 1

I don't know if it's their own personal upbringing as well, of who asks for help and who doesn't. I know in my family we have the pride of you don't ask for help. You do it yourself. If you're sick, you get better on your own. (Personal Communication, January, 2016).

Respondent 2

We'll, for caregivers a lot of our culture is you take care of your own. You also keep your problems at home too. You don't go around sharing or—it doesn't seem like it's—it's part of life to take care of your grandparents or your parents. A lot of the times they don't see themselves as caregivers. They just see themselves as family (Personal Communication, January, 2016).

Language Barrier

Language barriers came up in some of the interviews. These participants expressed how language barriers prevent Latinos from utilizing services.

Respondent 6

“Language barriers always seem to be an issue when I have worked with the Spanish speaking community. I don’t speak Spanish, but they try to explain to me what they need.” (Personal Communication, January, 2016)

Respondent 1

I think it’s difficult to cater to the Latino community because of that language boundary. Sometimes things are not explained correctly and they just don’t understand.” (Personal Communication, January, 2016)

Respondent 2

“Finding providers and doctors that can come in and do conferences in Spanish has been a challenge for us. We use to combine everything together, and it didn’t always work.” (Personal Communication, January, 2016)

Fear

Each one of the interviewees expressed that fear of something appeared to be a barrier for Latino caregivers. From a few of the interviewees they stated that these fears included not qualifying for services because of their legal status.

Respondent 3

“A lot of them are afraid of not qualifying for services because they’re undocumented. So, that’s a big problem with providing services or even trying to get their confidence or trust.” (Personal Communication, January, 2016)

Respondent 5

Because I do a lot of outreach and sometimes it’s like they’re scared because maybe they’re undocumented. So, they see social services and

they think they are going to send them back to their country or something so they're a little bit leery about it. (Personal Communication, January, 2016).

Lack of Knowledge about the Diagnosis

The lack of knowledge about the diagnosis also came up as one of the main themes during the interviews. The interviewees expressed that many Latinos don't understand what Alzheimer's, so they're unaware of something being wrong with their loved one.

Respondent 2

"There needs to be more education on what Alzheimer's is and what dementia is so that—there's a lot that think it's just part of aging." (Personal Communication, January, 2016)

Respondent 4

Some challenges of obtaining services are lack of education. Lack of knowledge on the diagnosis and the disease. Many people think Alzheimer's or any symptoms pertaining to the disease are a normal part of aging. And therefore, they don't believe it's necessary to seek assistance or seek medical advice until other complications come across. (Personal Communication, January, 2016)

Summary

The results of this study were presented in this chapter. The basic demographics of the interviewees in the study were discussed. The participants discussed what they observe as the barriers for Latino caregivers of persons with Alzheimer's. A qualitative thematic approach was used to identify the major themes that emerged during the interviews which included culture, language barriers, fear and lack of knowledge of diagnosis. These interviews provided by social service workers described what some of the barriers are for Latino caregivers of persons with Alzheimer's.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will provide and discuss the key findings of the themes that were found and discussed in chapter four. The discussion will include an analysis from the participant's narratives and key findings important to the research. The Limitations of the study will also be presented in this chapter along with recommendations for social work practice, policy and future research. Finally, the chapter will conclude with final thoughts about how social service workers can better reach the Latino population.

Discussion

The purpose of this research study was to explore the barriers that contribute to the underutilization of services of Latino family caregivers of persons with Alzheimer's through the observation of social service workers. The interviews with the social service workers revealed four major themes that they have observed while working with the Latino Population. These interviews demonstrated that culture, language barriers, fear, and lack of knowledge about the disease are contributing factors to why Latino family caregivers do not utilize services that are available.

Culture

Culture was identified as one of the four major themes that emerged during the interviews with the social service workers. In the literature review culture was also identified as being a barrier for Latino family caregivers in utilizing services. According to Ibarra (2003), Latino caregivers are more likely to feel obligated to care for their elders as a form of respect. The literature also states, the caregiving experience varies depending on the cultural values and norms which will also determine the service utilization (Becker, Beyene, Newsom & Mayen, 2003).

Respondent 2 observed that, “for caregivers a lot of our culture is you take care of your own” (Personal Communication, January, 2016). In the other interviews, the participants also described how in the Latino culture the families rely more on the families than asking for help.

