**Caring of Caregivers Organically (CoCO): Health Education for
Latina Alzheimer's Family Caregivers**

BY

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THESIS

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This labor of love is dedicated to the woman that gave me life more than once, my mother Socorro "Quita Coco" Rocha. Alzheimer's disease has been quite the journey with Mom and I could not think of a better teacher than she has been through this Ph.D. process. *Madre usted me llena el corazón y el alma cada día y aunque se le olviden las cosas que es como usted identifica su enfermedad, espero siempre sienta cuanto su "baby" la quiere y cuida a manos llenas. ¡Gracias Señorina!*

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SUMMARY

Latinos have a 50% greater chance of having Alzheimer's disease or related dementia (ADRD) as compared to their non-Latino White counterparts. Higher levels of caregiver burden, depression and lower general health as compared to non-Latino Alzheimer's caregivers affect those who assume the caregiving. Two-thirds of ADRD caregivers are women thus it is crucial to identify practices that address the health and well-being of Latinas specifically.

A qualitative study was conducted to assess and adapt an intervention that has rendered promising outcomes for a different group of Latina caregivers, Latina mothers of children with intellectual and developmental disabilities, who share some similar physical and mental health outcomes. Five focus groups were conducted with Latina ADRD family caregivers and other stakeholders that included service providers and content area experts to identify what aspects of the existing intervention were relatable and adaptable. Based on Knight and Sayegh's (2010) revised sociocultural stress and coping model, the caregiver experiences relating to cultural values and caregiver burden were also considered for this adaptation as the model suggests these are factors that inform coping styles and social supports, which ultimately define the caregiver's health.

Through the use of thematic analysis, some of the findings included the need for information about ADRD and the trajectory of care, interest in an accompaniment model versus the *Promotora de Salud* model that the original intervention uses, and more discussion on the family dynamics that may evolve while care is being provided. An 8-week health education intervention for Latina ADRD family caregivers was developed that was informed by the focus group findings and existing literature. Implications for future research, practice and policy are offered.

I. INTRODUCTION

A.   Background, Rationale, and Significance of the Study

1. The Alzheimer's disease or related dementia panorama in the United States.

As a result of the aging of the baby boomer generation, the nation's population of adults over the age of 65 will grow dramatically over the next four decades (U.S. Census Bureau, 2010). Nearly one in five residents of the United States (U.S.) will be age 65 or older by 2030 and the racial and ethnic make-up of this age group will also drastically change (U.S. Census Bureau, 2010). It is estimated that the Latino population, the fastest growing U.S. population, will grow more than six-fold in the age group of 65 years or older. This translates to a jump from 2.9 million in 2010 (U.S. Census Bureau, 2010) to 17.5 million in 2050 or about one in five individuals age 65 or older being Latina/o by 2050. The demographics of the U.S. population with regards to age, race, and ethnicity will be experiencing a major transformation in the years to come.

One implication of having a larger populace that is older age is the propensity for chronic illness, particularly Alzheimer's disease or related dementia (ADRD). Older age is the greatest risk factor for Alzheimer's disease (AD) and most Americans with this condition are age 65 or older, with one in ten currently in this age range suffering from the condition (Alzheimer's Association, 2018). According to the Alzheimer's Association (2018), someone develops AD every 65 seconds and by 2050 that is projected to change to every 33 seconds, with nearly a million new people affected by the condition every year. By 2050 the projected number of AD cases in older adults is expected to almost triple to 13.8 million from 5.5 million in 2018 (Alzheimer's Association, 2018). Latinos have a 50% greater chance of having AD, compared to their non-Latino White counterparts (Alzheimer's Association, 2010). Some factors associated

with the higher prevalence are longer life spans and more health-related risk factors such as diabetes, high blood pressure and obesity (Alzheimer's Association, 2010).

When an individual has this condition, the impact is felt not only by the ADRD patient but also by the people that surround this individual. Particularly affected are those who assume caregiving roles at any point in the trajectory of the illness. Much of the attention and funding in the medical and political arenas regarding AD is given to finding a cure and less to the provision of quality care for those individuals with the condition. *Caregiving,* as defined by the Alzheimer's Association (2018), is tending to another individual's health needs often including help with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). Examples of ADLs are bathing and dressing, while IADLs include managing finances and using transportation among other activities.

The Alzheimer's Association 2018 Alzheimer's Disease Facts and Figures report estimates that at least 16 million people in the country are providing 18.4 billion hours of unpaid care (by family and others) to someone with ADRD which is valued at $232 billion. Although scarce, some literature examines the impact of family caregiving on Latina/o AD caregivers (Borrayo, Goldwaser, Vacha-Haase, & Hepburn, 2007; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Hinton, Chambers, & Velásquez, 2009). Other research explores effective interventions that target the caregivers' declining health and quality of life (Wisniewski et al., 2003; Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008; Morano, 2003). Fewer studies have focused on the way cultural values, norms, perceptions, and traditions play a role in the caregiving experience (Aranda & Knight, 1997; Aranda, Villa, Trejo, Ramirez, & Ranney, 2003; Arévalo-Flechas, Acton, Escamilla, Bonner, & Lewis, 2014; Gallagher-Thompson et al., 2003; Hahn, Giyeon, & Chiriboga, 2011).

2. Implications of caregiving.

Current literature is not easily generalizable to all family caregivers and even less can be used to describe the experience of all Latinos since there is subgroup diversity. The caregiver experience can be distinct due to demographic differences such as age, gender, socioeconomic status, and level of education. Other factors that may also alter the caregiving experience include citizenship status (of the caregiver and care recipient) and current place of residence (because of availability of services that are culturally/linguistically appropriate). Additionally, the level of acculturation defined by Aranda and Knight (1997) as the "process of cultural change resulting from continuous intergroup contact" (p. 348) may impact whether traditional attitudes around caregiving are upheld or not. Coon et al. (2004) indicated that "less acculturated Latinas in contrast to more acculturated Latinas did report significantly poorer overall health" (p. 337).

According to a recently released report on Caregiving in the U.S. from the National Alliance for Caregiving and American Association of Retired Persons (2015), the mean age of caregivers is 49.2 years old and the majority are women (60%). Additionally, the report suggests that almost half (47%) of caregivers earn less than $50,000 (net). The number jumps to just over half (54%) when caregivers are providing 21 hours of care or more per week. More than one-third (36%) have a high-school education or less and that number increases (43%) for caregivers offering at least 21 hours of care (NAC & AARP, 2015). The report was derived from interviews (n=1,248) primarily conducted online with targeted sampling of racial/ethnic groups. Of the 208 Latino respondents, almost half (45%) selected the Spanish version of the interview. A significantly higher number of Latinos (21%) were reported to provide 21 hours of care or more as compared to the other racially/ethnically diverse groups (African American 16%, Asian American 6%, and other 3%). Understanding the current profile of caregivers in the nation aids

in the development of adequate programs, supports and policies that can serve a critical role in ensuring the health and well-being of this population.

Latino families will be faced with an obvious increase in the number of family caregivers for older adults in the next few decades based on the prevalence data and other factors. Some reasons for the increase can be attributed to the continuous population growth (U.S. Census Bureau, 2010), longer life expectancies (Centers for Disease Control and Prevention 2010), and common Latino cultural values of *familismo* [familism or filial piety] and *marianismo* [Marianism or women seen as self-sacrificing and assumed caregivers derived from the religious figure, the Virgin Mary, and the role she played in religion] (Arévalo-Flechas et al., 2014). Moreover, immigration status affecting available eldercare services coupled with already existing financial constraints, not uncommon in this population (Evans, Belyea, Coon, & Ume, 2012; Ruiz, & Ransford, 2012) can generally contribute to an increased need for family support of Latino older adults.

Some evidence-based interventions focused on ADRD caregivers such as the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II (Acton & Kang, 2001; Wisniewski et al., 2003), Savvy Caregiver Program (Hepburn, Lewis, Sherman, & Tornatore, 2003), and NYU Caregiver Intervention (AAR, AOA, & MetLife, 2012) have been tested with Latinos. There have been some promising results for Latino caregivers from psychoeducation (Gallagher-Thompson et al., 2001) and cognitive behavioral approaches (Gallagher-Thompson et al., 2008). Translated material to the Spanish language was made available to those participants that preferred it but language is not the only factor to consider when adapting interventions to be culturally tailored.

3. An intervention showing promise with a different Latina caregiver group.

The health education intervention titled *By Caring for Myself, I Can Better Care for My Family,* or *Caring for Myself* for short, has been tested and has produced promising outcomes for Latina mothers caring for children and young adults with intellectual and developmental disabilities (Magaña, Li, Miranda, & Paradiso de Sayu, 2015). After further research and several iterations of testing, the intervention has continued to produce positive outcomes for the study participants. Developed in Wisconsin and tested initially in Madison, Wisconsin and Chicago, Illinois, focus groups made up of Latina mothers of children with intellectual and developmental disabilities (IDD) guided creation of a manual for the 8-session intervention.

Grounded in a theoretical framework that addressed health-related self-efficacy (Bandura, 1977), *Caring for Myself* systematically incorporated elements in the intervention that promote changes in healthy behaviors that may be feared, unknown or avoided (Magaña, et al., 2015). Bandura's (1977) self-efficacy theory posits that behavior change occurs when self-efficacy increases, thus a person is more encouraged to change a behavior to a healthier one when they feel more confident about carrying out the behavior. According to this theory, four major principles aid in the development of self-efficacy: (1) performance accomplishments; (2) vicarious experience; (3) verbal persuasion; and (4) emotional states. As described by Bandura (1977), an experience where the mastery of skills occurs enhances the individual's expectations of positive outcomes. Thus, repeated performance accomplishments strengthen the sense of self-efficacy. Coupled with the self-modeling that occurs with performance accomplishments, vicarious experience shared by those in similar circumstances allows for the individual to feel less threatened by skills that may seem difficult to develop. The ability for an individual to experience coping and skill building through those doing live modeling that have also lived through adverse consequences already in their development of self-efficacy is influential. Being

led to believe that an individual is capable of successfully coping with difficult situations by means of praise and being informed of what to expect next serve as <u>verbal persuasion</u>. Individuals are more likely to put forth additional effort with this type of persuasion than when none is present. Finally, the level of stress and difficulty that a threatening situation produces builds an individual's anxiety and emotional arousal, which in turn affects their performance and hinders positive outcomes. Regulating an individual's <u>emotional state</u> thus increases the opportunity for arousal to be at a more manageable level where there is less of a negative impact derived from fear and avoidance.

The original intervention was tested in two modalities. One group of participants received the intervention in the form of individual home-visits and another was a part of the group model hosted at a community-based organization (CBO). A control group was made up of Latina mothers that were on the waiting list, which would receive the intervention upon completion of the study and were given the manual to review at their leisure during the waiting period. The sessions averaged two hours in duration and were facilitated by peer educators identified as *Promotoras* (based on the Public Health *Promotora de Salud* or lay health promoter model) that had been trained by the researcher on the material and the format of home-visits/groups. Training for the *Promotoras* consisted of taking part in the intervention as participants themselves to have first-hand exposure of the material from the participant's perspective with guidance on structure of sessions and pointers on presenting the material with the researcher as a role model (Magaña, Lopez, Paradiso de Sayu, & Miranda, 2014).

Topics covered in Magaña, et al.'s (2015) eight sessions (see Table 1 on page 7) included: "(1) taking care of yourself, (2) health care for you, (3) well-being activities, (4) nutrition, (5) exercise, (6) reducing stress and understanding depression, (7) including others and

social support, and (8) sustaining personal growth" (p. 42). Similarly, some of these topics have been incorporated into several interventions that have been created for dementia family caregivers including techniques for relaxation as a way to reduce stress (Gallagher-Thompson, Arean, Rivera, & Thompson, 2001; Wisniewski et al., 2003), involving others in the care (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Wisniewski et al., 2003), and setting self-change goals as a means for personal growth (Wisniewski et al., 2003).

Table 1 Content of *By Caring for Myself I Care Better for my Family*

Session topic	Details of session
Taking Care of Yourself	Introduction to programme and content; discussion about what it means to care for oneself in the context of caring for a child with IDD; setting goals
Health Care for You	Exploration of the importance of regular health visits and age appropriate tests to be aware of; role play of asking health provider questions; making plan for scheduling healthcare visit
Well-being activities	Discussion of the meaning of physical and emotional well-being; practice a well-being activity (i.e. a guided drawing activity)
Nutrition	Discussion of the importance of eating healthy and how to eat healthy in the context of cultural tradition and family
Exercise	Discussion of the importance of exercise and how to exercise while caring for a child with IDD; promotora engages participant in a stretching activity
Reducing stress and understanding depression	Discussion about the signs of stress and case study of a parent in a stressful situation; discuss symptoms of depression and when to seek help; breathing exercise
Including others and social support	Discussion about including others in household chores and caring for child with IDD; work on an ecomap to identify people and resources that can provide support
Sustaining personal growth	Review of materials covered and discussion about what goals were accomplished and what new goals will be set

IDD, intellectual and developmental disabilities.

Table 1. *By Caring for Myself I Care Better for My Family* Health Education Intervention for Latina Mothers of Children with Intellectual and Developmental Delays (Magaña, et al., 2015).

A randomized control trial was conducted with baseline and 3-month post-intervention measures administered. Variables studied included (1) health-related self-efficacy, (2) health behaviors (exercise, self-care, and nutrition), (3) depressive symptoms, and (4) caregiver burden (Magaña, et al., 2015). Upon completion of the intervention, focus groups were conducted with the intervention participants to evaluate the project. A separate set of focus groups were held with the *Promotoras* after one or two sessions had been completed for a continuous check on the peer educator experience and evaluation of the project from their perspective (Magaña, et al.,

2014).

4. Addressing an impending health crisis for Latina ADRD family caregivers.

There is a looming crisis created by ADRD afflicting the Latino community in higher numbers as compared to their White counterparts (Alzheimer's Association, 2010) and high prevalence of physical and emotional burden endured by ADRD Latina/o family caregivers (Arévalo-Flechas et al., 2014). Given the extent of this problem and the gaps in literature relating to the cultural exploration of family caregiver experiences for Latinas/os, the effect of caregiving on this population's health and well-being, and effective health promotion interventions for this group, I developed this study to assess and adapt a culturally responsive health education intervention that has demonstrated promising outcomes for a different group of Latina caregivers, Latina mothers of children with IDD. Latina mothers of children with IDD and Latina family caregivers of persons with ADRD seem to experience similar health outcomes such as depression and lower general health (Arévalo-Flechas et al., 2014). The original intervention was previously tested with Midwest Latina mothers providing care to children with IDD (Magaña, et al., 2015). Through this study, I attempted to learn more about how to address the health issues associated with Latina ADRD family caregivers and develop an intervention that intends to counter some of their negative health outcomes. Results of this study may serve as preliminary findings to inform large-scale research in the development of a culturally responsive evidence-based health education intervention for Latina caregivers of persons with ADRD.

Several significant factors make caregivers vulnerable to illness and poor quality of life if promising interventions are not tailored and tested for effectiveness. This study is significant because it examines what elements may be important in developing a feasible, acceptable and potentially effective health education intervention for a population of caregivers that is expected

to exponentially grow in the coming decades. The findings derived by this study may lead to the creation of a promising practice (short-term) and an evidence-based intervention (long-term) that is manageable in community-based settings. There is an empowerment component that allows peer educators, who are family caregivers themselves, to be trained in providing much-needed health education to other Latina ADRD family caregivers, as they accompany them in the journey for at least the eight sessions of the intervention. Thus, the study can further inform not only the knowledgebase of health education interventions for Latina ADRD family caregivers but also build the literature relating to the use of peer educators for health education with this population.

B.   Conceptual Framework: The Revised Sociocultural Stress and Coping Model

Some available research attempts to explore the implications cultural diversity may have when evaluating the specific needs and effectiveness of interventions, particularly with regards to caregiving in ethnically/racially diverse groups such as Latinos, African Americans, and Asians (Borrayo et al., 2007; Gallagher-Thompson et al., 2008; Gallagher-Thompson et al., 2003; Hahn, Giyeon, Chiriboga, 2011; Mahoney et al., 2005). Various theoretical models are considered in the literature, such as the Leininger's transcultural model of nursing care (Mahoney et al., 2005), Lazarus and Folkman's stress, appraisal, and coping model (Morano, 2003), and Schulz's stress process model (Gallagher-Thompson et al., 2003). The models each define constructs and variables relevant to caregiving whether formal, as in the case of the transcultural model of nursing care, or informal. Factors considered in stress and coping models include: demographics of the caregiver; the stressors and strains on the individual that are directly derived from providing care as well as the implications for other aspects of the caregiver's life like work and family; how the caregiver makes sense of the demands of

caregiving in terms of satisfaction or stress; coping strategies, behaviors and social supports as possible mediators of burden; and finally the effects of caregiving demands on health (physical and mental) and quality of life (Aranda & Knight, 1997, p. 343).

The theoretical basis for this study is derived from Knight and Sayegh's (2010) revised sociocultural stress and coping model (see Figure 1 on page 10), which gives a framework for understanding culturally specific caregiving of older adults with dementia. Aranda and Knight (1997) originally created the sociocultural stress and coping model based on the argument that culture and ethnicity are significant elements of caregiving of older adults, in culturally diverse populations. Originally used as a framework to review older adult caregiving literature in the Latino community, the sociocultural stress and coping model serves as a seminal component of this body of knowledge. The model has since been revised by Knight and Sayegh (2010) and is used as the theoretical basis for this research project.
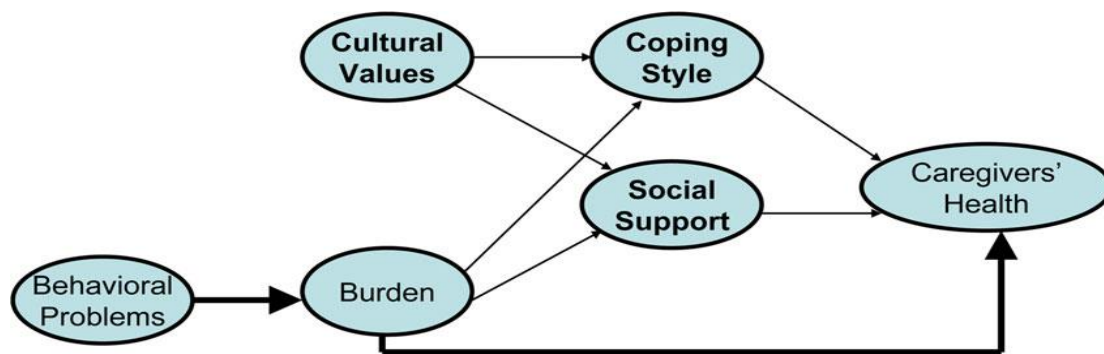
Figure 1. The Revised Sociocultural Stress and Coping Model for Caregivers (Knight and Sayegh, 2010, p. 6). Note. The revised sociocultural stress and coping model is derived from Aranda and Knights' (1997) sociocultural stress and coping model.

Building on previous caregiving and stress models, the sociocultural stress and coping model uses core elements used in other models and suggests that the care recipient's behavioral problems are directly linked to the caregiver's burden, which is mediated by the coping style and social supports that are defined by cultural values and ultimately impacting the caregiver's health

(Knight & Sayegh, 2010). Aranda and Knight (1997) maintain that culture and ethnicity play a role in caregiver burden appraisal, social supports and coping styles. The development of the sociocultural stress and coping model considered the following three factors: (1) disparity of health and disability risk factors; (2) differences in the way potential stressors are defined (i.e., appraisal); and (3) the impact created by the mediating constructs of social support and coping (Aranda & Knight, 1997, p. 343). The three factors guiding the model provide the context that can better inform multifaceted cultural aspects of caregiving.

Aranda and Knight (1997) explore individualism and familism when considering how to best analyze the way burden of caregiving is understood by family caregivers. The Western view of individualism is described as being negatively affected by caregiving because it disturbs the individual's (caregiver's) life (Knight & Sayegh, 2010). Familism, or *familismo* as it is known in Spanish and a prominent Latino community value, is interpreted as the notion that the family values, interests, and needs come before those of the individual and as such, different social supports and coping that are informed by cultural values are utilized when care is provided among families (Knight & Sayegh, 2010). Rather than interpreting cultural differences as a mere distinction between individualism and familism, the model defines the aspect of culture in relation to caregiving as multidimensional and potentially group specific.

Knight and Sayegh (2010) offer a revision of the sociocultural stress and coping model that focuses on the relationship between cultural values and the types of social supports and coping styles that are utilized. The revised sociocultural stress and coping model proposes that implications for the caregiver's health are affected by cultural values as shown in Figure 1 (see page 10). Knight and Sayegh (2010) argue that although burden appraisal may or may not be culturally distinct and a cornerstone in caregiving research as considered in the original

sociocultural stress and coping model, cultural values are most influential in social supports and coping styles. Therefore, understanding the relationship between the presence, use, and decisions around coping resources, and physical/mental health outcomes is significant, particularly in culturally diverse groups where disparities may be present (Knight & Sayegh, 2010). The model aids in the exploration of culture in caregiving and guides development of a culturally responsive intervention for this study.

C. Qualitative Methodological Approach

The study used a qualitative methods approach by way of focus groups to capture more comprehensively the experiences of Latina ADRD family caregivers, which then helped inform the adaptation of the health education intervention *Caring for Myself*. Two phases were used to carry out the study. Phase I consisted of the original intervention being assessed to determine if it was relatable and adaptable to Latina ADRD family caregivers. In this first phase, focus groups were conducted with Latina ADRD family caregivers and other stakeholders to learn more about the elements of culture and experiences of burden that define ADRD caregiving for Latinas. In Phase II, the adapted intervention was developed using the data collected in Phase I and a review of relevant literature. Qualitative findings were derived from the participant responses during focus groups that took place at the assessment phase (Phase I) and from field notes and reflexive journaling that occurred throughout the study. The findings from this study may help inform larger scale research relating to caregiver interventions and health education for this population in the future.

D. Theoretical Sensitivity

Personal and professional factors have been influential in my decision to carry out this research. I am a Latina caregiver and I, along with my sister, provide care for my mother who

has been diagnosed with AD for over twelve years. I have first-hand experience of what caregiving has meant for our family. This journey has largely driven my desire to better understand how this experience can be best negotiated in Latina/o families, particularly with regards to keeping the caregiver's health as intact as possible. Self-reflection on the physical and emotional toll of caring for a loved one with this condition has led me to develop this type of project. Although I have the personal experience of caregiving as a Latina, I recognize that I may have a very different experience than others within the same ethnic group dealing with a similar situation. Various factors that include: being a U.S. born Mexican Latina, bilingual, having attained formal schooling in this country through the graduate level, currently in the middle-class, a care recipient that is a naturalized U.S. citizen and eligible for various services; all limit my personal experience to very specific terms of caregiving. Given the complexity of caregiving and the multifaceted aspect of cultural influence, I acknowledge that my own experiences may influence the research. As I begin, I identify the differences that already occur from the power differential between myself as the researcher and research participants. Continuous self-reflection has been crucial in the research process to maintain the rigor in administering the study and objectively examining the findings. As a means to ensure a more robust implementation of the project and analysis, I will apply peer debriefing and member check techniques to obtain feedback from colleagues and research participants throughout the study.

Much of my social work career has consisted of providing social service support in the Latino community, in the City of Chicago. This work has allowed my knowledge base to increase in the area of cultural sensitivity and responsiveness to the diverse needs of predominantly Latino neighborhoods in the city that are afflicted by poverty, lack of adequate (accessible, affordable, culturally appropriate) resources, and health disparities. The professional

expertise built during my career helped inform the recruitment process and the rapport building that occurred during the research study. My professional network served as a great resource for extending my reach in the recruitment plan as well as for identifying available and adequate locations for hosting focus groups.

E.   Research Questions

The study examined the following research questions:

1) Is the health education intervention *By Caring for Myself I Care Better for my Family* relatable and adaptable to fit the needs of Latina family caregivers of persons with Alzheimer's disease or related dementia (ADRD)?

2) What elements of culture need to be considered when adapting *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

3) How do the experiences of burden in providing care to a family member/loved one with ADRD help inform the adaptation of *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

The research questions were studied by way of two phases:

- Phase I – Assessment of the original health education intervention to determine if it is relatable and adaptable for Latina family caregivers of persons with ADRD; and

- Phase II – Adaptation (Preparation) of the intervention

Phase I and Phase II produced qualitative findings that informed the development of the adapted intervention. Given the nature of this exploratory study designed to extract a greater understanding of the experiences of Latina ADRD family caregivers from themes that surfaced through qualitative data, no hypotheses were offered regarding expected findings that informed

the adaptation of the health education intervention *Caring for Myself*.

II. LITERATURE REVIEW

This chapter reviews relevant literature on Alzheimer's disease or related dementia (ADRD) and caregiving, Latina/o caregiver health and well-being, and caregiver interventions in the Latino community. Both theoretical and empirical literature mostly from 2000 through the present (with the exception of some seminal literature cited by studies) was identified using various academic search engines such as EBSCOhost, Google Scholar, ProQuest, PsycINFO, PubMed and references cited in related peer-reviewed journal articles. Search terms included: Alzheimer's disease, dementia, Latino/Hispanic, caregiving, (family) caregiver, care(r), coping, social support, caregiver burden, depression, health and intervention. Different combinations of the key terms were used to identify the relevant published literature. The following review presents the results that informed this study.

A.   Alzheimer's Disease or Related Dementia and Caregiving in the Latino Community

1. Latinos' perceptions of the condition.

Literature specific to Latina/o family caregiving of a family member/loved one with ADRD oftentimes examines the lack of understanding of the condition and diagnosis as well as the undeveloped and/or underdeveloped skills for providing care (Borrayo et al., 2007; Mahoney et al., 2005). There is family caregiver literature that explores perceptions of the diagnosis (Mahoney et al., 2005), neuropsychiatric symptoms such as depression, aggression, delusions, etc. (Hinton et al., 2009) and care (Borrayo et al., 2007) for an individual with AD in racially/ethnically diverse communities. The studies reviewed, qualitative in nature, provide the landscape of how ADRD is viewed in the Latino community and the implications of care for the caregivers that are most often family members. Based in Minnesota, Colorado, Florida and California, the studies' racial and ethnic makeup included African Americans, Chinese, and

Latinos from various nationalities (e.g., Colombian, Mexican, Puerto Rican, Peruvian, Dominican, Panamanian, Argentinian). Mahoney, Cloutterbuck, Neary and Zhan (2005) suggest that the racially/ethnically diverse caregivers studied tended to normalize the initial memory loss symptoms as signs of typical aging and the caregivers reported difficulty with accessing diagnostic services that were well informed and responsive. Some of the literature suggests that culturally and linguistically adequate services and sources of information were identified as barriers for the Latino community (Neary & Mahoney, 2005). Yet a different study proposes that across racially/ethnically diverse groups, ethnic similarity with medical providers was not valued as much as expertise in Alzheimer's disease (Mahoney et al., 2005). Two different Latino caregivers describes this in the following way:

> She [the doctor] was not that well trained to imagine that it was Alzheimer's and because in that time there were so many AIDS cases [the doctor misdiagnosed the father as having AIDS]. (Mahoney et al., 2005, p. 790)

> The doctor always said ''No, that isn't anything.'' That my mother's had bad headaches, that she always dreamed that she was lost, she had nightmares, her mind, she couldn't keep it from thinking and thinking and she couldn't control it. We kept telling this to the doctor and the doctor said ''No, that isn't anything.'' It was a Hispanic doctor. (Mahoney et al., 2005, p. 790)

There are data that suggest a lack of knowledge about symptoms and the condition (dementia) itself as the initial barrier for diagnosis in the Latino community (Neary & Mahoney, 2005). Hinton, Chambers and Velásquez (2009) in their study propose lack of knowledge exists in this population and posit that Latino dementia caregivers were more likely to attribute neuropsychiatric symptoms to other causes such as medical conditions, personality traits that existed prior to the condition, emotional distress, aging or genetics and not to ADRD.

2. Cultural values in caregiving.

A dearth of literature exists that directly studies the family caregiver experience in connection with issues around cultural values, norms, traditions and acculturation in relation to the care of a loved one with ADRD. The studies found relevant to the Latino community reinforce the notion that more research is needed (Aranda et al., 2003; Gallagher-Thompson et al., 2003; Hahn, Giyeon, & Chiriboga, 2011). Arévalo-Flechas, Acton, Escamilla, Bonner and Lewis (2014) propose that cultural values may have a level of influence on how similar experiences may be perceived, reported and coped with by various groups of caregivers, thus culture may significantly impact the care being offered to the care recipient as a result. Some of the cultural implications for Latino caregivers that were found in the literature included how care decisions particularly regarding long-term care negotiate the value of familism (*familismo),* where caring for family is done by family and could take priority over individual needs; and the norm around gender roles in the provision of care (*marianismo)*, which commonly holds the woman as the self-sacrificing nurturer of the family unit (Borrayo et al., 2007; Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011; Evans, Belyea, Coon, & Ume, 2012; Mahoney et al., 2005; Mier, 2007; Neary & Mahoney, 2005). Additionally, significant to note is that caregivers reported how traditional values in Latinos relating to care being provided in the home may be challenged with acculturation, thus giving way to more consideration for institutional care to be utilized instead (Mahoney et al., 2005).

Arévalo-Flechas et al. (2014) offer an exceptional overview of some of the cultural values that are a part of Latino culture that may impact ADRD caregiving in the following table (see Table 2). This table offers definitions for such Latinos cultural values as *personalismo, familismo, marianismo, machismo, respeto,* and *dignidad* as well as the intersection of these

values and ADRD caregiving in the Latino community, outlining some potential implications for

the caregiving experience.

Cultural Values	Description	Potential impact on caregiving experience
Personalismo (Personalism)	Strong orientation toward close personal relationships and friendships	Results in underutilization of formal care programs for person with ADRD
	Exemplified by traits of warmth and empathy for others	Caregivers expect health care provider to take the time to listen and have a personal interest
	Willingness to be of service and to help others	Trust must be established with caregiver and family members before offering suggestions or starting care
	Need to feel that another is personally concerned and interested	
Familismo (Familism)	Strong identification and attachment with family	Individuals turn first toward family for advice rather than seeking professional opinions or utilizing health care system
	Ultimate responsibility to the family	Distrust of outside help may result in family delaying needed medical treatment
	Prioritize family needs over individual needs	Deters caregivers from delegating caregiving responsibility for a family member with ADRD to formal health care institutions
	Sense of mutual obligation among family members	Appears to protect individuals against physical and emotional stress by providing support system
	Strong feelings of loyalty, reciprocity, and solidarity among members of the same family	
Marianismo (Marianism)	Derived from the Virgin Mary (or "Maria")	Expectation and assignment of the caregiving responsibility falls to female family members, who see it as their duty and "cross to bear"
	Set of cultural expectations for females that includes submissiveness, self-sacrificing for the family, subservience to men, and complete devotion to family	This duty may feel forced upon the female, thus experiencing greater dissatisfaction in the role and greater distress
	Female counterpart to machismo	Adult daughters believe it is important to be perceived and feel as the "good daughter" regardless of negative impact of caregiving duties
Machismo (Machism)	Set of cultural expectations for men that include honor, pride, courage, responsibility, family responsibility, and the belief that men are superior	Male caregivers with strong *machismo* beliefs may be hesitant to seek help out of fear of appearing weak
	Teaches male role as protector of the family and of women	Females may have the tendency to underestimate the caregiving abilities of males and hesitate to delegate duties
	Enables males with rights and privileges denied to females	
	Male counterpart to *marianismo*	

(continued)

Cultural Values	Description	Potential impact on caregiving experience
Respeto (Respect)	Conviction that all people deserve to be treated with courtesy	Diseases that affect mental status and behavior are shameful to family and may result in isolation from established support networks
	Includes humility, deference, submissiveness, and obedience	This sense of shame further discourages caregivers from seeking professional or informal support from others
	Guides the deferential and appropriate behavior toward others based on gender, social position, and other factors	Admitting distress caused by caregiving duties can be seen as being ungrateful and therefore disrespectful
	Guides the hierarchy of power within the family dynamics	If speaking Spanish, the use of *usted* vs *tu* conveys respect and is preferred during initial encounters
	Main factors include age, gender, and education	
Dignidad (Dignity)	Innate worth and integrity of all people	There is a strong desire to be seen as dignified people, especially in public
	Sense of self-respect	Asking for help shows lack of dignity
	Sense of self-pride	Causes resistance to sharing problems with outsiders or admitting that caregiving is too difficult
		Activities of daily living become difficult for persons of opposite sex (e.g. not dignified for a mother to be bathed by son)

Table 2. Latino cultural values and potential impact on caregiving experience (Table taken from Arévalo-Flechas et al., 2014).

3. Coping styles in caregiving.

There are several labels to identify coping styles in relation to dementia caregiving identified in the literature. Pratt, Schmall, Wright and Cleland (1985) examined internal (i.e., confidence in problem-solving, reframing, and passivity) and external (i.e., spiritual support, extended family, friends, neighbors, and community services) coping strategies, while Morano (2003) studied emotion-focused and problem-focused coping. Despite the variations in label names, there seems to be consistency in their definitions for some of the coping strategies. There are those coping strategies where caregivers are more engaged in seeking to solve particular problems and handle tasks more practically, identified as problem-focused (Morano, 2003) or confidence in problem-solving (Pratt, Schmall, Wright, & Cleland, 1985) coping strategies. Moreover, coping strategies that deal with making sense of the particular situation, in this case

the aspects of caregiving, have been identified in the literature as reframing (Pratt et al., 1985) and emotion-focused (Morano, 2003). Passivity or avoidance coping is the strategy where the caregiver is not acknowledging the implications of care at all (Morano, 2003; Pratt et al., 1985).

Mixed results exist in terms of which coping styles are associated with positive outcomes for caregivers. According to Pratt et al. (1985), confidence in problem-solving, reframing, spiritual support and extended family were significantly correlated with reducing caregiver burden, while passivity was significantly associated with increasing caregiver burden. In a more recent study, Morano (2003) studied 204 Latino and non-Latino White Alzheimer's disease caregivers to learn more about what moderating and mediating effects coping had on the caregivers' stress and psychological well-being. Moran's (2003) findings suggest that emotion-focused coping had moderating effects on depression and life satisfaction, where more emotion-focused coping interacting with problematic behavior of the care recipient showed less depression and more life satisfaction. Both emotion-focused and problem-focused coping demonstrated mediating effects that were statistically significant in relation to increased feelings of mastery and personal gain, dimensions of the caregiving experience, when faced with problematic behavior of the care recipient (Morano, 2003).

In terms of what types of coping strategies, the Latino community utilizes, Arévalo-Flechas et al. (2014) examine the literature as they discuss their findings of a study on the perception and psychosocial impact of caregiving for Latino ADRD family caregivers as compared to non-Latino White caregivers. An inventory of coping resources in five areas that included cognitive, social, emotional, spiritual/philosophical and physical coping resources was administered to 200 study participants. The findings indicated that there was a statistically significant difference in the coping physical resources of Latinos as compared to non-Latino

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Whites. The perception is that Latinos have much help and support from family given the cultural value of *familismo,* thus coping would occur through external physical resources. Though, much of the literature continues to suggest that the reality is different (Arévalo-Flechas et al., 2014; Gelman, 2014). Mexican-American caregivers were observed to use more escape/avoidance and less use of social networks as their method of coping in comparison to White caregivers (Adams et al., 2002). Valle et al. (2004) found that Latinos were less likely to speak about their caregiving situation or seek out professional help and more reluctant to have others provide support versus non-Latinos Whites. Prayer and involving relatives to help was reported to be higher in Latinos, while non-Latino Whites reported less prayer and more frequently seeking help from friends (Valle, Yamada, & Barrio, 2004). Religious coping that includes frequent prayer, attendance at religious activity and importance of religion is greater for Latinas as compared to non-Latina White counterparts (Coon et al., 2004).

4. Social support in caregiving.

The level of care needed for a family member or loved one with ADRD varies from person to person but what may be true for most, if not all cases, is that the care required is progressively greater as the condition continues to worsen over time (Alzheimer's Association, 2018). According to the Alzheimer's Association (2018), ADRD family caregivers provide care more extensively to the care recipient as compared to those caring for people with other conditions, even though the caregiving tasks carried out are somewhat similar. Given the intensity of care involved, social support can be critical for ADRD family caregivers. Uchino (2006) posits that social support can be defined in various ways and typically considers who forms part of an individual's social life (e.g., group memberships, familial ties, etc.) as well as what these structures offer to the individual (e.g., emotional support, physical support, etc.). Regardless of

the definition one agrees upon, the literature strongly suggests there is a link between someone's

health and their social support (Uchino, 2006; Knight & Sayegh, 2010).

When considering the intersection of culture and social support, there is a range of data

that examines the level of perceived social support found in diverse ethnic/racial populations

(Janevic & Connell, 2001). In the Latino community, *familismo* (familism or care for family by

family that may take precedence over individual needs) is understood as more of a traditional

cultural expectation, thus caring for family members is thought to feel less burdensome and more

satisfying (Borrayo et al., 2007) by family caregivers. Culturally, when there is an expectation

that family is who cares for other family members, primary family caregivers may not be as open

to express burden and/or seek additional support for the caregiving due to the responsibility they

feel to carry this out. A systematic review of the literature by Janevic and Connell (2001)

suggests that "non-White caregivers may not have more informal support available to them than

White caregivers," which counters the assumption that ethnically diverse groups like Latinos

have large social networks supporting them (p. 343). According to Valle, Yamada and Barrio

(2004), Latino caregivers experience more pessimistic views of their situation and have smaller

social support networks compared to other White caregivers. Other literature posits similar

findings relating to not only social support and pessimistic views (Adams et al., 2002) but also

support from extended family that is inadequate (Arévalo-Flechas et al., 2014; Gelman, 2014;

Pinquart & Sörensen, 2005) for Latino caregivers.

B. Impact of caregiving on the health of Latinas/os

Much of the literature relating to family caregiving for loved ones with ADRD in the

Latino community, as in other populations, identifies stressors that create a negative impact on

the caregiver. Both the physical and emotional burden of caregiving have been documented in

the literature (Arévalo-Flechas et al., 2014). There are obvious links between mental health and physical health that are imperative to address through the caregiving trajectory as factors such as age, economic status, and decline in the functioning of the care recipient all may vary with time and length of the condition. Several significant factors make family caregivers vulnerable to illness and poor quality of life; thus, it is crucial to consider their health and well-being holistically.

1. Physical health.

Latinos' health is already at a disadvantage prior to becoming caregivers considering the existing health disparities with diabetes, liver disease and other conditions (Pew Research Center, 2002; Vega, Rodriguez, & Gruskin, 2009). When caregiving is factored in, the prevalence of certain health conditions is heightened. Based on the literature reviewed, poorer physical health of family caregivers is more closely associated with increased levels of the care recipient's behavior issues, higher age of the caregiver, lower socioeconomic status as well as lower level of informal support (Montoro-Rodriguez, & Gallagher-Thompson, 2009; Pinquart, & Sörensen, 2007). Arévalo-Flechas et al.'s (2014) findings suggest that Latino Alzheimer's caregivers experience more bodily pain and somatic symptoms than non-Latino White caregivers. Almost a quarter (22%) of family caregivers reported their health had gotten worse and one in five (19%) reported more physical strain, both due to the caregiving (NAC & AARP, 2015). According to Richardson, Lee, Berg-Weger, and Grossberg (2013), this worsening in physical health may be attributed to the physical exertion used in the care of the dementia care recipient and the physiological changes that occur as a result of the stress-induced cortisol increase. The rise in cortisol can then result in diminished cognitive function, obesity particularly in Latinas as compared to Whites (Pew Research Center, 2002), inflammation and

hyperinsulinemia, and when paired with little or no time for exercising and preparing healthy meals, may easily amount to unfavorable health outcomes in caregivers (Richardson, Lee, Berg-Weger, & Grossberg 2013). Etkin, Prohaska, Connell, Edelman, and Hughes (2008) propose that mental health factors and attitudes around exercise are better predictors of exercise as opposed to caregiver factors. There is great complexity in the effect of caregiving on physical health impacting not only the physiology of a caregiver's body that may lead to medical conditions but also the way a caregiver may handle external determinants of health such as nutrition and exercise.