Language Barriers

Language barriers was observed by the participants as being another one of the barriers Latino family caregivers encounter in utilization of services. Language barriers has been an ongoing issue with information provided by agencies that offer service for Alzheimer’s disease. For many Latino caregivers, their primary language is Spanish, and oftentimes Public awareness information is not accessible in Spanish (Gallagher-Thompson et al., 1996). According to the literature it is evident that language barriers are the cause for the underutilization

of services. Public awareness campaigns on Alzheimer's disease are usually delivered in English rather than Spanish; yet Spanish is the preferred language for many Latino caregivers (Gallagher-Thompson et al., 1996).

Respondent 1 stated, "I think it's difficult to cater to the Latino community because of that language boundary. Sometimes things are not explained correctly and they just don't understand." (Personal Communication, January, 2016) Language barriers can range from but are not limited to, pamphlets only in English, presentations and conferences only in English, and the lack of bilingual social service workers working in the field.

Fear

Although the literature did not demonstrate that fear was one of the barriers for Latino caregivers in the utilization of services, it did appear to be observed by the social service workers as one of the common reasons Latinos do not utilize services.

Respondent 3 stated, "A lot of them are afraid of not qualifying for services because they're undocumented. So, that's a big problem with providing services or even trying to get their confidence or trust (Personal Communication, January, 2016)."

Respondent 5 stated, "Because I do a lot of outreach and sometimes it's like they're scared because maybe they're undocumented. So, they see social services and they think they are going to send them back to their country or something so they're a little bit leery about it (Personal Communication, January,

2016).” Social service workers found that fear of being deported has not only prevented Latino family caregivers of receiving services, but it also has prevented the Latino community from confiding in the social service system.

Lack of Knowledge About The Disease

Lack of knowledge about the disease was also one of the major themes that emerged in the interviews, but it was also found in the literature. Oftentimes families do not realize what is wrong with their loved one. They may think it is just a simple part of aging. One respondent stated, “Some challenges of obtaining services are lack of education. Lack of knowledge on the diagnosis and the disease. Many people think Alzheimer’s or any symptoms pertaining to the disease are a normal part of aging. And therefore, they don’t believe it’s necessary to seek assistance or seek medical advice until other complications come across (Personal Communication, January, 2016)”. Many families do not know the signs of Alzheimer’s; this is not limited to only Latino families.

Limitations

This study came across a couple of limitations. The first limitation was the non-probability data that was collected along with the small sample size. The researcher initially had over twenty volunteers; however due to unforeseen circumstances only six were able to participate. Since the sample size was small it limits the ability to make a generalization about what the barriers Latino family caregivers encounter in receiving service for their loved one with Alzheimer’s.

Another limitation was the study did not have enough of diversity in race and gender. Since the sample was taken from an organization where the employees are majority Latina/Hispanic and female it is difficult to determine if the data collected was precise.

Recommendations for Social Work Practice, and Research

The data collected in the study, clearly exhibits the need for social service workers and agencies to find ways to meet the needs of the Latino population. As the Latino population continues to grow the need for services will also continue to grow. It is imperative for the field of social work to understand the barriers that continue to keep the Latino population from utilizing services.

This study is significant for social work practice, so that the data obtained can provide a possible technique to reach Latino family caregivers to assist with potential utilization of services. This study is also important for social work practice and in research because it can potentially reduce the burnout of Latino family caregivers that try to take care of their loved ones on their own. It is the responsibility of social workers to be cultural competent in all aspects of practice. The Latino population does not always know what is available to them, and with cultural and language barriers, it is difficult for them to receive effective services.

Future studies that could be conducted on the utilization of services by the Latino population would be ways to break the barriers that prevent them from utilizing services. This future research could be conducted in the Latino community, and would be significantly beneficial if the sample size was larger.

Also, outreach to the Latino community by Spanish speaking social service workers would also be valuable in the utilization of services.

Conclusions

The purpose of the study was to explore the barriers for Latino family caregivers of persons with Alzheimer's and the underutilization of social services. Through the data collected it was evident that social service workers felt that there were unique barriers Latino family caregivers experience in the utilization of services. Additionally, it was evident that culture effects all aspects of the utilization of these services for the Latino population.

APPENDIX A:
QUESTIONNAIRE

Interview Questions:

1. What has been your experience with working with the Latino Population? What education have you received that may benefit working with the Latino Population?
 - a. Before college?
 - b. During your undergraduate schooling?
 - c. Prior work experience?
 - d. During your graduate schooling?
 - e. Additional work experience?