2. Mental health.

a. Emotional caregiver burden and depression.

The literature suggests varying levels of stress and burden experienced by the family caregivers (Iavarone, Ziello, Pastore, Fasanaro & Poderico, 2014; Wisniewski et al., 2003). Strained family ties and lower income (Molina & Alcántara, 2013), the care recipient's impaired ADL functioning, heightened mobility issues and neuropsychiatric disturbances due to cognitive decline (Kim, Chang, Rose, & Kim, 2011; Rote, Angel, & Markides, 2015) and emotion-focused or passive (avoidant) coping by the caregiver (Morano, 2003; Pratt et al., 1985) were found to be significant predictors of higher levels of psychological distress and burden. According to the Alzheimer's Association Fact and Figures Report (2018), almost 60% of ADRD caregivers report they are experiencing high or very high emotional stress from caregiving and about 30 to 40 percent are dealing with depression compared to 5 to 17 percent of non-caregivers in the same age range. Pinquart and Sörenson (2005) suggest that Latino and Asian American caregivers experience more depression than their non-Latino White counterparts, while African American caregivers reported lower levels. When considering outcomes of caregivers versus

noncaregivers, some research indicates that caregivers experience depressive symptoms more so than noncaregivers and are at least "12 times as likely to meet or exceed the cutoff for depression on the CES-D scale" (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013). Latino family caregivers report higher levels of caregiver burden and lower general health as compared to non-Latino Alzheimer's caregivers (Arévalo-Flechas et al., 2014). The prominence of caregiver burden and depression in Latino caregivers calls for an understanding of signs and symptoms by the caregiver in order to seek the necessary treatment and avoid further complications for the caregiver's well-being and that of the care recipient and family at large.

Latina/o families can possibly face a longer lasting effect of caregiver burden since Latinas/os with AD may have a longer survival rate as compared to White persons with AD (Mehta et al., 2008). Additionally, as the condition causes higher levels of impairment in the care recipient with time, the implications on the caregiver likely increase and can cause higher levels of emotional stress and depression as well as new or worsened health problems (Alzheimer's Association, 2018). Furthermore, the multigenerational household that is common in Latina/o families, which is arguably also increasing among the general population, seems to negatively affect the health and well-being of these 'sandwich generation caregivers' (Alzheimer's Association, 2016). Compared to 'non-sandwich generation caregivers' and non-caregivers, this group of 'sandwich generation caregivers' that care for an older adult with ADRD as well as young children report a lower quality of life and reduced health behaviors that include being less likely to choose foods based on health values, use seat belts, or exercise (Alzheimer's Association, 2015).

b. Financial caregiver burden.

Not only experiencing the physical and emotional toll ADRD caregivers negotiate in their

lives, there are also financial implications. In 2017, caregivers of persons with ADRD reported an additional $11.4 billion in health care costs for themselves as a result of the physical and emotional burden of caregiving (Alzheimer's Association, 2018). This out of pocket expense does not include the cost of care for the care recipient, which according to the Alzheimer's Association (2016) was nearly double ($10, 697) for dementia caregivers compared to non-dementia caregivers ($5,785). A striking four in 10 care contributors (those providing care or payment for directly related expenses once a month or more, in the prior year) struggle to have enough money for basic necessities such as proper meals and medical care (Alzheimer's Association, 2016). Factors of longevity and intensity of care, additional responsibilities of care with young children, lack of access to healthcare insurance and financial limitations, which can be found in the Latino community, all may translate to elevated stress and overall negative health outcomes for caregivers.

3. Culture, caregiving and health.

The Latino value of *familismo* may be considered a protective cultural factor in some regard, but despite the expectation that this exists in families, caregiving for Latinos may still be seen as stressful and challenging (Borrayo et al., 2007). Results from a mixed methods study in Southern California with family caregivers of Mexican decent caring for an older adult who needed assistance with at least one ADL propose that in fact less acculturated caregivers reported higher levels of stress and burden and lower level of satisfaction even when they had more family members that could provide additional support in the care (Jolicoeur, & Madden, 2002). Another study conducted in New York City supports a similar discrepancy of the benefits of *familismo* where the findings indicate that while some Latino Alzheimer's caregivers reported familism to facilitate the caring process, for others this value system was not relevant to their

caregiving experience currently and expressed negative feelings resulting from the care being provided (Gelman, 2014). Ruiz and Ransford (2012) propose that *familismo* is being reframed by Latino older adults to include others that are "like family," who play a more significant part of their care regardless of not being blood relatives. In terms of physical health, one report examining the effect of familism on Latino's health suggests that when a family is experiencing financial difficulties, Latinas will buy the foods preferred by their husband that many times are high in fat and therefore unhealthy (Perez & Cruess, 2014).

The most recent Alzheimer's Association Facts and Figures report (2018) proposes that two-thirds of caregivers are women, with over one third being daughters and more commonly wives caring for a husband rather than the reverse. Caregiving primarily by women is consistent with the value of *marianismo* (Latinas culturally expected to be self-sacrificing and nurturing caregivers) in the Latino community. Studies that explore the gender difference in caregivers with regards to presence of psychiatric symptoms (Yee & Schulz, 2000), depression (Friedmann & Buckwalter, 2014) and distress due to gender differences in coping styles (Iavarone et al., 2014) suggest that females fare worse, experiencing more psychiatric symptoms and depression than male caregivers and higher levels of distress as a result of more consistently using emotion-focused coping that includes the caregivers responses to caregiving needs in an emotional manner with self-preoccupation as opposed to task-oriented or avoidance-oriented coping.

C.   Caregiver Interventions in the Latino Community

According to the recent Alzheimer's Association Facts and Figures reports (2018), some of what has been found to be effective in caregiver interventions includes actively involving caregivers rather than just giving them the information, approaching dementia care as a family issue, and training caregivers on skills that help manage behaviors expressed by the care

recipient. A 2012 review by the Alliance for Aging Research, Administration on Aging and MetLife Foundation found 44 caregiver evidence-based interventions for community-dwelling individuals with AD and their caregivers. Among these interventions some that have been tested with Latino communities include Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Protocol (Acton & Kang, 2001; Wisniewski et al., 2003), Savvy Caregiver Program (Hepburn, Lewis, Sherman, & Tornatore, 2003), and NYU Caregiver Intervention (AAR, AOA, & MetLife, 2012). The literature posits that psychoeducation (Gallagher-Thompson et al., 2001) and a use of cognitive behavioral approaches (Gallagher-Thompson et al., 2008) in interventions for this population have demonstrated some promising results. A systematic review conducted by Llanque and Enriquez (2012), interventions tested with Latinos caregivers between 2000 and 2011 suggested a reduction in depressive symptoms and anxiety.

Extensive quantitative data were collected from the notable Resources for Enhancement of Alzheimer's Caregiver Health (REACH) Project studies conducted in two phases. The REACH I phase examined 15 different types of interventions tested in Birmingham, Boston, Philadelphia, Memphis, Miami, and Palo Alto to determine their effectiveness (Wisniewski et al., 2003; Gallagher-Thompson et al., 2008; Morano, 2003). These interventions focused on various components that included education around the illness, skill building, and support in group settings as well as regular contact over the phone to check on status. REACH II focused on the differences across racial/ethnic groups with the structured multicomponent intervention that had been informed by the results of REACH I (Belle et al., 2006). REACH II aims at improving the quality of life of dementia caregivers, decreasing their depression, and avoiding or delaying institutionalization of the care recipient. Conducted over six months, the intervention consists of nine home-visit sessions, three phone contacts, and participation in a support group over the

phone for five sessions. The caregivers are given guidance on how to manage challenging behaviors the care recipient may be expressing, how to reduce the negative responses to challenging behaviors, stress management, and ways to elevate the support provided by others (Wisniewski et al., 2003).

Savvy Caregiver, originally known as the Minnesota Family Workshop (MFW), has been tested in states like Maine, Minnesota, Colorado, Alaska, Mississippi, Michigan, New Mexico, and California (Hepburn, et al., 2003). The intervention consists of six 2-hour sessions conducted in a community setting. Caregivers are provided workshops on ADRD caregiving knowledge, skills, and attitudes that will help them in their role and with managing their stress (Hepburn, et al., 2003).

New York University Caregiver Intervention (NYUCI) has been tested with Latinos in upper Manhattan (AAR, et al., 2012). This intervention addresses the spouse caregiver's well-being both emotionally and physically and aims to delay institutionalization of the care recipient. Through six in-person counseling sessions conducted over a 4-month time span, NYUCI is conducted in the home or elsewhere in the community. As a technique to gain more support for the caregiver, four of the six sessions require the participation of at least one additional family or friend. Involvement in a support group is recommended for the caregiving spouse and telephone counseling can be offered as needed.

Although the interventions mentioned were made available to Latinos in their preferred language (i.e., English or Spanish), a need to culturally tailor these interventions still exists (Gallagher-Thompson et al., 2003). The REACH studies incorporated aspects of community-informed interventions such as psychoeducational small group classroom settings with informal socialization at the beginning of the session and refreshments offered at each session. The

closing of the intervention included a "graduation" type celebration with family caregivers being able to invite families that showed to be more significant for Latino families and less for Caucasian family caregivers (Gallagher-Thompson et al., 2003).

As with ADRD Latino family caregivers, family caregivers of persons with other conditions such as children with an Autism Spectrum Disorder (ASD) or intellectual disability (Magaña, et al., 2015), relatives of individuals dealing with depression (Valdez, Padilla, Moore, & Magaña, 2013), psychosis (Tsai et al., 2015) or cancer (Rush et al., 2015), all may view their role as caregiver or support for the care recipient through a cultural lens. Magaña, Lopez, Paradiso de Sayu and Miranda (2014) describe the importance of incorporating not only linguistic appropriateness in interventions for caregivers but also cultural context that is relevant. In their study, Magaña, et al. (2014) incorporate Latina *Promotoras* (peer educators) and consultation from community partners and themselves to ensure that the cultural context is well embedded in the health education intervention. In the manual, examples, recipes and exercises are relevant to the lived experiences of the intervention participants as they depict scenarios that may reflect the environment and activities that are familiar to this population. A key element in the intervention is the role of *Promotoras*. These peer educators not only are community members but are also mothers of youth and adults of IDD themselves, allowing for a better understanding of issues relating to care for this population. Learning in this environment is more interactive and less didactic, bringing in a component of empowerment as participants see *Promotoras* as allies rather than figures of authority.

Consistent with the *Promotora* literature relating to the Latino community, health education has been effective in various areas such as heart health where *Promotoras* were able to significantly increase physical activity, understanding of heart health and efficacy in preparing

healthy meals in seven Latino communities in the U.S. (Spinner & Alvarado, 2012). Similarly in mental health, *Promotoras* have demonstrated a positive impact as they empower Latino communities in further promoting mental health and have helped in avoiding the worsening of community members' mental illness, with the most impact occurring as a result of potentially reaching those that have minimal or no access to mental health services (Stacciarini, Rosa, Ortiz, Munari, Uicab, & Balam, 2012). Health education via *Promotoras* has helped these other Latino populations to promote better health outcomes. The peer educator model may in fact produce more sustainable results due to its more organic nature.

Very few interventions are focused on health education for the caregiver. Most address the psychosocial aspect of providing care. Given the dismal health outcomes of caregivers it is concerning that interventions do not offer more content relating to the caregivers physical and mental health. In their study, Marquez, Bustamante, Kozey-Keadle, Kraemer, and Carrion (2012) examined physical activity, psychosocial and mental health of older ADRD caregivers compared to non-caregivers. Although only a small difference was found in the physical activity of caregivers compared to non-caregivers, anxiety, depression, stress as well as negative health outcomes were significantly higher for caregivers. Based on the results of the study and the importance of physical activity in connection with better health outcomes, shorter spans of time for physical activity (i.e., 10-minute segments throughout the day rather than 30 minutes continuous) were recommended for caregivers, making it more realistic and manageable given the large amount of time spent on caregiving often times (Marquez, Bustamante, Kozey-Keadle, Kraemer, & Carrion, 2012). There is a definite scarcity of interventions for this population that specifically focus on the promotion of health for the caregiver as a means for ensuring their quality of life and that of the care recipient.

D.   Conclusion

In conclusion, the literature suggests that in the Latino community the following exists: 1) a lack of understanding of ADRD; 2) some symptoms like memory loss are normalized, as part of classic aging; and 3) barriers to being diagnosed and receiving services. While values of familismo and marianismo may be descriptive of the family-centered and gendered care handled by the women that usually are associated with the Latino community, there is more to be understood about how family roles that are shifted and experiences of burden impact Latino families in general. Although a dearth of studies focused on the cultural implications of ADRD caregiving in the Latino community exists, there has been a growth of quantitative and qualitative knowledge regarding the physical and psychological toll this type of caregiving takes on Latinos. Health outcomes are already concerning based on existing health disparities found in the Latino community. Factoring in the physical and mental health implications caregiving may bring only makes the outlook bleaker for this population. Interventions currently used for the ADRD caregiving population in the nation are several and their focus varies with a large number of them addressing the psychosocial aspect of caregiving and managing transition points and difficult behaviors of the care recipient. Less has been done to make physical and mental health of the caregiver the primary focus. Some have been translated to the Spanish language and have been implemented and tested in Latino communities with positive results. According to further examination, adapting aspects of the intervention to better fit the community has been well received. There is much more to be studied and implemented for the well-being of Latina/o family caregivers of persons with ADRD. With the anticipated growth of this population and the complexity of developing culturally responsive and feasible interventions, it is only logical to further expand the empirical basis of this area in social work. Health education interventions

with the use of *Promotoras* have been effective with generally improving the health outcomes of Latinos dealing with various chronic conditions, thus offering a compelling justification for the use of *Promotoras* in a study focused on the health of Latina ADRD family caregivers. It is essential to not only address aspects of caregiver burden and depression given the population but also to incorporate an understanding and promotion of healthy behaviors and health-related self-efficacy. This study addressed a gap in the caregiver literature by exploring these research questions:

1) Is the health education intervention *By Caring for Myself I Care Better for my Family* relatable and adaptable to fit the needs of Latina family caregivers of persons with Alzheimer's disease or related dementia (ADRD)?

2) What elements of culture need to be considered when adapting *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

3) How do the experiences of burden in providing care to a family member/loved one with ADRD help inform the adaptation of *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

III. METHODOLOGY

A.   Research Design

This study used a qualitative methodological approach and consisted of two phases (i.e., assessment, adaptation) that are detailed in the sections that follow and referred to as Phase I and Phase II. I used steps 1 through 3 from the Center for Disease Control and Prevention (CDC) Map of Adaptation Process (2006) as an adaptation framework for this study. The complete 5-step framework includes the following:

- Step 1 – <u>Assess</u> for goodness of fit with the intervention, target population, stakeholders, and organization.

- Step 2 – <u>Select</u> to adopt the intervention (without modifications), adapt the intervention or select another intervention.

- Step 3 – <u>Prepare</u> the adaptation of intervention, pretest with the target population, and preparation of the organization.

- Step 4 – <u>Pilot</u> the implementation plan for the adapted intervention and successfully pilot-test the adapted intervention or its components if not feasible to test the entire adapted intervention.

- Step 5 – <u>Implement</u> adapted intervention (with minor refinement after pilot-test).

This study used Step 1 through 3 to delineate the tasks that guided the research as the scope of this study was to assess and adapt an intervention. The CDC Division for HIV/AIDS Prevention (DHAP) drafted this adaptation framework as a systematic approach for adapting evidence-based behavioral interventions (EBIs). A multidisciplinary team developed this comprehensive framework using previous frameworks and literature in health education, social work, participatory research, and community empowerment principles. Three overarching phases in the

framework include the (1) Assessment Phase (Step 1 – Assess), (2) Preparation Phase (Step 2 –

Select and Step 3 – Prepare), and the (3) Implementation Phase (Step 4 – Pilot and Step 5 –

Implement) depicted in Figure 2 (see page 35). The use of the framework's first two phases (i.e.,

assessment and preparation) were used to inform this study in assessing and adapting the

culturally responsive health education intervention for Latina ADRD family caregivers.
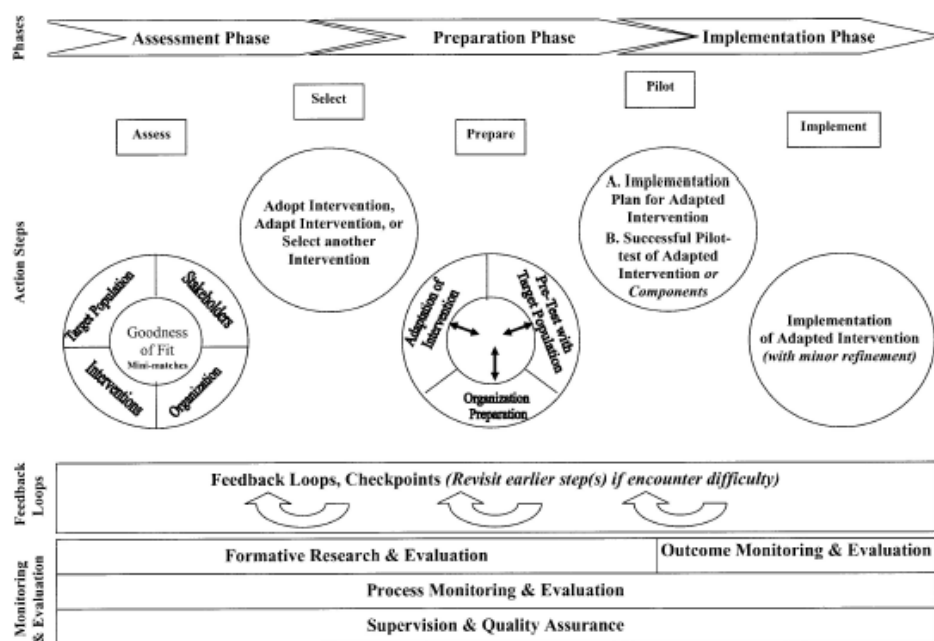
FIGURE 1. Map of Adaptation Process: A Systematic Approach for Adapting Evidence-Based Behavioral Interventions
Note. This is a *working draft*. Investigators will distribute a revised draft at the conclusion of ADAPT project activities.

Figure 2. Map of Adaptation Process: A Systematic Approach for Adapting Evidence-Based Behavioral Intervention (McKleroy et al., 2006, p. 65). Note. Framework developed by the CDC.

According to Wilkinson (1998), focus groups in health research allow for further

exploration of the meaning and understanding that people place on health and illness. The

interaction of participants in groups builds a richness and quantity of data that may not be

possible with any other method (Wilkinson, 1998). Such is the case especially when there are

intimate topics being discussed where one participant of a focus group shares an experience (e.g.,

the behaviors of a care recipient); this may encourage others to join in the conversation with their

own experiences as well. Focus groups lend themselves to having participants feel more relaxed and safer to say as much as they would like, thus enhancing disclosure (Wilkinson, 1998). Given the value this understanding would add to the adaptation of the intervention, focus groups were used for this study.

In Phase I, the health education intervention *By Caring for Myself I Care Better for my Family,* considered a promising practice for Latina mothers of children with IDD, was reviewed in focus groups to determine if the content of the intervention was relatable and adaptable to Latina family caregivers of persons with Alzheimer's disease or related dementia (ADRD). Participants of the focus groups were invited to a member check for review of the findings of the focus groups regarding components needing to be adapted (Research Question 1). At Phase II, preparation of the adapted intervention occurred based on the findings from the focus groups and a continued review of the literature. Informed by the findings from the participant member check, the literature and a review of the adapted intervention in its entirety with two selected readers that are content area experts and one reader offering translation, the resulting final version of the adapted health education intervention now titled, *Caring of Caregivers Organically (CoCO)* was developed for Latinas caring for a family member/loved one with ADRD (Research Question 2 & 3). Community participation by way of having Latina family caregivers themselves and other stakeholders taking part in focus groups encouraged a more organically developed intervention. The study tried to capture the community's expertise on the subject matter through questions in the focus groups that informed aspects of the adaptation.

B. Sampling and Recruitment

The literature on caregiving in the Latino community describes gender differences rooted in *marianismo*, or women being the caregivers in families (Arévalo-Flechas et al., 2014). Often

the Latina daughter assumes care (Mier, 2007) thus, participants of the study were women that identify as Latina/Hispanic and were the caregiver of a family member/loved one with ADRD. An attempt was made to replicate the number of participants in the focus groups used when developing *By Caring for Myself I Care Better for my Family*. Typically, six to eight participants make up a focus group (Wilkinson, 1998) but given the hard to reach population and the very specific criteria for participation of Latina family caregivers and their already limited availability, I expected to recruit five to seven participants for each set of focus groups. Moreover, participants were given the option to participate in one single focus group or multiple if their availability permitted.

In the initial stage (Phase I), four individuals were recruited that identify as Latinas/Hispanic females who provide care to a family member/loved one with ADRD to attend up to three 2-hr focus groups. Additionally, four other stakeholders that are service providers, organization/community leaders, academics, researchers etc. who have a direct link to or expertise in the areas of aging, caregiving, the Latino community and/or ADRD agreed to participate after being invited (others were also invited but unavailable) to take part in this assessment phase to attend up to two 2-hr focus groups that were different than the Latina family caregiver focus groups. These stakeholders were included in the study to offer a different perspective to the adaptation and/or further corroborate the findings from the literature and the Latina family caregiver perspective.

Recruitment was multifaceted. An invitation was made to potentially eligible participants from a Rush Alzheimer's Disease Center (RADC) database that stores contact information of individuals that have come to the center seeking information and/or services relating to Alzheimer's disease (AD) and are willing to take part in research studies. Institutional

stakeholders (e.g., service providers, organization/community leaders, academics, researchers) were invited from the researcher's network of community leaders, organizations and institutions that serve or hold an expertise in Latina/o families, ADRD, caregiving and/or older adults. Bilingual flyers were also distributed in local, predominantly Latino Chicago neighborhoods such as Pilsen, Little Village, Brighton Park, Back of the Yards, Gage Park, Chicago Lawn, South Chicago, Humboldt Park, Albany Park, and others that have more than 50% Latino population according to the U.S. Census, and among community-based providers. Interested individuals that live in the suburbs were not excluded from the study but were made aware that the study sites were located in the central region of Chicago (i.e., UIC West Campus, Pilsen Senior Center).

During the screening process that I conducted over the phone, the following was explained: eligibility requirements, voluntary participation, language of preference (i.e., Spanish, English), location of study sites (i.e., UIC West Campus, Pilsen Senior Center), and date/time availability. Preference for participation was given particularly to those Latina family caregivers that were 50 years of age or older (for the Latina family caregiver focus group) but this was not a criterion for excluding participants from the study. Participants were screened for eligibility based on the participation criteria already mentioned as well as availability, due to the time commitment needed for each focus group. Participants were able to take part, if their time allowed, in one of the 2-hr focus groups or several of the 2-hr focus groups.

C.   Data Collection

Community input, by way of a series of focus groups with the perspective of Latina ADRD family caregivers as well as other stakeholders, was used to assess if the original intervention was relatable and adaptable to the needs of Latinas caring for a family

member/loved one with Alzheimer's disease or dementia. In Phase I, one set of focus groups consisted of four Latina ADRD family caregivers, meeting three different times (i.e., three focus group discussions occurred total). The second set of focus groups was made up of four institutional stakeholders (e.g., service providers, organization/community leaders, academics, researchers), meeting two different times (i.e., two focus group discussions occurred total). A total of five focus groups were planned and participants were free to take part in one or multiple 2-hr focus groups (i.e., Latina family caregivers were a part of up to three focus groups; other stakeholders were a part of up to two focus groups). This format allowing for participation in one or multiple focus groups was done to ensure ease of participation while also accommodating the length of the interview guide questions. The focus group size of five to seven participants was used in the parent study (Magaña, et al., 2014) and an attempt to replicate it was made.

Each focus group participant reviewed content from the manual of *By Caring for Myself I Care Better for my Family* in the language of preference (i.e., Spanish or English) to consider whether the content was relatable and adaptable to the Latina ADRD family caregiver population. Focus group participants were asked to provide feedback on what was relevant and applicable (i.e., relatable), and what was not (i.e., requiring adaptation) for Latina ADRD family caregivers, given their own understanding and knowledge of caring for a family member/loved one with ADRD as a Latina (see Appendix A for Phase I Focus Groups Interview Guide on page 121). Points were shared with the participants from existing literature to corroborate or supplement the data obtained during the focus groups. Audio recordings and a note-taker were used during all focus groups with subsequent transcription and translation, as needed.

To end Phase I, all participants of the focus groups were invited to a member check. A member check consisted of the researcher and the selected participant(s) reviewing the summary

of the findings from the Phase I focus groups (see Appendix B for Phase I Member Check follow up on page 129). Participants were provided with a draft of a manual detailing the adapted intervention. The adaptations that were made were discussed in depth. I shared with the participants what I understood as the findings for analysis and how those were considered for the development of the adapted intervention. The member check was audio-recorded and transcribed with a note-taker present to capture any additional information.

At Phase II, I used existing literature describing the experiences of Latina family caregivers and other interventions for ADRD caregivers along with the findings from Phase I focus groups to more fully explain, validate and explore the richness of data through triangulation of themes (Miles, Huberman, & Saldana, 2014). Per the Alzheimer's Association (2015), some of the interventions that have shown successful results include the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Protocol (Acton & Kang, 2001; Wisniewski et al., 2003), Savvy Caregiver Program (Hepburn, Lewis, Sherman, & Tornatore, 2003), and Skills2Care Program (Gitlin et al., 2001) among others. A review of the literature was used to identify trends of health-related needs and relevant caregiver topics that supplemented and/or corroborated the data gathered during the Phase I focus groups.

Upon completion of a full draft of the intervention adaptation, two readers were asked to review the main manual describing the curriculum for the intervention. A third reader was asked to translate the curriculum (i.e., peer educator and participant manuals). This third reader offered feedback on the content of the curriculum for any adjustments needed. The identified readers were content area experts that were familiar with the population and circumstances for which this adaptation is intended. Feedback provided by the readers was documented and collected as notes further for review as the adaptation process continued. The insight provided by the readers was

further discussed between the researcher and the readers until all clarifications were made and consideration was given to the feedback when developing the final version of the adapted health education intervention *CoCO*.

D.   Data Analysis

The qualitative data from the audio-recorded Phase I focus groups, including the member check and note-taker's notes (taken by a research colleague), as well as the notes offered by the selected readers during Phase II and the researcher's reflexive journaling carried out through the study were studied and systematically coded using thematic analysis (Braun & Clarke, 2006). In Braun and Clarke's (2006) process, text data is actively reviewed and themes are extracted through a 6-phase process: "(1) familiarizing yourself with your data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report" (p. 87). Given the use of focus group discussions as the unit of analysis, thematic analysis renders an adequate strategy for examining data where the level of depth achieved may differ from that of a structured or semi-structured interview. The more egalitarian nature of focus groups allows for themes to surface freely (Wilkinson, 1998), thus making the extensive study of the themes imperative.

Data that related to the elements from the original intervention manual that were considered relatable and adaptable for Latina ADRD family caregivers (Research Question 1) underwent a more inductive thematic analysis (Braun & Clarke, 2006). The data were read and reread in search of any themes related to what was considered relatable and adaptable in the existing intervention. Although literature exists in terms of ADRD caregiver interventions, there is a dearth of knowledge relating to evidence-based interventions that are Latina-centered. This study looks to further expand this body of knowledge using input from Latina family caregivers

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and other stakeholders using an inductive approach.

Additionally, theoretical thematic analysis (Braun & Clarke, 2006) was used to systematically review the text data for codes and themes in relation to the implications of culture and experiences of burden that Latina ADRD family caregivers face, which helped inform the adaptation of *By Caring for Myself I Care Better for my Family* (Research Questions 2 & 3). With theoretical thematic analysis it is understood that there is a pre-existing theoretical framework informing the use of particular coding categories in the analysis (Braun & Clarke, 2006). Knight and Sayegh's (2010) Revised Sociocultural Stress and Coping Model for Caregivers (see Figure 1 on page 10) is widely referenced in dementia caregiver health literature to map the intersection of culture with caregiver health. Informed by the theoretical framework, codes and themes relating to any care recipient's behaviors, caregiver burden, cultural values, coping style, social supports and caregiver's health were highlighted in the audio transcripts of the focus groups and member check, as well as on all written material to include note-taker's notes, selected readers' notes and researcher's reflexive journaling. Additional codes were developed and studied as a semi-open coding process was used to determine themes that are not considered in Knight and Sayegh's (2010) revised sociocultural stress and coping model.

With the support of a second bilingual researcher through the technique of peer debriefing and review (Miles et al., 2014), the data were read, recording initial thoughts of codes found in the data by highlighting extracts and annotating additional thoughts (Phase 1 of thematic analysis). Each researcher independently developed a list of initial codes related to the experiences of Latinas caring for a family member/loved one in terms of the behaviors of the care recipient, caregiver burden, cultural values, coping styles, social supports, and health (Phase 2 of thematic analysis). The independent lists of the two researchers were then reconciled by

sharing the results of each list with the other to determine a consolidated list of preliminary codes. All relevant data were collated using post-it cards. The data set was reread to further collate codes, identifying potential themes (Phase 3 of thematic analysis). The themes were reviewed with the existing coded extracts first, then with an additional read of the data set again making sure the themes continued to make sense, ultimately generating a thematic map of analysis between the two researchers (Phase 4 of thematic analysis). Continued analysis of data occurred to refine, define and name themes (Phase 5 of thematic analysis). Finally, one last analysis produced extracts that were compelling examples of the data and extracts that relate back to the research questions and literature (Phase 6 of thematic analysis).

As with all qualitative data, saturation is desired. Krueger (1994) and Morgan (1997) suggest that saturation is possible with three to six focus groups, thus saturation was expected to be reached given the five focus group discussions for the study and a member check. Similar themes were consistently expressed in the data suggesting saturation was reached for themes expressed by caregivers. Triangulation of data occurred based on having data offered by the study participants that was considered along with peer-reviewed published literature and then a final read of the adaptation by content area experts. All qualitative data obtained during the focus groups and notes from the selected readers were coded and analyzed. Suggestions for adaptations were noted and shared with the other focus group participants across groups to further explore validity of adaptation suggestions. These suggested adaptations were reviewed again during the member check and additional times with the selected readers, to discuss further insight in considering the use of these in the adaptation before the final version of *CoCO* was developed.

E. **Ensuring Trustworthiness of Data**

All research including qualitative research calls for measures to be taken in order to

reduce researcher bias at the time of data collection and analysis (Emden & Sandelowski, 1998). The following section reviews my positionality and the steps taken to address this possible bias.

1. **Researcher Positionality**

I identify as a Latina of Mexican descent and have provided care to my mother since she was diagnosed with dementia in 2005 and AD six months later in 2006. Along with my older sister, I have experienced firsthand various aspects of family caregiving that many of the participants in the study may have lived themselves. As an advocate for alleviating some of the challenges that Latinas/os face in family caregiving and quality of life for the caregiver and care recipient, I have become involved in a coalition that looks to address key disparities for the Latino population dealing with ADRD. Furthermore, I have been involved with a couple of studies relating to caregivers. One study was specific to ADRD caregivers that consisted of individual in-depth interviews. The second study was a pilot of *Caring for Myself*, the original intervention focused on Latina mothers caring for children with IDD, which is the one being reviewed and adapted for this current study. The pilot was to test more objective measures of data collection as well as the feasibility and acceptability of the use of technology (i.e., texting) to reinforce the material being reviewed by the participants and as a means for improving communication between the participants and their assigned *Promotoras*. I served as the project coordinator for the pilot study and the Principal Investigator was Dr. Sandra Magaña, who originally developed the intervention and now serves on the dissertation committee for this adaptation to the population of Latina ADRD family caregivers.

2. **Ensuring Trustworthiness During Data Collection and Analysis**

In order to maintain integrity of this study, I, as a professional licensed clinical social worker, used transference and countertransference skills learned in social work training that

allowed me to actively listen and be diligent about putting the necessary value on the feedback acquired from the study participants' experiences. Through reflexive journaling and consistent consultation with and feedback from my dissertation committee chair, Dr. Hsieh, opportunities for processing the study process were requested, especially to address any issues of transference/counter transference. Dr. Magaña served as a critical guide with development of the adapted intervention and through the expertise and support of the entire defense committee intervention integrity was possible and sustained.

An external measure used to minimize researcher bias consisted of having a member check after the five planned focus groups. I held a group meeting where both Latina caregivers and other stakeholders that participated in the focus groups and were willing to take part in an optional member check, were invited. Three Latina family caregivers and one stakeholder took part in the member check. The dialogue that ensued during this optional member check was an opportunity to present to the participants what information I received during the focus groups. The participants of the member check were then able to confirm if the data I captured was accurately depicting what they had shared during focus groups. Having representation from both the Latina caregiver focus groups and the other stakeholder groups allowed for a more comprehensive review of the material and further sharing of common or differing themes.

Additionally, a second coder that served to conduct a peer debriefing allowed for data to have the perspective of a different person that was removed from the actual focus groups and member check. The second coder has the expertise of public health research and Alzheimer's disease in the Latino community. This second coder's pre-established knowledge facilitated the process of understanding theoretically the connection between the guiding conceptual framework and the themes that surfaced during the coding and peer debriefing process.

F.   Human Subjects Protections

1. Potential risks to research participants.

Participants of this study were exposed to no more risks than they would experience in everyday life. During focus groups, participants disclosed sensitive information regarding their personal caregiving experience that was emotionally challenging, and/or potentially causing some temporary distress. During the informed consent process, participants were told of this and other risks or discomforts they may experience. At the time of consent as well as at the beginning of each focus group, participants were encouraged to only share what they felt comfortable disclosing while engaging in discussion during the focus groups. In order to counter the risk that participants may have faced during the study with sensitive topics, a packet of local and national resources was available to all participants of the study that may be useful if distress persisted.

Additionally, another risk of participating in focus groups is the loss of privacy (revealing to others that you are taking part in this study) and/or confidentiality (revealing information about you to others to whom you have not given permission to know this information). Privacy and confidentiality were addressed in various ways throughout the study. When starting the focus groups and member check, participants were asked to use pseudonyms or no names at all when speaking, during the time these discussions were being audio-recorded. Participants were asked to respect the privacy and confidentiality of other participants by not revealing the identity and personal information of other focus group participants outside of the group discussions. Moreover, participants were told it would be difficult to ensure complete privacy and confidentiality even though all participants were asked to not share information further and thus everyone should consider this as they decided to disclose information. In order to address the matter of understanding better and safeguarding confidentiality as best as possible, everyone in

the study team underwent training on the protection of confidentiality in human subjects research.

In an effort to further protect confidentiality of participants, I assigned an identifying number to each participant at the time of the phone screening that would be used on any written documentation for the study, other than the informed consent. All study files including the initial phone screening forms and informed consents were filed in a locked cabinet at an Institutional Review Board approved university office. A master list containing the participants name, address, phone number and study ID number was stored electronically in a password protected computer drive. Identifying information will be destroyed upon completion of the study. Audio recordings will be destroyed after they have been transcribed, verified and fully analyzed. Any study documentation that does not include identifying information will be kept in locked files indefinitely. During dissemination of the findings in publications and conference presentations, there will be no information shared that would reveal the identity of any of the participants.

2. Procedures for ensuring voluntary and informed consent.

Voluntary participation was explained at the time of the phone screening, during the informed consent process, at the start of the focus groups and member check. Review of informed consent occurred at the time the participants took part in the first face-to-face contact after becoming identified as eligible for the study through a phone screening. During the informed consent process, participants were reminded that participation in the study was voluntary and could be terminated at any point without having this affect their relationship to the university or any entity that provided them with the information about the study. Informed consent was obtained in a language understandable to the participant. As I am fluent in Spanish and English, I was able to carry out informed consent procedures in the participant's preferred

language with documents that were in the language of their choice (i.e., Spanish and/or English). Informed consent was obtained at the start of the first focus group session each participant attended. I read through the form to the participants and allowed for questions before, during and after the review of the form, prior to asking them to sign the form if they still agreed to participate in the study. The participants each received a signed copy of their own informed consent form and were encouraged to review the form more closely at home in case there were any questions in the future about their participation. A room that was safe of any distractions and private was used for the informed consent process and focus group sessions that occurred both at the university and community site.

IV. FINDINGS

A.   Introduction

The aim of this study was to review the *By Caring for Myself, I Can Better Care for My Family* health education intervention and test if it was relatable and adaptable to Latinas providing care to family members/loved ones with Alzheimer's disease or related dementia (ADRD). Informed by Knight and Sayegh's (2010) revised sociocultural stress and coping model, the adaptation process consisted of explicating elements of culture and experiences of burden impacting this population to make the intervention culturally responsive to the health needs of the identified population. The research questions examined for this qualitative study were the following:

1) Is the health education intervention *By Caring for Myself I Care Better for my Family* relatable and adaptable to fit the needs of Latina family caregivers of persons with Alzheimer's disease or related dementia (ADRD)?

2) What elements of culture need to be considered when adapting *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

3) How do the experiences of burden in providing care to a family member/loved one with ADRD help inform the adaptation of *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

The results of the study will be described further in this chapter by demographics of the participants and the themes that surfaced from the data. Rather than presenting the findings in a linear manner by research question, the use of thematic analysis (Braun & Clarke, 2006) calls for the development of a thematic map for analysis (see Figure 3, page 51) and thus reporting the

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results by themes seems to align more efficiently with this process. In speaking of the findings, the term 'caregiver' is used to describe the person offering support to a family member or loved one with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). The term 'care recipient' identifies the family member or loved one receiving support in ADLs and/or IADLs. Unless otherwise noted where there are significant differences, the data are described for both the Latina Caregivers and Other Stakeholders focus groups together. Combining the data in this way is done given the majority of the participants of the Other Stakeholders focus groups (75%) were currently or had been family caregivers of a person with ADRD and offered their perspective as a caregiver as well as that of a service provider or content area expert.

The research questions were explored by way of the focus group interview guide that included the following (see Appendix A for the complete Phase I Focus Groups Interview Guide on page 121):

- Please tell us a little about yourself and how you know about taking care of persons with Alzheimer's disease or related dementia (ADRD).

- We will review the manual together and I would like you to take notes where you think changes need to be made to make this fit to a Latina taking care of a family member/loved one with ADRD. Based on your notes and your thoughts, what changes are needed?

- Do you think this program, if we make the changes you are suggesting, would be helpful for Latinas taking care of a family member or loved one with ADRD?

- Is there anything that you would like to add that we have not discussed yet?

These questions served as the starting point since dialogue was much more extensive during the

review of certain key sections of the actual intervention manual. As the manual was being

reviewed, I provided the Latina Caregivers focus group participants an opportunity to do some of

the activities that the *Promotora* would carry out with intervention participants. Having hands-on

exposure to some of the material in the manual resulted in further interchange of how relatable or

adaptable these activities were to the population of interest based on how engaging these were to

their own interest and situations. Figure 3 (See page 51) is a visual depiction of my findings as

analyzed in a thematic map (Braun & Clarke, 2006). The thematic map served as a model to be

examined against the conceptual model, the revised sociocultural stress and coping model that

was used as the guiding framework for this study (Knight & Sayegh, 2010 - See Figure 1, page

10), and will be interpreted further in the next chapter on the discussion of the study results.
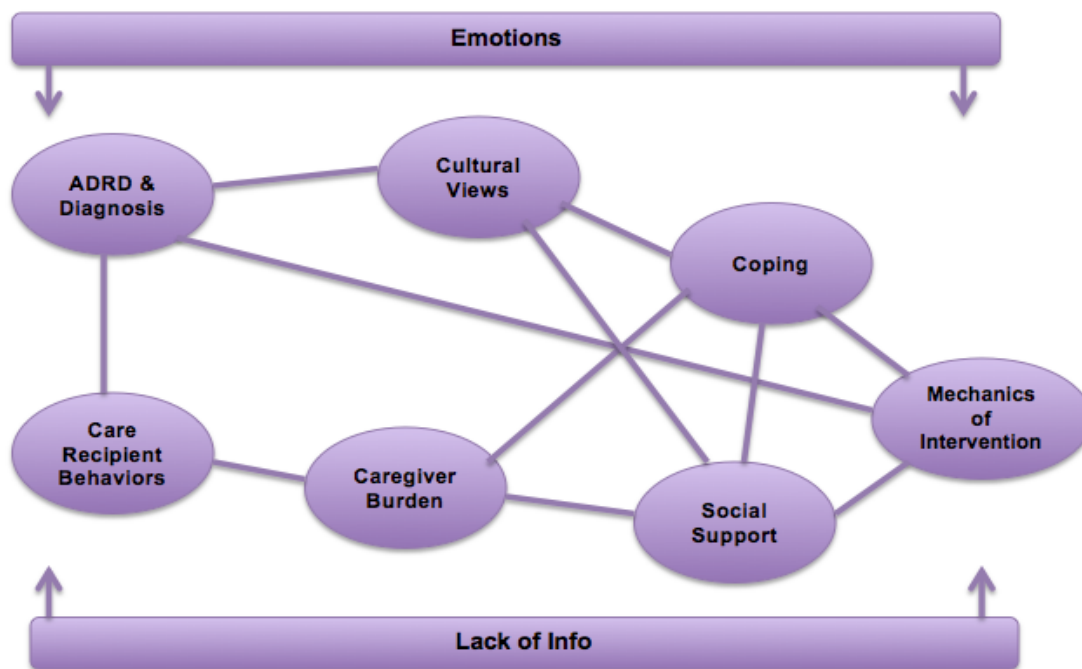

Figure 3. CoCO Study Thematic Map for Analysis.