2. Are you comfortable working with this population?
 - a. If “No” – Can you please explain why not?
 - b. If “Yes” – When and how do you believe you developed this comfort? Was it taught in school, did you learn from personal experience, training from working in this facility, exposure, etc.?

3. What do you perceive to see as the challenges of obtaining services for Latino caregivers of persons with Alzheimer? Do you perceive any difficulties in communicating and providing services to this population?

4. What do you believe makes serving this population unique compared to other populations?

5. What do you think are some methods to reach out to this particular population?

6. Do you have any other thoughts or comments on this topic?

Question Created by: Kimberly Holton

APPENDIX B:
INFORMED CONSENT



INFORMED CONSENT

The study in which you are being asked to participate is designed to explore the barriers that Latino caregivers of persons with Alzheimer may experience from the perspective of social service workers. This study is being conducted by graduate student Kimberly Juarez with the supervision of Assistant Professor Armando Barragan, School of Social Work, California State University, San Bernardino. This study has been approved by the School of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

PURPOSE: The purpose of this study is to understand from an administrator's perspective the barriers Latino caregivers of persons with Alzheimer may encounter in receiving services.

DESCRIPTION: In this study you are being asked to take part in a face-to-face interview. You will be asked a few questions about your title and organization. You will also be asked to discuss your perspectives on barriers Latino caregivers of persons with Alzheimer may experience.

PARTICIPATION: Your participation in this study is voluntary. Refusal to participate will not result in any loss of benefits you are entitled to and you may discontinue participation at any time without penalty.

CONFIDENTIALITY: Any information from this interview will remain completely confidential. All data will be stored in recording device in a locked file cabinet and on a password protected computer such that the researcher will have sole access to it. Upon completion of research, all data will be destroyed.

DURATION: Your participation in the study should take 20-30 minutes to complete.

RISKS: There are no foreseeable risks to you for your participation in this study.

BENEFITS: A benefit of taking part in this study is to have a role in reaching out to the Latino population that can highly benefit from underutilized services.

VIDEO/AUDIO/PHOTOGRAPH: I understand this research will be Audio Recorded.

I agree to be recorded _____ I do not agree to be recorded _____

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College of Social and Behavioral Sciences
School of Social Work

CONTACT: If you have any questions related to the research of this study, you can contact my research advisor, Dr. Armando Barragan, Assistant Professor, School of Social Work, California State University, San Bernardino, 5500 University Parkway, San Bernardino, CA 92407 abarragan@csusb.edu (909) 537-3501.

RESULTS: The results of this study will be available at the Pfau Library, California State University, San Bernardino after September, 2017.

CONFIRMATION STATEMENT: I have read and understand the consent document and agree to participate in your study.

Place an X mark here: _____ Date: _____

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APPENDIX C:
DEMOGRAPHICS

1. What is your age?

- ☐ 18-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50 years and over

3. Ethnicity:

- ☐ African American/Black
- ☐ Asian
- ☐ Latino/Hispanic
- ☐ White
- ☐ Native American
- ☐ Other

4. Level of education completed?

- ☐ Less than High School
- ☐ High School Diploma
- ☐ Some College (2yr)
- ☐ Bachelor's degree (4yr)
- ☐ Postgraduate degree

5. Religion

- ☐ Christian
- ☐ Catholic
- ☐ Muslim
- ☐ Hindu
- ☐ Jewish
- ☐ Other

6. Language Preference

- ☐ English
- ☐ Spanish
- ☐ Other _____

7. Other languages spoken

- ☐ Spanish
- ☐ Arabic
- ☐ Portuguese
- ☐ Hindi
- ☐ Japanese
- ☐ Korean
- ☐ Chinese
- ☐ Vietnamese