Each main theme and sub-themes (not listed in the image) are explained at greater length

in the sections that follow. Incorporated throughout the description of the themes are excerpts of

the dialogue that occurred in the focus groups to highlight the themes and sub-themes being defined. I provide the participants' accounts in the language they were shared to keep the integrity of their meaning as intact as possible but I describe those in English to keep consistency of this document. I conclude the chapter with a synthesis of the findings in relation to the research questions with a more extensive interpretation of the study results in the chapter that follows.

B.   Sample Description

During data collection I planned for five focus groups and one member check, each for the duration of up to two hours. The goal was to recruit five to seven eligible participants for each set of focus groups (i.e., Latina ADRD Family Caregivers focus groups, Other Stakeholders focus groups). Three focus groups were planned with Latina ADRD family caregivers to review different portions of the intervention manual and discuss the adaptation needed. The first of three focus groups turned out to be an individual discussion as only one Latina caregiver was present and one was a no-show due to a family situation. The second group included four Latina caregivers, one of which was the one that attended the first focus group. The third group included all the same participants from the second focus group.

The focus groups conducted with other stakeholders who were service providers and content area experts were carried out in two parts. The first of the two focus groups consisted of two stakeholders. The second focus group included four different stakeholders, two of which were the ones that attended the first group. Three of these four participants were caregivers themselves or had been caregivers in the past, although this was not a requirement of this stakeholder group. The demographics of all the participants in both sets of focus groups are further described in Table 3 (See page 53).

All eight focus group participants were invited to an optional member check interview. Based on those that would be available to partake, the member check interview was done as a group meeting combining representatives from both sets of focus groups. Four participants attended the member check that included three participants from the Latina Caregiver focus groups and one participant from the Other Stakeholders focus groups. Three (75%) were female and one (25%) male. Half (50%) of the member check participants were family caregivers to parents and the other half (50%) to husbands. In terms of age, three quarters (n = 3) of the participants were age 50 or older (one participant in this group was older than 70 years old) and the fourth participant was under the age of 30.

Participant Characteristics	N = 8 Frequency (%)
Gender	
Female	7 (87.5)
Male	1 (12.5)
Age Group	
Under 50 years old (majority under 30)	4 (50)
50+ years old (1 participant 70+ years old)	4 (50)
Relationship to care recipient(s), if applicable	[N = 7]
Daughter (1 participant from Other Stakeholders group)	3 (43)
Wife	2 (28.6)
Granddaughter (participant in Other Stakeholders group)	1 (14.3)
Son (participant in Other Stakeholders groups)	1 (14.3)
Language	
Bilingual (Spanish/English)	5 (62.5)
Spanish (monolingual)	3 (37.5)
English (monolingual)	--
Ethnicity	
Mexican	6 (75)
Puerto Rican	1 (12.5)
Mixed (Mexican/Colombian)	1 (12.5)
Birthplace	
U.S. born (majority in the Other Stakeholders group)	4 (50)
Foreign born (majority in the Latina Caregivers group)	4 (50)

Table 3. Demographics of CoCO Study Phase I Focus Group Participants.

C.   The Medical Aspect of Alzheimer's Disease and Related Dementia

1. The Diagnosis.

Participants from both sets of focus groups (i.e., Latina Caregivers, Other Stakeholders) were asked to describe how they knew about the subject matter, meaning ADRD caregiving. They were also asked to review the existing health education intervention keeping a lens of a Latina ADRD family caregiver to comment on what was relatable and adaptable. All those that were, at the time or in the past, family caregivers (in both sets of focus groups) shared the fact that their family member had been diagnosed either with dementia or Alzheimer's disease. One woman in particular revealed in more detail the length and barriers of her process with obtaining a formal diagnosis for her husband. She expressed her concern repeatedly on the "lack of information" (Participant 1 – Latina Caregiver) she felt she had received from the husband's doctor and had available throughout the diagnosis process to the present. She told her husband's doctor the symptoms he was expressing and found herself having to be persistent in getting a formal diagnosis after several appointments, even after medication for dementia had already been prescribed with no diagnosis or information about the condition having been given to the couple:

> Ahora, ese neurólogo nuevo que lo está viendo le ha sacado estudios, pero, es como dice la señora, no dice nada el doctor. Nada más llega, ¿cómo te sientes? ¿Cómo te sientes con la medicina? ¿Qué cambios has tenido? Tómate esta medicina y regresa en tres meses, y ya así pasaron como dos ocasiones, ¿no? Ya a la tercera vez que fuí, yo le dije, bueno doctor, usted le dice, tómate esto esto y esto, pero los resultados– y yo le dije, ¿tiene Alzheimer?¿Ese es el problema de él? Y fue cuando el doctor dijo, sí. Entonces, bueno, ¿cómo es posible que viene viene y el médico no empapa a uno de su problema? Y yo por ese lado sí sentí mal, porque dije, bueno, yo tengo que preguntar cuando el de la obligación es él que comunique, ¿no? (Participant 1 – Latina Caregiver)

A different participant similarly commented on the quality of medical attention as she expressed the lack of follow up doctors may have, especially when they do not understand the patients

culturally. She states that through her work it has been her experience to see that no matter how compassionate a doctor may be, they will just "drop the bomb" [report the diagnosis] without thinking of the family's reaction and how much of an impact this will have for them:

> … desafortunadamente un médico por más compasivo que sea le va a dejar ir la bomba sin pensar en la reacción de la familia. Especialmente si no tiene la cultura ni el conocimiento, porque eso implica muchas cosas. (Participant 7 – Other Stakeholder)

Additionally, another concern that appeared in terms of the diagnosing process was the stage that the doctor identified the family member to be in at the time of the diagnosis. The participant felt the functioning level and symptoms seemed more severe than the early stage of the disease the doctor diagnosed the husband to be in:

> Como en el caso de mi esposo, …que apenas dijeron que tiene principios, pero yo ya noto que más que principio, yo ya lo noto un poquito más. (Participant 1 – Latina Caregiver)

An aspect of diagnosis that also prevailed was when the diagnosis occurred for the participant's family member. One participant offered his account about how his paternal grandmother had the condition 10 to 12 years ago and has since deceased. Now his father has had the diagnosis for three and a half, almost four years (mentions both at two different times) but had showed symptoms for at least five years prior to the diagnosis. Although the father is a person that actually likes to go to the doctor regularly, he was not diagnosed sooner, even given the family history that existed:

> …él sospechaba; su mamá tuvo hace diez, 12 años. O sea, él sospechaba que algo estaba mal, la ventaja de mi papá es que él está obsesionado con ir al médico, siempre quiere ir, toda la vida ha sido así; lo opuesto de todos mis tíos por parte de mi mamá, ellos no; raramente, a menos que esté en la sala de emergencia nunca se hacen un examen de la próstata y mi papá no. A él no le tenían que decir, él iba; y hasta la fecha, a él le gusta ir, pero él se quejaba que no – se confundía cuando compraba algo, iba a tomar un café y cuando le daban el cambio no entendía cuanto, se le hacía demasiado lo que le cobraban pero no era. Entonces, pues sí él estába preocupado por eso… (Participant 5 – Other Stakeholder)

> …he estado cuidando a mi papá, tiene Alzheimer hace tres, casi cuatro años. Lo ha tenido

por lo menos unos cinco años antes, antes de que lo diagnosticaran, pero sí lo he estado cuidando hasta, tratando de cuidar hasta ahora. Su mamá también tuvo Alzheimer. (Participant 5 – Other Stakeholder)

Furthermore, a participant shared that she felt her mother's onset came at a very early age. She compared her own age (early 60s) to that of her mother's by declaring that her mother had already received a diagnosis of dementia followed by one of Alzheimer's at the age that the participant was currently:

Mi mamá tenía Alzheimer en una edad muy joven. Yo puedo decir que fue joven porque yo ya le gano en años a mi madre cuando le descubrieron primeramente demencia y después el Alzheimer. (Participant 7 – Other Stakeholder)

The majority of the participants expressed some knowledge of the diagnosis process as they revealed their own experiences or what they knew from members of the community when going through this process. A participant that is a long distance caregiver, first for her father with Alzheimer's disease who now is deceased and currently for her mother that has dementia, expressed her understanding of the diagnosis process as being long since there is a need to rule out other reasons for symptoms that are present in the person:

…para lograr un diagnóstico de Alzheimer tiene que haber pasado por muchos descartes. Para empezar, bueno, tiene diabetes, el medicameto, o sea, sabemos que hay otras enfermedades que pudieran asentuarle síntomas muy parecidos a una persona que de verdad tiene Alzheimer, pero después de filtrar todas las demás posibilidades es que al final se queda con un diagnóstico de Alzheimer. (Participant 2 – Latina Caregiver)

Just as important to many of the participants was noting that not everyone has formal ADRD diagnoses but is providing care just the same. One participant supported this by revealing she knew someone in this situation where there are "obvious" signs the family member has the condition but there is not more of an acceptance of the condition because the doctor has not officially given a diagnosis yet:

Hay personas que no reciben diagnóstico, ¿verdad? Y todavía saben que lo tienen… Porque esas personas a veces siguen pensando que el doctor no me ha dicho nada, y yo

conozco a alguien que eso me dice, cuando es bien obvio que el señor está enfermo. Pero ella no hace por llevarlo al médico y no quiere. (Participant 3 – Latina Caregiver)

Even when the formal diagnosis was given in a different case, the participant attributed her husband's refusal to accept the diagnosis because of denial and the thought that dementia meant he was mentally ill which he did not feel he was, per the participant's report. To this account, a second participant contextualized how denial could in fact be one of many reasons for obtaining a delayed diagnosis in the Latino community. This response to obtaining a diagnosis that could be interpreted as the use of denial to cope is expanded on in future sections including one titled "Coping," as it was a theme that surfaced in various aspects of the caregiver experience.

2. Understanding the Condition.

As the participants spoke about the condition and how they made sense of it, there were some commonalities in attempting to explain the condition and a few less typical responses. The responses were comprised of descriptions of the condition that seemed to be what participants have been told by healthcare professionals or content area experts. Moreover, there were those descriptions that involved more personal views and emotions that have been evoked by attempting to understand the condition. The less typical responses included how society in general may view disabilities and illness.

In the realm of what participants have been told about the condition by healthcare professionals were responses like the fact that the condition is progressive, that the ADRD stages vary in each person and that although some similarities exist in the condition, there are very unique realities for each person. One participant, given her nursing background, offered some factors she felt have been identified in the media as contributing to the unleashing of the condition, which included things like food and nutrition habits as well as culture by way of racial/ethnic background:

…sí es una enfermedad que continuamente se está informando en los medios de cuáles son los factores que nos llevan a esta enfermedad; y llama la atención que la comida, los hábitos alimenticios, la cultura que nosotros traemos ya de nuestras raíces, ya sea cultura hispana, anglosajona, afroamericana y que todo esto nos lleva a una posible – a desencadenar esta enfermedad. (Participant 6 – Other Stakeholder)

Some participants were given visual methods of understanding certain aspects like the difference between dementia and Alzheimer's disease as well as the progression of Alzheimer's disease. Participants revealed they had been given some of those themselves by professionals or other content area experts in the past. One participant described how she was able to see the relationship between dementia and Alzheimer's disease when a healthcare professional described that dementia was like an umbrella that encompassed many symptoms including depression. Alzheimer's disease sits under this umbrella as well and is understood as one of the types of dementia based on her description and the reason why it is identified in people as dementia first followed by a diagnosis of Alzheimer's afterwards:

A mi me explicaron que la demencia viene a ser como un paraguas y debajo de ese paraguas viene la enfermedad de depresión, porque es real, existe. La gente de verdad se deprime y debajo de esa demencia también está el Alzheimer. Entonces, tal vez, de ahí viene que primero le dicen demencia, pero es una de las ramas que cuelgan debajo de ese paraguas. (Participant 3 – Latina Caregiver)

The other visualization was offered by a participant that described how a former professor of hers presented the progression of Alzheimer's disease to her class as an onion being peeled one layer at a time until it is completely open, empty and no longer existing, resembling how parts of the person are lost in every aspect imaginable:

…uno de los profesores me acuerdo que él compartió algo muy profundo que no – y uno a veces lo pone a pensar. Dice, Alzheimer es como una cebolla. La cebolla comienza entera, y como usted acaban de explicar anteriormente acerca desde el momento de que naces empieces a perder. La cebolla le quitas las hojas, le vas quitando hasta que queda completamente abierta y vacía y ya no existe, that's Alzheimer, porque se van perdiendo partes de la persona en todo sentido de la palabra. (Participant 7 – Other Stakeholder)

Being able to connect certain concepts or processes visually and in a more succinct manner was a

theme that appeared regularly in both sets of focus groups (i.e., Latina Caregivers, Other Stakeholders). Furthermore, the importance of having material that was visually appealing and compact was noted particularly when referring to the manuals that would be used for the intervention as is further discussed in a later section on the "Mechanics of the Intervention."

As participants defined how they try to make sense of the condition, most communicated through their responses the emotions that are deeply immersed in that process of understanding. The gamut of emotions ranged from feelings of sadness, frustration, loss and mourning in terms of the condition that is affecting their family member/loved one, to feelings that the care involved is overwhelming, tiresome and something they were "thrown into" and not ready for as one participant describes:

> …nos agarran y te avientan ahí como quien dice en algo en lo que no estamos preparados y mucho depende de nosotros como buscamos la ayuda. (Participant 3 – Latina Caregiver)

This participant felt strongly about how a family caregiver receives information and support for dealing with this condition is subjective and highly dependent on how the caregiver themselves seeks the help. There was a common thought that with more information about ADRD, better care could be provided to the family member and with the dearth of information and culturally responsive (e.g., appropriate language, accessible, available for particular needs) resources that currently existed, this was difficult. Age differences in terms of how information was sought were acknowledged by a couple of middle-aged participants who felt younger family members easily seek information online but both participants felt the need to find information in different ways, with more human contact.

Many of the feelings expressed were connected to the implications of the condition such as associating the illness as being tiresome with the progressive aspect of the condition and

losing social support. Some feelings of sadness were related to the fact that the disease affects

many things, and feelings of frustration were linked to how they felt they knew the person a

certain way and family roles were established, and suddenly all that changed:

> …tú lo conociste con tal lazo afectivo y de pronto no tenerlo creo yo que es la peor
> frustración… (Participant 2 – Latina Caregiver)

Some less typical responses, predominantly from the Other Stakeholders focus groups,

included the comparison between having ADRD and other conditions such as autism or renal

failure. In one comparison, the participant makes the distinction between children with "special

needs" and a child with autism, indicating that the challenge is greater when you have to care for

a child with autism and that is how she sees the level of care required for ADRD caregiving:

> …Alzheimer no se puede considerar algo como una necesidad especial. Yo comparo,
> recordando a mi madre, yo comparo más que nada como a una criatura autista, autistic,
> porque no hay – con una criatura que es autistica o autistic, el reto es mucho más grande.
> (Participant 7 – Other Stakeholder)

Another comparison came from a nurse that provided care to people with renal failure going

through dialysis. She goes on to explain how both renal failure patients and people living with

ADRD require a caregiver as both conditions are degenerative and caregiving takes a toll on the

person that is providing that care because the majority of it usually falls on one person. An

additional less typical response included a comment on how society does not have the same level

of compassion for people with illness as before, particularly in industries focused on care such as

hospitals and nursing homes:

> …en la actualidad el mundo ya no tiene compasión, ya no les interesa, ya no ven y lo
> vemos en los hospitales y lo vemos en un nursing home, y lo vemos en todos lados, que
> no hay un grado de compasión o humanismo para la persona enferma. (Participant 6 –
> Other Stakeholder)

D.   Care Recipient Behaviors

   1. The Behaviors.

Many care recipient behaviors were described in the focus group dialogue, at various stages of the discussion. Behaviors in relation to grooming and food along with the emotional state of the family member and changes in socialization were more commonly voiced. Those shared less often included matters around finances, driving and moments when the care recipient appears more lucid.

Changes in grooming seemed to be at the top of the list for these participants. Instances of care recipients refusing to bathe or bathe with a showerhead, male care recipients preferring to be bathed by the daughters rather than the wife, a different male care recipient becoming aggressive with daughters attempting to bathe him were all described. Additionally, other aspects of grooming included dressing considerably more casual which was not typical for the person prior to the condition, needing to use diapers, and cutting own toenails with a kitchen knife.

Other slightly less prominent behaviors but still mentioned included those in relation to food, eating and cooking. Care recipients were described as not wanting to or forgetting to eat and losing weight as a result. There was also a report of a care recipient burning food while cooking and not managing cooking ingredients adequately. This care recipient also demonstrated the tendency of throwing out food from the refrigerator that was recently prepared or still edible and as a result, eating out rather than buying groceries and preparing home cooked meals was more cost effective for the caregiver:

> … me sale mucho más barato ir a comer a un restauran con él que tratar de comprar comida y cocinar porque se va a la basura… (Participant 5 – Other Stakeholder)

Another prevalent set of behaviors described was related to the emotional state of the care recipient. Depression, anxiety, denial, frustration and aggression were all reported. Participants offered various examples of these in their accounts. There was the care recipient that was experiencing depression and not sleeping at times, and a different care recipient that exhibited

anxiety and distrust when the son's friend was asked to go to the home and provide companionship to the care recipient. Care recipients were described as getting frustrated at themselves for not remembering certain things or having done certain actions as forgetfulness was increasing. When these scenarios occurred, the care recipients would refuse help or redirection from others including the caregiver and at times responded in a physically or verbally aggressive manner. Some care recipients seemed to demonstrate a happier, more willing demeanor when interacting with people other than the primary caregiver. Some examples of this included a father's willingness to do what the daughters requested rather than the wife, or a mother drastically changing her mood to a happier, positive one when the transportation attendant for the adult day center was picking her up from the daughter's home.

Some of the behaviors that were articulated involved changes to tendencies that were more isolating. Such behaviors included having hearing impairment and not tolerating long conversations with others anymore. Additionally, this male care recipient felt discouraged from walking or jogging which were physical activities the care recipient previously enjoyed. Another male care recipient refused to do activities such as swimming at the YMCA with his wife or attending monthly gatherings with friends which the care recipient use to do regularly:

> … vino conmigo a la "Y", a la alberca, hasta que ya no quiso. Y no quiere, y no quiere, y no quiere. Y la reunión de amigos que teníamos cada mes, en un grupo que nos juntábamos ya no quiere ir. (Participant 3 – Latina Caregiver)

A Latina family caregiver gave the example of how her father would give her the physical boundaries he was comfortable with in regards to the affection he wanted or needed. Her father would do the same with his wife (the caregiver's mother) so the physical contact would not feel threatening to the care recipient. This conversation ensued during the focus group when another participant inquired about the level of affection toward the care recipients that is acceptable,

appropriate or required. The daughter mentioned that her demonstrations of affection toward her father were still well received, but when her mother tried to greet her father with a kiss, he was not as welcoming of that level of affection:

> Y en el caso de afecto a mi esposo, tengo que darle afecto, cariño, como dicen ahí, chiquearlo… (Participant 1 – Latina Caregiver)

> El parámetro se lo va a dar su mismo esposo. Porque, por ejemplo, yo soy muy cariñosa y demás, y había una diferencia. Por ejemplo, mi mamá también quería saludar a papá de beso y demás, y él ya el tocar, el invadir, ya lo toma agresivo, por ejemplo. Entonces, él le va a ir marcando cuando ya no requiere ese apapacho de usted, sino al contrario, él quiere estar como que en - su segura zona es él mismo. Entonces, ya él le va a ir marcando como puede relacionarse mejor con él. (Participant 2 – Latina Caregiver)

Lastly, there were behaviors not mentioned much or elaborated upon as compared to the ones already described. Some of these behaviors least mentioned included having confusion over money matters when getting charged for things like a coffee and missing the turn while driving and having to be reminded by the wife that was a passenger in the car. One participant described how her mother experienced moments of lucidity acting herself when the "cloud would lift" momentarily. (Participant 7 – Other Stakeholder)

2. Understanding the Behaviors.

Although minimal, the responses in connection to understanding the care recipients' behaviors were telling. Participants declared they understood the behaviors were part of the disease and vary in each person. They expressed that having more information helps to make sense of the behaviors. Indicating that they felt they had a lack of information currently, some participants, particularly in the Latina Caregivers focus group, expressed the importance of having access to caregivers that are at different stages of the condition with their family member. One participant relates that this would allow more opportunities to share information, resources and support between those that have experienced a stage that is further along than their own "to

be stronger in confronting this very emotionally difficult situation:"

> Ese confort, yo entiendo a Lolita que ya pase por ahí, pero también la entiendo a ella [other participant in the group] porque ya está en la etapa avanzada donde yo acabo de pasar. Entonces es como que eso es lo que más necesitamos para estar un poco más fuertes ante esta situación que emocionalmente es tan difícil. (Participant 2 – Latina Caregiver)

A different aspect of understanding the behaviors consisted of the implications these had in the relationship with the care recipient. Some responses considered how communication and trust issues had developed because of the care recipient's continued lack of acceptance of having the condition. In one particular situation, a caregiver (spouse) developed feelings of uncertainty at her own observations of the family member's decline because of his denial; he would tell her she was always just making up things:

> …no sé si estas personas que pasan por este problema niegan el problema, lo niegan. Dicen, yo estoy bien, yo no tengo problemas. Y mi problema con mi esposo es ese, que siempre, siempre está diciéndome, tú inventas. Esas son las reacciones de las personas que no se quieren, ¿cómo decir? Ver la realidad de que posiblemente tengan ese problema. (Participant 1 – Latina Caregiver)

The spouse (caregiver) reported that the care recipient presented well at the doctor's office but she (caregiving spouse) always made sure to tell the doctor of the symptoms that were worsening. There was a shift in autonomy where caregivers were having to make more decisions on behalf of the care recipient and handling more of the ADLs and IADLs for them. The change in relational roles between spouses or between parents and adult children was defined by who now has the power to decide for the care recipient's well-being. At times, these decisions were negotiated between the care recipient and caregiver in the early stages of the condition. One example shared was of a participant that works full time and had been considering an adult day center for the care recipient, her husband. She was having issues with qualifying for a subsidy that is offered by the State to pay for the service so would have to pay out-of-pocket if she

decided to use it. She went on to mention that she was not sure if she should trouble herself with that process at all if her husband might not be willing to go. The response of a second participant was to mention that there comes a time when the caregiver has to make that decisions for him, to which the wife responded that she understood that but she felt they were not at that stage yet and was taking it one step at a time:

> Los que no tenemos Medicaid tenemos que pagar $60 o $70 por día y yo no quise hacer esa solicitud porque sabía que de todos modos no iba a calificar. A fin de cuentas, no sabía yo cuales iban a ser los - como me perjudicaba después de haber metido la solicitud. Si estoy trabajando - no llegué a ese siguiente paso y aparte dije, ¿para qué hago todo esto sin ni siquiera saber si va a querer ir? (Participant 3 – Latina Caregiver)

> Pero es que ya llega en una etapa en que usted tiene que decidir por él. (Participant 2 – Latina Caregiver)

> Ya se. Pero no estoy en esa – y me esta, o sea, me estoy yendo como un paso a la vez. (Participant 3 – Latina Caregiver)

> Claro. (Participant 2 – Latina Caregiver)

3. Managing the Behaviors.

Participants offered responses on how they managed behaviors at home and in public. A couple of participants reiterated the importance of sticking to routines with the care recipient to counter some of the problematic behaviors. There was also an understanding that not every technique will work for any given behavior in all care recipients or caregivers so there is a need to offer a range to everyone and allow for trial and error to determine which will be successful.

A caregiver declared he would store some food in his room to avoid getting it thrown out by the care recipient, his father. Another caregiver acknowledged that when her mother repeated the same conversations she had responded differently depending on the stage her mother was in. Initially, she would correct her to try getting her grounded and avoid the mother being more confused. As the condition progressed, she would not tell her she had already said what she was

repeating. Music was described as helping to keep the care recipient engaged in any given task or to keep their spirits up.

A caregiver reported in the focus groups that he often had to navigate behavior problems in public. He asserted that he did not see the condition as embarrassing after another participant who is not an ADRD family caregiver suggested that the narrative he, the caregiver, was sharing seemed to show that the response from the public was of this condition being a taboo or embarrassing. He affirmed that what he knew was that he just had to intervene because others who were not aware that his father had Alzheimer's disease may respond with aggression in reacting to certain behaviors of the care recipient like cursing at others if he feels threatened:

> Aprender cómo, decirle en dos segundos al – por ejemplo si está uno en una reunión, como decirle a los demás que "¿sabes qué? Él tiene Alzheimer por eso está, por eso - te está mentando la madre. (Participant 5 – Other Stakeholder)

> Yo pienso que eso está muy mal, el tipificar esa enfermedad así de – es como un tabú o una vergüenza. No, o sea yo creo que no–. (Participant 6 – Other Stakeholder)

> No que sea vergonzoso, sino que a veces la gente no puede – [el] puede comportarse –. (Participant 5 – Other Stakeholder)

> Desconoce. (Participant 6 – Other Stakeholder)

> Sí, se puede comportar de cierta manera y los demás dicen "bueno, ¿y este?" (Participant 5 – Other Stakeholder)

Tips shared to deal with some of these behaviors in public included telling others upfront or learning to disclose the condition quickly if faced with having to intervene spontaneously. This participant's response was in relation to behaviors that occurred in public. There was a different participant that spoke of how, culturally, many people were not willing to share with "the entire world" what they were experiencing at home, particularly the care recipient's behaviors:

> …nosotros [Latinas] tenemos otra vista que tampoco todo el mundo no puede saber lo que estamos pasando, qué pasa en casa, que mami hizo esto, que papi hizo esto. (Participant 8 – Other Stakeholder)

E. **Caregiver Burden**

1. Physical and Mental Health.

An overwhelming majority of the responses suggested that caregiving has had an impact on the physical and mental health and emotional well-being of those providing the care. ADRD caregiving compromised this group of caregivers' health and well-being. One participant describes his own health as being a "joke," and another participant expresses she could probably die even before the care recipient, her mother. The intensity of the caregiving was described by one participant like being sucked into a whirlwind without warning and spit out, with some moments of serenity:

> Bueno, en lo muy personal, en lo muy profundo de mi, de lo mío, yo puedo decir que de mi parte yo sentía que yo estaba en un remolino, y ese remolino como que de repente me chupaba para abajo y de repente me escupía para arriba, y en ocasiones estaba bien calmadito. (Participant 7 – Other Stakeholder)

Certain behaviors of the care recipient such as wandering in the home at night and the decline in the care recipient's abilities and independence increased the burden felt by the caregivers. Some participants used the term "*carga*" that translated literally to English means "load" and the closest the participants came to identifying these implications of caregiving on their physical and mental health as a burden. One participant that described it more intentionally stated that as much as the family member is loved, caregiving is a burden because that caregiver's life ceases to exist and there are feelings of guilt in just even thinking that way:

> …por más que quiera uno a su padre, a su madre, a su abuela, lo que sea, son una **carga**, porque su vida deja de existir. Y a eso se siente uno culpable en poder ni pensarlo. (Participant 7 – Other Stakeholder)

Although not as prominently mentioned or described, the physical health of ADRD family caregivers was impacted. Some of the physical issues included weight gain, diabetes, high

blood pressure, their body feeling progressively weaker, low blood pressure at times. Other

physical aspects reported were not sleeping well, skipping breakfast, being less able to exercise

and how one caregiver's own aging at 70+ years old was being affected by caregiving.

Participants connected a few of these physical implications to other factors such as experiencing

weight gain due to anxiety the care was causing, which translated to more impulsive eating.

Another participant expressed his worry of many responsibilities, with caregiving, work and law

school, as the reason for not sleeping well or having time for breakfast in the mornings. He went

on to say how even though people tell him to take care of himself and exercise, he does not have

20 or 30 minutes to go to another place or go take a walk because that would mean leaving his

father home alone:

> … cómo cuidarse uno mismo o hacer ejercicio; yo en realidad no tengo media hora, ni 20 minutos para irme a otro lado o darme una vuelta. Lo puedo hacer, pero tengo que dejar a mi papá – solo. (Participant 5 – Other Stakeholder)

A more common theme was the impact on mental health and the emotional toll that

ADRD caregiving has for these participants. Anxiety, stress, anger, frustration, and feeling

overwhelmed were all expressed throughout the dialogue and in response to different aspects of

reviewing the existing intervention. A participant felt very strongly about making sure that the

adaptation considers the aspect that Latina family caregivers are very emotional, particularly

with their feelings that no one else will be able to care for their family member like they will.

She suggests adding more personalized elements throughout the sessions that are Latina-specific

to address this emotional aspect:

> Creo que en cada sección que usted haga que pase diferente a lo que yo vi o que yo he ido a clases, es como algo personal y que se refiere exactamente a los latinos y especial a las mujeres latinas porque somos bien emocionalmente, nadie va a cuidar a las personas como nosotras los cuidamos… (Participant 8 – Other Stakeholder)

Other participants elaborated on where some of these feelings were coming from such as feeling

doubly frustrated because the care recipient continued to deny he had a condition but she would remind herself to try and understand. Participants that worked jobs outside of the home described how overwhelming and more involved all tasks seemed now to her. The participants declared that the emotional toll might not allow the caregiver to prioritize their own medical and health-related needs. They saw caregiving as limiting their time for socializing that in fact might offer an opportunity for an emotional release. A participant that has experience running immigrant women's support groups and an ADRD former caregiver herself affirmed that caregivers do not allow themselves the luxury to unpack the emotions being experienced through this caregiving process:

> …yo creo que una persona, y lo digo por experiencia mía, no nos damos ese lujo de poder hacer eso, de desempacar. (Participant 7 – Other Stakeholder)

There was one expression of how a participant's mother seemed to be doing very well after the participant's father, who had Alzheimer's disease, passed away, explaining that she (the mother/wife) felt like she had no more worries/tasks to do:

> …ahorita ella está super bien después de que mi papá falleció porque lo que ella me dice es que estoy − ya no tengo ningún pendiente. (Participant 2 – Latina Caregiver)

2. Financial Matters.

Some participants expressed a high level of frustration because of not being able to provide better or more care for the care recipient due to money matters. Some of the difficulties included not qualifying for a certain subsidy to cover the cost of a program, or not being able to pay for additional care out of pocket with the existing household income. One participant shared how she was able to acquire support services in the home through the caregiver's own medical insurance. When this participant suggested this support as an option to a second participant, the other caregiver stated her own age (caregiver's age) did not allow her to receive Medicare yet,

which is what was covering those services. A future section will elaborate more on the accessibility, availability and acceptability of "Social Supports."

3. Overall Burden.

Overall, participants expressed several aspects of burden and the implications these had in their lives. There were varying descriptions on how these implications were presenting in each caregiver. Some not mentioned already included burden on time and level of effort it takes to provide care. One reoccurring theme that will be expanded on in a future section on "Social Support" was that of no or little support translating to higher burden. Additionally, there was an underlying thread that connected the lack of support from others in the family to feeling a sense of burden over the shift in family dynamics that seemed to develop as a result. Negotiating their feelings that resulted from a perception that other family members did not "want to" provide support was difficult and many times a lengthy process that changed the landscape of their family life during and post care. One participant stated that she, the youngest granddaughter, was the only one that was willing to offer care to her grandmother in the home versus a nursing home. She described the lack of support from other family members (six adult children of the care recipient and other grandchildren) as they "disappeared." Even her aunt, the daughter of the care recipient, said she would not care for her. The participant goes on to explain that when she made the decision to become the caregiver she told her family to not bother her or call her anymore:

> Mi tía también me dijo que no a mi también. Y es hija de mi abuela, claro, y también me dijo que no. Y yo soy la menor de las nietas, y ella tenía seis hijos también y todo el mundo se desapareció. Ponla en un asilo. Y yo fui la que dije, no. No, yo me quedo con ella, ni te preocupes, ni me molesten, ni me llamen. (Participant 8 – Other Stakeholder)

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1. Gendered Care.

Although the majority of focus group participants were females (seven of eight

participants) and the focus was on Latina family caregivers, the responses provided by the

participants did describe how care in the Latino community seemed to be gendered in general. It

was usually a daughter, a wife, a granddaughter, a female cousin, and even an ex-wife or

daughter-in-law that provided care. There was mention from a couple of participants on how

some care was offered by a male such as the husband helping with certain things, although it

sounded like most of the care was being offered and managed by the daughters. There was

another participant who explained that although her sons helped some with the care for her

husband, it had to be planned ahead of time to accommodate their availability. What the sons

would do was typically just spend time with their father while she went out to meetings or to run

errands that she wanted or needed to do on her own. She reports that she could not expect them

to help with other tasks like cooking, running their errands or doing laundry but does consider

the companionship as part of their responsibility as his sons, and not that they are doing her a

favor; someone else affirmed this way of framing it for her:

> Por ejemplo, ahorita estoy aquí sentada y uno de ellos se tuvo que quedar con él. Se lo
> llevó a comer y se lo llevó al cine para que él no sepa que yo vine, porque él no sabe que
> vengo a reuniones. Entonces mis hijos, porque son mis hijos y porque es su padre, no me
> están haciendo ningún favor, alguien me lo dijo así. También a ellos les toca. Entonces la
> ayuda que me dan es como ahorita, y si les digo de última hora no funciona porque a lo
> mejor tienen algo que hacer, están trabajando. Pero si pueden sí me ayudan, pero no para
> mandados, no para lavar. (Participant 3 – Latina Caregiver)

The instances when a male was providing the primary care seemed to be because there

was not a woman more readily available to take over more of the care. Even when the primary

caregiver was a male, there was a woman offering some type of occasional support like an ex-

wife (caregiver's mother). For example, in one family, the male caregiver approached his aunt (sister of the care recipient) to help since he was the only caregiver available in Chicago, as the rest of the care recipient's family lives in Colombia. Her response to him was to offer prayer for God to help his situation rather than offering direct help herself. In another transnational caregiving situation, there were only sons living in Mexico with the parents and the sister living in the U.S. was sought out often for tips and information about the condition and care required. She served as a significant emotional support during the time the father had Alzheimer's before his passing and now that the mother has dementia. She makes trips to Mexico a few times during the year to provide support and care in person and every time takes literature for the family to review to learn more about ADRD and caregiving. A third scenario involved a participant's maternal aunt that was diagnosed with Alzheimer's disease who only had sons. The oldest son assigned shifts of time to provide care for the mother between the brothers, where the mother would go to each son's home for a few weeks/months. The wives' felt forced into that caregiver role without being asked their input knowing well the care would fall on them while the mother-in-law would be in their home. Some of the wives complained about not being able to complete their own tasks and the care recipient leaving the home and wandering. After some time passed the decision was made that the care recipient would be sent to Mexico for six months at a time to be cared for by a female cousin:

> Yo me acuerdo mi tía también tenía Alzheimer, una hermana de mi mamá. Y ella tenía, o tiene cinco hijos, todos hombres, todos hombres. Y yo no – me acuerdo después de que murió mi mamá, cuando le descubrieron a ella el Alzheimer el hermano mayor se impuso, ante todos los hermanos les dijo, "cada uno de ustedes va a cuidar a mi mamá de tal día a tal día, de tal hora a tal hora y nadie puede hacer nada." y las esposas nomás se quedaban, ¿qué, cómo? What? Era increíble pero así estuvo y así fue. Una semana acá, una semana allá, otra semana acá, y mi pobre tía pues andaba como la pelota, de un lado para otro. Entre cinco hijos. Y que una no le gustaba, una de las esposas, "ah no, no me gusta tener a mi suegra ahí porque no me deja hacer lo que tengo que hacer." "Ah no, pues se me sale. Ah no, pues –" (Participant 7 – Other Stakeholder)

¿Y funcionó? (Participant 6 – Other Stakeholder)

Por un ratito y luego la mandaban seis meses a México con otra prima hermana. (Participant 7 – Other Stakeholder)

2. Self-identified Cultural Views.

There were different responses that were prefaced by the participant as being culturally specific. A few of the participants across groups declared that "culturally" there was a resistance to ask for help. As previously mentioned, there was this strong feeling that no one else can take care of the care recipient like that caregiver, as they felt they understand that person's needs better than anyone else. Another related perception of care was that a husband did not "culturally" understand why the daughter decided to put her mother (his wife) in a nursing home rather than continue providing care in the home by the daughters and him, even though he was also requiring care himself due to cancer. Another element that was noted as "cultural" was not being able to reject the offer of someone wanting to help even when this option was more stressful than beneficial to the caregiver. This was demonstrated by an ex-wife who offered to provide care for participant's father (his parents had divorced years ago), which usually ended in the two (care recipient & ex-wife) having a strong disagreement about something and then the son having to hear his father complain to him about this altercation with the ex-wife (caregiver's mother) when they returned home. When the caregiver would tell his mother (care recipient's ex-wife) that he rather not leave his father with her, she would take it personal as an indication that her son did not love her:

> …mi mamá ella quiere ayudar pero mis papás están divorciados, por una buena razón, bueno varias, pero ella se enoja si le digo, 'no, está bien'. Me dice, ¿por qué no dejas a tu papá aquí el sábado? Y ya eso después causa problemas entre ella y yo, porque no – dice que no, ella lo toma personal, como si no la quiero a ella y no es así, sino que pues no – en este caso ella no debería ayudar porque pues – Eso es malo para los dos. Malo para la salud de ella, la de mi papá, y luego al final pues yo me lo tengo que llevar a casa. A

veces como decir ¿no? sin - en nuestra cultura creo que a veces no, en algunas veces no existe 'no'. (Participant 5 – Other Stakeholder)

One focus group participant speculated that there is a fear the caregiver will be perceived as ungrateful saying 'no' to help, offending the person offering the help even if it is not support that will be helpful to the caregiver. Furthermore, there was this notion expressed by more than one focus group participant that "culturally" there was a great sense of emotional comfort in being able to exchange and learn from other Latinas going through ADRD caregiving. This vicarious support and parallel processing was at times seen as more helpful than just reading up on the information.

3. Implied Cultural Views.

There were some responses that although not identified by the participants themselves as being culturally specific, implied cultural views and values. The importance of having affectionate and personable exchanges in the support being offered, as eluded to at the end of the previous section, or *Personalismo*, is seen as superior at times than the information itself that is being shared. Things like hugs, casual conversation about what is happening in the day to day, and opportunities to be validated are all examples of what *Personalismo* looks like. In my sample, there were nuclear families consisting of one to eight adult children where at least one , if not both, required care. Although some of the nuclear families were large in size, this did not indicate more support with ADRD caregiving. Being a wife and mother through a woman's adult life was commonly expressed. At least three examples were provided of women being married to much older men.