Question Created by: Kimberly Holton

REFERENCES

- Alzheimer's Association. (2015) Alzheimer's disease facts and figures.
Alzheimer's & Dementia 2015; 11(3)332;
<http://www.alz.org/facts/downloads/factsfigures2015pdf>.
- Arora, K. & Wolf, D. (2014). Is there a trade-off between parent care and self-care? *Demography*, 51(4), 1251-1270. doi:10.1007/s13524-014-0309-6
- Barth, R.P. (1986). *Social and cognitive treatment of children and adolescents*.
San Francisco: Jossey-Bass Publishers
- Beker, G., Beyene, Y., Newsom, E., & Mayen, N. (2003). Creating continuity through mutual assistance: Intergenerational reciprocity in four ethnic groups. *Journal of Gerontology: Social Sciences*, 58B(3), S151-S159.
- Buss, A. T, Perone, S & Spencer, J. P. (2011). Twenty years and going strong: A dynamic systems revolution in motor and cognitive development. *Child Development Perspectives*, 5(4), 260–266. <http://doi.org/10.1111/j.1750-8606.2011.00194.x>
- Chenoweth, B., & Spencer, B. (1986). The experience of family caretakers. *Gerontologist*, 23, 209-213.
- Cox, C., & Monk, A. (1993). Hispanic culture and family care of Alzheimer's patients. *Health and Social Work*, 18(2), 92-100.
- Familism. (n.d.). Retrieved December 5th, 2015, from
<http://www.yourdictionary.com/familism>

Gallagher-Thompson D., Talamantes M., Ramirez R., Valverde I., (1996).

Service delivery issues and recommendations for working with Mexican American family caregivers. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity and the dementias* (pp. 137–152). Washington, DC: Taylor & Francis.

Kondrat, M. (2015). Person-in-Environment. *Oxford Bibliographies in Social Work*. doi: 10.1093/obo/9780195389678-0092

Harwood DG, Barker WW, Ownby RL, Bravo M, Agüero H, Duara R. (2000).

Predictors of positive and negative appraisal among Cuban American caregivers of Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*. 2000;15:481–487.

Hepworth, D.H., Rooney, R.H., Rooney, G. D., Strom-Gottfried, K., & Larsen, J.

A. (2013). Direct social work practice: theory and skills. Belmont, CA: Brooks/Cole, Cengage Learning

Ibarra ML. The tender trap: Mexican immigrant women and the ethics of elder

care work. *Aztlan: A Journal of Chicano Studies*. 2003;28(2):87–113.

Kelly, J. J. (2010). NASW. Family Caregivers of Older Adults. Retrieved February

28, 2016, from:

<https://www.socialworkers.org/practice/standards/naswfamilycaregiverstandards.pdf>

Leon, F.T. (Ed.) (2008). *Encyclopedia of Counseling*. (Vols.1-4). Thousand

Oaks, CA: SAGE Publications, Ins. doi:

<http://dx.doi.org/10.4135/9781412963978>

Merluzzi, T. V., Philip, E. J., Vachon, D. O., & Heitzmann, C. A. (2011).

Assessment of self-efficacy for caregiving: The critical role of self-care in caregiver stress and burden. *Palliative & Supportive Care*, 9, 15-24.

Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009). The role of resources

and appraisals in predicting burden among Latina and non-Hispanic white female caregivers: A test of an expanded socio-cultural model of stress and coping. *Aging & Mental Health*, 13(5), 648-658.

National Alliance for Caregiving/American Association of Retired Persons.

(1997). *Family caregiving in the U.S.: Findings from a national survey*.

Washington, DC: Author.

Olin J. T., Pawluczyk S., Kaufman G. T., Taussig I. M., Henderson V. W.,

Schneider L. S., (1997). A comparative analysis of Spanish- and English-speaking Alzheimer's disease patients: Eligibility and interest in clinical drug trials. *Journal of Clinical Geropsychology*. 3:183-190.

Ortega, A. N., Rodriguez, H. P., & Bustamante, A. V. (2015). Policy Dilemmas in

Latino Health Care and Implementation of the Affordable Care Act. *Annu. Rev. Public Health Annual Review of Public Health*, 36(1), 525-544.

- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*, 250–267.
- Scharlach, A., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. (2006). Cultural Attitudes and Caregiver Service Use. *Journal of Gerontological Social Work, 47* 1/2, 133-156. doi:10.1300/J083v47n01_09
- Valle, R., Yamada, A.-M., & Barrio, C. (2004). Ethnic differences in social network help-seeking strategies among Latino and Euro-American dementia caregivers. *Aging & Mental Health, 8*(6), 535–543.
doi:10.1080/13607860410001725045
- Whittaker, J.K., Schinke, S.P., & Gilchrist, L.D. (1986). The ecological paradigm in child, youth, and family services: Implications for policy and practice. *Social Service Review, 60*, 483-503.