G.   Coping

1. Managing Emotions.

An emotion that helped to cope was that of love. They saw it as what gave them the

needed strength and made things seem a bit more manageable and possible at times. Love was also a factor that helped in wanting to be there for the family member through the progression of the condition. Participants offered various examples of how love and strength were key when withstanding the evolution of the condition that was visually described by one participant as a palm tree that would sway in strong winds and storms but not break easily. Grieving, through the incremental loss of the family member's abilities, independence, their (the person with the condition) role in the family and how others perceived their behaviors now, was occasionally done through crying and becoming frustrated. This was at times followed by shifting gears to express more compassion and understanding to the care recipient, which one caregiver identified as an uphill experience that required determination, patience and love. There was a commonality in some responses regarding the initial coping that occurs. What was shared included thoughts that the person would get better or denying there was a condition at all, and having difficulty in providing any needed care initially. A participant further explains that as the condition progresses it becomes more "real" and the caregiver does not want to deal with it and that is when depression and stress set in:

> …al principio como que la emoción es, se va a componer, ¿no? y así se queda uno. Y yo lo digo cuidando a mi padre, y no, decía, "no, no, él se va a componer." Pero cuando ya empiezas a reconocer que realmente es real ya no quieres lidiar con Alzheimer. Y más con lo que acabas de decir, que ese es su ser querido, y lo que fue, lo que hizo, lo que logró, lo que vivió, todas esas cosas como que se quedan fuera de uno, de su vida. Y ahí es donde entra la depresión, ahí entra el estrés. (Participant 7 – Other Stakeholder)

Yet others found strength in wanting to help care for the family member and accepting the condition as time progressed. There was one person who felt she went from being "hard" [resisting there was a condition] to being "strong" [being more accepting of the condition and learning how to be more confident in providing care]. Some tried to cope by trying to make more sense of the condition and their feelings first while others were more focused on problem-solving

almost immediately. One participant caring for her husband detailed how she felt there was a gender and potentially a generational difference in terms of coping as she felt her sons were more likely to feel like they "knew it all," by seeking out information online rather than attending support group meetings like she did. The importance of seeking ways to process feelings externally was commonly reported.

There was a theme that seemed to suggest a need for reciprocity as a coping mechanism. Whether it was a wife that still expected the husband with the condition to continue to offer consideration, care, understanding, and compassion to her (the caregiver) so they could work through the condition better, or the daughter that felt more motivated to offer care because she saw her mother was still active like before. This same participant acknowledges that she feels she has gained more from the experience of caring for her mother than what she feels she has given to her mother in the process, as the mother seems to be handling the situation well:

> Entonces ahorita es la que me necesita y yo creo que ella me está dando más a mí que lo que yo a ella, porque está procesando esta situación increíblemente… (Participant 2 – Latina Caregiver)

2. Self-discovery.

A component of coping included the caregiver's realization of being in that role and coming to terms with that identity. This realization went beyond just the shift that occurs in the established family roles of parents/grandparents caring for the children of the family or spouses providing mutual support to each other. There was a description of coming to terms with this new role or shift and understanding that the care recipient requires something different than the caregiver. One participant wrestled with this a bit when she shares how you are not having a conversation with the person you love and know since your childhood, but now you should see this person as a person that "needs more love than you," and she does not know why that is but

knows that is how it is:

>…ya no es tener una conversación con la persona que tú amas y que conoces desde tu infancia, es ahora ver a esa persona como una persona que ahora necesita más amor que tú. No sé por qué. Porque así es. (Participant 7 – Other Stakeholder)

On the other hand, some responses seemed to contest this notion by acknowledging that the caregivers need help and the extra support too. While their own needs were unmet, there was still some difficulty asking for help, particularly when they may have tried before and received a response that was not expected nor fulfilling their needs. A participant indicated it was easier for her to ask for help when others were in need but not when she needed help. Another participant related the heightened level of responsibility she felt to not only provide the standard of care required for the family member but also manage her own chores she was accustomed to doing. There was a desire to offer optimal care for the family member but consensus existed among the participants that indicated they believed this was difficult to do if they themselves were not okay. A statement was made by a participant, which outlines a sense of self-discovery as she describes how she feels the personal experiences of caregiving have helped her develop her own manual of resources, building strength from the lessons learned and becoming a self-developed resource to others moving forward:

>Yo en el camino fui descubriendo y ahora yo tengo mi propio manual en la base de experiencia personal… (Participant 2 – Latina Caregiver)

3. Religion and Spirituality.

The mention of God and religion were a common thread in the responses dealing with the ability to cope. Within the Latina Caregivers focus groups, the majority of participants described a positive connection to God and faith in religious leaders such as priests. There was a sense of feeling closer to God as a result of their current circumstance with the family member's condition. And although there is a fatalistic sense of "God doing things for a reason," there was

also a feeling of hope and sustainability they find in their faith in God and the priest's advice and comfort offered. A woman goes on to claim that she felt God put her and her husband on Earth together for a reason, and thus they will continue on their uphill journey together as she feels a strong commitment to her marriage vows that state, "in sickness and in health":

> …hasta donde lleguemos porque para eso tomé mis votos, en la salud y en la enfermedad. (Participant 3 – Latina Caregiver)

The Latina caregivers offered different examples of being thankful for God's hand in things like allowing for a better day through the joy of seeing a nice sunrise, or the ability to celebrate another year and holiday like Christmas together with the care recipient and the rest of their family.

There was not as much talk about God in the Other Stakeholders focus groups. There was one participant that worked at a faith-based institution who expanded on some models in the faith community that may be applicable or useful to consider for the development of the intervention. She mentioned things like support circles that come together to help people emotionally when there has been a death in the family. She suggested this intervention might have the potential to organically develop a similar process but for families that were offering ADRD care to a family member that was still alive. The other model she described was one of accompaniment where trained community members would pay regular visits to a person with a terminal illness and the family member(s) caring for the person, in the hospital or at home. At least two people would make the visits to offer support or just a shoulder to lean on until the end.

There were some limitations expressed in this notion of hope in God and the church. A participant felt supported by the church but would not ask for support with direct care for her husband. She went on to mention that only a handful of people in her church community knew about his condition but just because they knew she did not dare ask them to stay with the

husband for an hour:

> …si voy a la iglesia hay dos o tres que saben de esta situación pero no por eso les voy a
> pedir, quédate con él una hora… (Participant 3 – Latina Caregiver)

A second participant declared his frustration with hearing from others that they would pray for

him and God would help him, when he would ask family members for support with his father's

care.

4. Self-care.

Some responses reflected on the importance and feasibility of self-care as the participants

further explained the coping process. Participants that spoke of self-care contemplated how

others, including the doctor, would mention the importance of self-care. One participant felt this

was not necessarily practical to do, feeling it like yet another chore to include to the already long

list. This participant offered suggestions on how to make this more feasible for the caregiver with

things like recommending the self-care be broken down into smaller units of time and combined

with other tasks that already have to be done. Additionally, being mindful of the tone used when

offering self-care tips was important for this participant and offering a higher level of sensitivity

when there is only one caregiver for the family member. Keeping self-care tips simple and

relatable to the particular caregiver were thought to likely be more effective. Another participant

felt self-care for her meant taking her own medication, providing "healthier things" to herself

and her husband who she was caring for identifying that her own care was very much enmeshed

with keeping the care recipient healthy as well.

5. Mentoring Others.

In a previous section there was a participant who suggested she had become a self-

developed resource. Her personal experiences and the information she learned through her first

caregiving experience with her father with Alzheimer's disease helped her feel more confident

now that her mother has been diagnosed with dementia and requiring care as well. Having gone

through several stages of the condition with her father, up through his death, she feels the need to

share information and experiences with other caregivers so that they do not start from zero like

she did but rather from five as she puts it:

> … yo empecé de ceros esto, cuando pude haber empezado de cinco si sé mucho más
> información de la que hoy sé. (Participant 3 – Latina Caregiver)

The importance of helping others through understanding better the progression of the condition

as well as tips for managing different aspects of caregiving was widely shared between the

participants of both sets of focus groups. Not only was this notion expressed, it was also

practiced while in the groups when members of the focus groups shared information on resources

and tips with each other, without being prompted. The "mentoring" seemed to be a part of the

coping process and allowed for the caregivers to feel like they were giving back by helping

others to not feel as hopeless and lost as they might have when they first started the journey

themselves. Although it may sound like they reached a level of mastery to be able offer

mentorship to others, participants felt they were all the same and experiencing similar things.

One participant confirmed that they were at the same level of experience and could support each

other mutually; no matter what stage their family member was in with the condition:

> … somos las mismas, hemos pasado por lo mismo, entonces estamos en el mismo nivel
> de experiencia. (Participant 2 – Latina Caregiver)

Another participant expressed the desire to help others in similar, better or worse situations.

Given these expressions of wanting mutual support, participants unanimously favored the

intended group setting for the intervention, led by individuals that had been caregivers

themselves.

H.   Social Support

1. Community-based Supports.

When the discourse involved what supports were available, needed and/or sought, there seemed to be two dominant themes that surfaced in the context of community-based supports, family and support groups. Atypical responses included the male caregiver suggesting that he had slightly supportive friends and the caregiver that is 70+ years old stating her neighbor would occasionally help clean the sidewalk without being asked. Social supports were considered important in caregiving since it was understood that caregivers grew tired, particularly those carrying the responsibility alone. Building community and support networks were identified as essential in easing some of the caregiving toll. Help seeking in the Latino community was previously described to be something that was difficult for caregivers to do. Some caregivers had not asked for help or had been discouraged from asking again due to an outcome that was not favorable. Despite sometimes not getting the help needed in the past, caregivers seemed hopeful in knowing there were possibly supports that other caregivers could share information about, that might be more effective. Books depicting testimonial experiences of caregivers were what prompted some participants to seek more help and information about the condition and caregiving. One participant in the Other Stakeholders focus groups claimed that it is important for caregivers to understand that it is okay to ask for help and say that they need help. She went on to give a specific example of what help might mean by stating that a person can come to the house to stay with the family member for 40 minutes, an hour, two hours, no matter, as long it is a person that is willing to give that kind of support:

> …saber que está bien pedir auxilio, y decir, necesito auxilio, y hablarle a otra persona que puede venir a la casa y quedarse con ellos por 40 minutos, una hora, dos horas, no importa, que siempre y cuando sea una persona en la cual tiene ese apoyo. (Participant 7 – Other Stakeholder)

All participants discussed to what extent other family members were involved with their caregiving experience. There was much conversation around how family responds to and copes with the condition and caregiving differently. They felt that this is due to the varying levels of understanding they have on the matter and the various stages of acceptance. Many participants expressed difficulty in managing the family dynamics that evolved as a result of this experience. A participant mentioned that family ties seem to change after these situations and some family members lose touch with each other because of the difficulty in this journey, as some of them accept the condition better than others and there are feelings of distress and anger toward the family member with the condition and toward themselves:

> Familia, después que hay una persona que padece de Alzheimer, a veces la familia no hablan más porque yendo por ese camino es algo difícil, algo duro. Algunos lo aceptan, algunos no lo aceptan, algunos sienten enojo, sienten odio. A lo mejor por la persona que tiene la enfermedad y también por las personas, por sí mismo. (Participant 8 – Other Stakeholder)

Several participants defined how one person many times ends up being the sole caregiver due to other family members being unwilling and/or unavailable due to distance or work schedules. The underlying tone of the conversation was that the participants felt the care of the family member with the condition was best when done by their own family and sharing the care between different family members would be optimal but not happening, or not happening fully, in the majority of the cases.

There was some retrospection offered that included feeling better with time about certain family members not helping with care. Some of the reasons shared were the following: the primary caregiver understood this person or set of people should not be caring for someone unwillingly or if there was an adverse relationship with the care recipient and that person; after the primary caregiver saw the level of care required they felt there was a certain level of

psychological capacity required that not everyone had; or that the primary caregiver was being honest up front before having the situation affect the existing relationship. One of the examples mentioned included a daughter caring for a mother. The daughter's husband expressed to her that he could not deal with "it" anymore, and after some time she (the caregiver) appreciated his honesty, even though initially this reaction "does hurt" as she puts it:

> … hay personas que te van a decir, 'no, no puedo lidiar'. Yo lo voy a decir por lo mío, más que nada. Mi esposo eso es lo que me dijo que, 'no puedo más'. Y claro, al momento eso duele, pero al mismo tiempo es una aceptación de una realidad, de decir, okay, por lo menos me está diciendo la verdad. (Participant 7 – Other Stakeholder)

A few suggestions were offered by the participants on how to address some of these family issues and these included being able to discuss as a family each of their perspectives on the matter; having a social gathering with family and over food sharing some information and allowing for conversation about the care that was being required; or more formally having a third party host a meeting where discussion of the condition, care and exploration of dividing up responsibilities could occur.

A second social support that participants mentioned after family was support groups. The importance of a human element and a preference to receiving information and tips in groups versus online or in written form was mentioned by several of the participants. Having emotional support, an opportunity to learn from each other's different levels of experience, sharing their stories and talking through their understanding of the condition live was stated frequently. Additionally, important was the availability of support groups in the Latino community that were accessible in terms of location given that families are everywhere, including the suburbs where scarcity was reported. Furthermore, a definite need was expressed for supports and resources that are linguistically adequate for monolingual Spanish, bilingual (Spanish/English) speakers. Not

only was language considered important but also the content. Participants stated a need for culturally responsive practices that are based on the values of the community in terms of caregiving, family roles, and long-term care expectations.

2. Institutional Services.

A participant delineated the caregiver's tasks to include the management of medical and financial matters as well as getting and managing services for the care recipient. Some participants described institutional supports and services they knew about, received or had pursued unsuccessfully. More prominent to the Other Stakeholders focus groups was the topic of nursing homes that is discussed further in this section.

Although a couple of participants in the Other Stakeholders focus groups stated there was more available now compared to decades ago, there was a consensus between groups that there were definite gaps that existed in terms of supports and services for Latino families caring for a loved one with ADRD. A lack of availability of physical resources such as those focused on Latinos supported by the Alzheimer's Association was noted. Also mentioned was the scarcity of Spanish-speaking, Latino-focused adult day centers throughout the Chicagoland area including the south side of Chicago given that there is one in the north side already. A participant expressed the lack of general social supports including support groups for Latinos in the suburbs, specifically Aurora where there is a large Latino population. Another limitation mentioned was the lack of access to the institutional supports and services that did exist. The reasons for lack of access included language barriers, citizenship status, age eligibility requirement for Medicare-based services, income eligibility requirement for State subsidy to cover adult day center care, and inability to pay out of pocket when services are not free or financially covered otherwise.

The third barrier expressed was the lack of information of what supports and services

existed and the requirements for those, which was an underlying theme for many matters in the caregiving experience. Not knowing about respite care; payment to family members that can be received for caregiving when the State covers homecare aide; legal processes that will be needed as the condition progresses; how applying for certain supports and services may have an impact on the future financial security and stability of others in the household, particularly when the care recipient is listed on the title of a home or other major assets and State subsidies are being sought; and counseling services specialized in processing the condition and care. One participant went on to declare that it was not until he worked for the State that he was able to learn about all the available services and understand better the eligibility criteria. Another participant stated there were even less government-based services in countries like Mexico but something that did exist there was regular in-home wellness checks that she did not see available here as a standard of care for older adults in general.

One atypical response that was given by a caregiver working full time shared that her employer offered her flexibility in her work schedule. She would take advantage of the flexibility when she had to take her husband (care recipient) to doctor appointments or she had caregiving related meetings during office hours. She specified that her employer was a faith-based institution who, at one point, had in their care a religious leader that had dementia.

There was a very strong sentiment shared during the Other Stakeholders focus groups on the need to normalize options of care such as nursing homes. It was understood that for many communities and particularly for Latino families, there was a negative perception of nursing home care. One participant in the group shared how in her personal experience placing her mother in a nursing home when her father was experiencing his own care issues due to cancer, was the biggest and most difficult decision of her life. She states that even having children was

not as difficult because "this" [dementia caregiving] is a process where you have to say [and admit] that the level of care required is out of your hands, left to feel like there is not much more she can do:

> Fue la decisión más grande y más difícil de mi vida porque ni tener hijos fue tan difícil. Porque es un, es ese proceso de decir, 'está fuera de mi control, ¿qué más puedo hacer?' (Participant 7 – Other Stakeholder)

Another participant shared that he was, at the time, looking for institutional care for his father, since there have been reports from the adult day center he attends about behavior issues. This behavior may result in termination of services there if it persists, and thus there might be a need for placement in a nursing home since the caregiver is working and going to law school.

I. Mechanics of the Intervention

1. Relatable.

Participants were given an overview of the topics covered in the original intervention manuals (i.e., *Promotora* manual, Participant manual), the format of the group sessions, and a copy of the resource folder that was given to the participants at the start of the intervention cycle. In Magaña, et al.'s (2015) original intervention (see Table 1 on page 7) there are eight topics consisting of the following: "1) Taking Care of Yourself; 2) Health Care for You; 3) Well-being activities; 4) Nutrition; 5) Exercise; 6) Reducing stress and understanding depression; 7) Including others and social support; and 8) Sustaining person growth" (p. 42). Certain topics were covered more in-depth during the focus groups as these were being tested more intentionally for relatedness and adaptability. Those topics included the '3) Well-being activities,' '6) Reducing stress and understanding depression' and '7) Including others and social support." The remaining topics (i.e., 1, 2, 4, 5, 8 identified above) were reviewed more briefly as that content is more generally based.

The list of topics overall were found relatable to the participants for purposes of being relevant to ADRD caregivers as well. When the sessions on '3) Well-being activities,' '6) Reducing stress and understanding depression' and '7) Including others and social support" were reviewed with the Latina Caregivers focus groups, these were well received. Participants were receptive and engaged in the activities of each of these sessions. The majority of the content in these sessions seemed to resonate at an adequate level for these Latina ADRD caregivers. Dialogue relating to the importance of doing well-being activities, stress, depression and including others in the help and social support provided much insight into the caregiving experiences of these Latinas.

There were responses that affirmed some of the content found under certain topics like the '2) Health Care for You,' '4) Nutrition' and '5) Exercise' sessions. Participants offered various thoughts and tips they found relatable to the needs of ADRD caregivers. The table describing health care screening exams for women broken down by age groups in the '2) Health Care for You' session was identified as practical. The participant that had a background in nursing suggested a review to update specifics on the table such as the current blood pressure readings considered normal. Listing ADRD Latina caregiver health outcomes and prevention techniques were also identified as important by this participant. These are offered in the manual and were updated to reflect any differences relevant to the current population based on the literature. For the session on '4) Nutrition' there were responses relating to the importance of knowing what staple foods are a part of the community's cuisine and understanding that changing someone's diet is "culturally" difficult. The existing manual is very intentional in incorporating information on how to maintain existing family recipes. Some healthier substitutions in the ingredients or ways of preparing the meal are offered, encouraging the notion

of keeping culture intact while still eating healthy. Recipes proposed as options already have some of the staple foods that may be typical of this population's cooking.

A response relevant to the '5) Exercise' session consisted of being able to do physical activity such as stretching exercises anywhere, including the home, and in short intervals due to lack of time. One participant offered suggestions of incorporating additional physical activity into daily tasks. Such examples were getting off a few stops before your bus/train stop or parking the car a few blocks away from your destination to allow yourself time to walk and just focus on the walking experience during that time. The existing material in the manual makes a strong point of focusing physical activity efforts to be a part of the caregiver's daily routines without requiring a gym membership or large blocks of time to engage in a workout routine.

All the reflections, or short stories with a moral found in each session, were read completely through with the Latina Caregivers focus groups. Although the participants considered all the reflections relatable, two of the reflections were specific to disability caregiving. When read, these two reflections seemed to incite responses of empathy and some sadness from the participants, but it was obvious from the commentary throughout the dialogue that the content would be more effective if it were relatable to ADRD caregiving specifically. The change of those particular reflections to more specific ones relating to ADRD caregiving was confirmed to be acceptable at the review of the adaptation during the member check. Their responses defined the reflections as adequately adapted, effective and excellent. The remaining reflections (the majority) were relatable as presented in the original intervention because these were more general in their content and inspirational for a broader population.

Another aspect that generally seemed relatable was the language used in the manual. Some of the responses obtained were that the manual was very descriptive, offered in "good"

language that was broken down well, practical, simple and easy to understand. A common theme between both sets of focus groups (i.e., Latina Caregivers, Other Stakeholders) was that this intervention and manual were a starting point for the caregiver and should not be expected to answer everything for the individual situations of each participant. For this reason, keeping the intervention's flexibility and varying levels of detail was considered relatable. One participant described the manual as a "handbook" and valuable as a first resource. In the Other Stakeholders focus groups, the question of who the audience was specifically was posed. These stakeholders recommended that if the sessions would be open to others besides the primary caregiver, the material should be offered in a more general manner. There was also a question regarding literacy as a possible issue to consider when providing the material in the intervention and being able to include others from the family that could further support primary caregivers who do not read and write, if needed. In the original intervention, the participants are given the option to invite others they feel would benefit from learning about certain topics that will be discussed in future sessions, and thus this notion of keeping it general enough for others while still focusing on the caregiver that was recruited for the intervention is relatable to the current population.

The format of the group sessions and distribution of local resources seemed relatable per the participants. Having the group model was identified as important given that just getting the information to read at their leisure on their own might not be practical or as fulfilling for their needs. The participants agreed that having sessions guided by someone that has lived the experience herself, was "culturally a good idea" and potentially more effective than having a professional or paraprofessional offering the information. Additionally, the majority of the handouts found in the original resource folder were considered relatable as they were focused on the health of women or the general population, including healthcare services offered at a free or

low cost in the Chicago area.

2. Adaptable.

In terms of the components that required adaptation, some elements were more obviously requiring adaptation than others. Participants agreed that for starters, the language should reflect the diverse family roles of the Latinas who would be offering the ADRD caregiving. These might be wives, daughters, sisters, granddaughters, nieces, daughters-in-law, female cousins or friends, etc. Some consideration was also given to a more adequate title for the trained Latina caregivers that would lead the group sessions. In the original intervention they are called *Promotoras,* which is derived from the public health model of *Promotoras de Salud*, or community health workers, promoters of health being the literal translation. A participant of the Other Stakeholders focus groups that works for a faith-based organization described a couple of models used in the faith community that offer accompaniment to individuals and families when there are moments of grief or loss, as such is the case during terminal illness and death. The majority of the participants in the Latina Caregivers focus groups described feeling a connection between faith in God and hope. Subsequently, given the information about the faith-based model that might be relatable and the association the group of Latina caregivers had with faith and hope, the term *Acompañante*, or Companion, was tested during the member check. The majority of the participants of the member check meeting agreed that this change in the title for the peer educators was applicable. One participant suggested using the term "director" or "coordinator" instead of using "*Promotora.*" Other participants expressed that although the group would be guided by someone, the group guide and group participants would all be the same based on their shared experiences and thus no hierarchies should exist. After more conversation, participants seemed to favor the use of the term *Acompañante*.

In the Other Stakeholders focus groups there was conversation by two participants that relayed information about other caregiver interventions that existed which did not have cultural relevancy. Although the topics shared in this intervention resembled those of other interventions as confirmed by one participant, she expressed her interest in seeing this adaptation having a definite cultural connection. Much of the conversation that followed included the components of family tension and the level of emotion that Latina caregivers have to negotiate in this experience, as cultural factors that require definite attention in the intervention. This notion of family dynamics and tension was prominent in the Latina Caregivers focus groups as well. The participants confirmed there was a need to add something about the family dynamic in the session on "Including others and social support." During the focus group dialogue, one Latina Caregiver participant felt that talking about family dynamics and asking for help was not possible in one 2-hour session. At the time of the member check, participants expressed that the addition on family dynamic was enough since it allowed for caregivers to express their own situations and for dialogue to occur based on these experiences rather than overextending the material that may not be applicable. A participant did not find one of the activities useful that asks to identify, in an "ecomap," the systems in her life that offer or could offer support. Her thoughts were that family members were the only source of support she could think of and that was limited because of their schedules and distance. The Other Stakeholders focus groups expressed the need to address elements of grief and loss. These participants also made mention of having to incorporate the feelings and perspectives of the caregivers and care recipients into the material, since this is often left out in other interventions. Additionally, stakeholders recommended the addition of content that normalized emotions of burden and guilt, particularly in help-seeking and consideration for institutional care such as assisted living and nursing home

facilities. Other suggestions included having activities at the close of each session that would help the caregiver relax and end on a more positive note. There was an expectation expressed in the Other Stakeholders focus groups that this intervention and potentially the peer educators (formerly identified as *Promotoras*) would organically inspire the creation of social networks or circles of support among the participants. This was actually visible during the Latina Caregivers focus groups when a couple of the participants exchanged contact information to share some resources outside of the group dialogue. Two other participants felt encouraged to attend a support group that a third participant attends.

Lastly, a significant adaptation to the intervention was the addition of a session on "Understanding Alzheimer's Disease and Dementia." The participants of both sets of focus groups (i.e., Latina Caregivers, Other Stakeholders) shared regularly the lack of information they felt or thought caregivers had in terms of the condition and level of care needed. Responses suggested a need to have information on signs and symptoms, stages and complications of the condition, examples of behaviors the care recipient may demonstrate, the trajectory of care, specific and real scenarios, and flexibility to easily incorporate the reality of the caregivers participating. The recommendation was that the session should be offered early on in the intervention so that caregivers could have an opportunity to have this information available almost immediately. This would allow for further discussion as the other sessions take place for the remainder of the intervention.

At the time of the member check, the participants were given an opportunity to review the session that was developed in response to this need of having a session on the condition incorporated to the intervention. The feedback was mostly favorable as participants expressed that the content helped to understand the symptoms, encouraged caregivers to be alert and ask for

help, as well as offered some insight into the feelings of getting a formal diagnosis and realizing

that it is not a misfortune or shameful but a diagnosis like any other:

> Todo este material me suena excelente, porque primero es ubicarnos, reconocer los síntomas, estar alertas, acudir a pedir ayuda, un segundo diagnóstico hasta poder descartar las otras posibilidades y quedarnos con Alzheimer. Pero una vez que pasa esto, también estoy de acuerdo en la otra parte de, pero, no es una desgracia. No es una vergüenza, es un diagnóstico como cualquier otro. (Participant 2 – Latina Caregiver)

There was a sentiment shared regarding the language used in the section relating to

already having a diagnosis. The participant felt strongly about making sure the language was

more inclusive to caregivers that did not have a formal diagnosis, as there are families that

provide care and know or it is apparent there is a condition but there is no diagnosis yet for

various reasons. Another participant felt that the description of signs and symptoms was effective

at giving a better understanding to someone considering that their family member/loved one may

have the condition if not diagnosed yet. Other favorable feedback related to a video clip used to

visually explain some of the behaviors that may present when an individual has ADRD. The

video also includes a brief overview of the experience of a wife, a daughter and of a person with

the condition offering their perspective and how this has impacted their lives. One participant

who claimed to be visual in nature appreciated the use of the video clip to drive the message

home of the session in a different way, affirming that the content of the clip was relatable to

different people at different stages. During an activity incorporated into the session on the myths

and realities of the condition, there was dialogue that was insightful in confirming that this

exercise was thought provoking for caregivers. One participant posed the genuine question of,

"Isn't dementia related to being 'crazy'?"

> ¿Osea que la demencia no está relacionado con la locura? (Participant 1 – Latina Caregiver)

The dialogue that ensued after this question suggested that there is importance in having this

exercise to allow caregivers an opportunity to talk about differences between ADRD, psychological illnesses and mental health over all. The exercise is set to encourage caregivers to have a safe and comfortable space to converse about myth and realities of the condition with the Companion (*Acompañante*) caregivers leading the activity, without any judgment so the participants feel free to share their own thoughts on the subject matter.

J. Conclusion

All participants were very candid and expressive in sharing their insight. There were many themes that surfaced in the focus groups. Two very prominent themes that seemed to be overarching in much of what was shared by the participants were the emotional experience ADRD caregiving is for Latinas, and the lack of information that existed and/or they felt Latina caregivers experienced. When considering the first research question posed for this study, the findings indicate that the existing health education intervention was relatable and adaptable to Latina ADRD family caregivers in many aspects. Some major ways the intervention was relatable included the level of description and clear language that made up the content of the intervention, along with the flexibility in the activities that allowed for relating to various situations. Also relatable were the topics covered in the intervention. The major adaptations include the addition of the session on ADRD to provide more information about the condition and care required, adding more content around family dynamics, and changing the title of the peer educators from *Promotoras* to *Acompañantes* (Companions in the English version of the intervention). Findings for the second research question suggest that the elements of culture needing to be considered for the adaptation included the values around family being the sole option for caregiving (*familismo*) and particularly the women (*marianismo, machismo*) in the family, as well as concerns of structural limitations for this community in terms of services and

supports that are not available, accessible, and/or acceptable. The findings in response to the third research question propose that the experiences of burden in providing ADRD care for this population help inform this adaptation by highlighting the level of emotion and personal connection (*personalismo*) that may be required to be considered effective, when offering material about health outcomes and healthy habits. The intervention manuals (i.e., *Acompañante* & Participant Manuals) that were produced reflect the adaptations mentioned in terms of additions to the existing session topics. Examples and activities in the content are directly connected with experiences and information shared during the focus groups, member check and final review by the content experts.

V. DISCUSSION

This qualitative study had the aim to review and adapt a health education intervention for Latinas providing care to family members/loved ones with Alzheimer's disease or related dementia (ADRD). The study consisted of five focus groups and a member check carried out in a group format. A total of eight different participants were a part of one or multiple focus groups that were divided into two groupings, Latina Family Caregivers and Other Stakeholders. Bilingual (Spanish/English) content area experts and a translator reviewed the initial version of the adapted intervention manuals after the member check process, offering further insight to the cultural responsiveness and adequacy of the material. This qualitative process and the use of thematic analysis aided in answering the following research questions: (1) Is the health education intervention *By Caring for Myself I Care Better for my Family* relatable and adaptable to fit the needs of Latina family caregivers of persons with Alzheimer's disease or related dementia (ADRD)? (2) What elements of culture need to be considered when adapting *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD? (3) How do the experiences of burden in providing care to a family member/loved one with ADRD help inform the adaptation of *By Caring for Myself I Care Better for my Family* for Latinas providing care to a family member/loved one with ADRD?

The overarching themes that were central to this study's findings consisted of the emotions being negotiated by Latina caregivers from beginning to end, and the lack of information that existed in terms of the condition, the caregiver process, and the supports and services that might help in that process. The theme labeled "Mechanics of the Intervention" offered what was relatable and adaptable from the original intervention of *By Caring for Myself I Care Better for my Family* (Research Question 1). Threaded throughout the findings were how

culture (Research Question 2) and the experiences of burden (Research Question 3) played a role in the lives of these women that would be necessary to capture in the intervention being adapted.

The beginning of this chapter will consist of a summary of the findings relevant to each of the three research questions and how the findings align with the literature reviewed for this study in Chapter II. In the second section of this chapter, I will use The Revised Sociocultural Stress and Coping Model for Caregivers (Knight & Sayegh, 2010 - see Figure 1 on page 10) to apply the findings in the context of the conceptual model in order to test the fit of this theoretical basis for this group of Latina caregivers. The next section will consider the implications of the findings for social work practice, policy and future research. The fourth and final section examines the limitations of the study.

A.   Summary of Findings

1. Is the Existing Health Education Intervention Relatable and Adaptable.

Based on the findings, the theme of "Mechanics of the Intervention" provided what was relatable and adaptable from the health intervention. The topics focusing on the caregiver, short stories sharing a moral, the language used in the content and having the sessions in groups led by peers that have been trained in the material, were all identified as relatable. The findings prominently suggest the health intervention *By Caring for Myself I Care Better for my Family* is relatable to the different type of caregiver, Latina ADRD family caregivers. According to the findings, the adaptations needed were adjustments to some of the language to make it more inclusive and reflective of all those that may be providing care (e.g. wife, daughter, sister, granddaughter, other relative or friend) and changing the title of the peer educators leading the group to reflect accompaniment (i.e. Companion/*Acompañante*) rather than health workers (i.e. *Promotoras de salud*). Additionally, there was an expressed need to add content relating to

family dynamics including tension as well as information about Alzheimer's disease and dementia. In the next section, I discuss these findings further in relation to what is relatable and adaptable, in connection with how they confirm or add to the existing literature.

Participants in both sets of focus groups (i.e., Latina Family Caregivers, Other Stakeholders) responded favorably to the topics covered and the language found in the content as Magaña, et al. (2015) presented in the original intervention. A participant that was from the Alzheimer's Association confirmed that the topics coincided with those found in caregiver interventions she was aware of and had reviewed. The mode of delivery through a peer education model in a group format was highly supported by participants as had been in the original intervention with mothers that had children with IDD (Magaña, et al., 2014). Service delivery by trained peers differs from the current interventions offered to ADRD caregivers. Professionals or paraprofessionals in the health and human service sectors typically administer the existing ADRD caregiving interventions (AAR, et al., 2012; Belle et al., 2006; Hepburn, et al., 2003; Wisniewski et al., 2003; Gallagher-Thompson et al., 2008; Morano, 2003). Additionally, having a strong focus on the caregiver's health and well-being with encouragement to continue to establish personal goals varies from some of the current evidence-based interventions. The Savvy Caregiver for example handles more information on behavior management and the interaction between the care recipient and the caregiver, with less intentional focus on the caregiver themselves (Hepburn, et al., 2003). The group modality is well supported in the literature as it is often the format for interventions or a component of multiple points of contact that may also include phone contact and/or individual home-based sessions (AAR, et al., 2012; Wisniewski et al., 2003; Hepburn, et al., 2003).

Major adaptations included the addition of a session on understanding the condition

better, and adding more content on family dynamic. Incorporating information on the condition itself is comparable to existing evidence-based interventions as much of the focus in those is to educate caregivers on the condition and caregiving tips (AAR, et al., 2012; Hepburn, et al., 2003; Wisniewski et al., 2003; Gallagher-Thompson et al., 2008). Addressing family dynamic more deliberately in the content on social support aligns with the literature on *familismo* and the impact ADRD has on Latino families, which suggests family can positively or negatively affect outcomes in an ADRD caregiving experience (Aranda & Knight, 1997; Aranda, et al., 2003; Arévalo-Flechas et al., 2014; Gallagher-Thompson et al., 2003; Hahn et al., 2011).

Additionally, a third major adaptation was the change in title of the peer educator to *Acompañante*, or Companion. The suggestion for considering an accompaniment model as a way to interpret the role of the peer educators came from a theological perspective. With its origins in Latin America, accompaniment is the practice of walking alongside individuals in their life journey and allowing for learning and interaction to occur in a bidirectional manner (Tomlinson & Lipsitz, 2013). This model looks to address oppression and inequities by removing hierarchies and processing experiences, while working towards social justice collectively. Community Health Workers, or *Promotoras de Salud*, in the Latino community have successfully offered physical accompaniment to other members in the community when navigating the healthcare system, while dealing with health conditions such as diabetes (Kenya et al., 2015) and serious mental illness (Sheehan et al., 2018). Although *Promotoras* carry on some accompaniment practices, participants seemed to feel that linguistically the term *Acompañante*, or Companion, was more fitting. They saw the role of the peer educators in the intervention as one that would be more engaged with helping negotiate the level of emotions involved in caregiving and this would have to be done with a stronger personal connection (*personalismo*), which was also mutually

beneficial.

2. What Elements of Culture Need to be Considered for the Adaptation.

The findings indicated that cultural elements were visible in many of the themes that surfaced in this study. There were both explicit and implied examples in the themes of how culture existed in the caregiving experience from the moment a diagnosis existed, or lack there of, and throughout the trajectory of care. In this section I will reiterate those findings as they pertain to what elements of culture needed to be considered for the intervention adaptation. A further discussion of the findings follows, that considers how this information fits into what is already known in this area through the literature.

a. Theme: The Medical Aspect of Alzheimer's Disease and Related Dementia.

There were some cultural implications focused on the diagnosing process that were described by participants in this study that are reflective of what is known for the Latino community. One participant shared her experience as the wife of someone who finally received a diagnosis, after she had to persist and navigate the process with lack of information every step of the way. This can be the case when medical practices are not linguistically and culturally responsive of the needs of those being served. Another participant confirms this same point by expressing that the quality of medical attention is lacking because doctors do not do follow up adequately, due to not understanding the patient culturally and just giving a diagnosis with no consideration for the level of impact this has on the person and their family. Additionally, a concern for the delay in giving a diagnosis with correct stage of severity was expressed, as a couple of participants reported having to wait what seemed a long time. In one instance, the person did not receive a diagnosis until at least five years of symptoms being visible, while also having a family history of the condition, even though the person was regularly seen by his

doctor. A participant stated how her mother was dealing with this condition at an early age (early 60s). Although the participant did not identify Early Onset Alzheimer's disease as a cultural implication, it is implied that it can be considered part of the cultural experience given the prevalence of the condition at early ages in the Latino community. An additional cultural component of the caregiving experience for this community that was expressed in the focus groups was undiagnosed cases, where the family knows something is happening but the person for one reason or another never receives a formal diagnosis. There were some participants that spoke about the participant and/or the family members being in a state of denial, whether as a coping mechanism or feelings connected to stigma and uncertainty due to lack of knowledge that was in the needed language and context. Delayed or no formal diagnosis, early onset, lack of linguistically and culturally relevant information as well as quality medical care, along with some denial and stigma are what these study participants shared as being particular to the experience of Latinas caring for a family member with Alzheimer's disease or related dementia (ADRD).

In terms of understanding the condition itself, there was some cultural relevance that was found. When a couple of participants described their understanding of the condition and difference between Alzheimer's disease and dementia, they explained visual images that had been shared with them previously by experts in the field. Culturally there is a high regard for receiving information from an expert in the field with formal education. Also, having visual components to training material is not only appealing to different types of learners but when there are individuals with little (3-6 years) or no formal schooling, which is not uncommon for those Latinos who grew up in rural areas, visual material is very important. Other participants aligned their understanding to conditions they were more aware of, such as Autism and renal

disease in terms of understanding the complexity of the care and dependence on a caregiver that was required. These conditions exist in the Latino community in high numbers as compared to other populations and may be the reason these participants had more information on these and an inclination to use the conditions as a reference point. A participant described her knowledge about the condition as a nurse and her understanding that given someone's culture, as she explicitly identifies it, meaning racial/ethnic background, some communities including the Latino community are at higher risk of having the condition. Findings in relation to understanding the condition indicated that providing material visually and with reference to other more known conditions or points of reference were important to this population of ADRD caregivers in terms of being culturally responsive to the level of formal schooling the community may or may not have.

       b.   *Theme: Care Recipient Behaviors.*

The participants spoke at length about the behaviors that care recipients demonstrated when ADRD symptoms were becoming more visible and as the condition progressed. Grooming, cooking and eating, emotional state and socialization were some of the behaviors most affected. One behavior that indicated a more cultural relevance in terms of socialization is the level of affection that a care recipient was able to tolerate. There was a participant that inquired how much affection she should be expressing to her husband. A different participant provided her family as an example when she mentioned that her father seemed comfortable with his daughter giving him hugs and kisses on the cheek but her father was not as welcoming of affection from his wife, her mother. It is not uncommon for the Latino community to greet and say good-bye to peers and sometimes people in the community they are just meeting for the first time with a handshake and kiss on the cheek. This level of closeness and interaction is seen as a sign of

respect and comradery that helps build trust and rapport. With a condition like ADRD where signals in relation to the senses are affected, it would be important to have caregivers and others in the community that interact with the care recipient understand these sensitivities exist. Additionally, it should not be taken personal when the level of affection expressed to the family member with the condition may have to vary and it is not due to feeling less mutual love or respect. The level of socialization, particularly relating to displays of affection, as a cultural construct was present in the findings impacting the trajectory of care for their loved ones that Latinas undertake.

The findings relating to the understanding and managing of behaviors of the care recipient included systemic limitations that are true for the Latino community in terms of lack of access to information in a format that is most effective both in terms of language but also in culturally relevant content that is easy to understand. Additionally, resources in terms of services and supports that would help manage behaviors through the day (e.g. adult day center services) are not available to everyone due to restricting eligibility requirements to qualify for the service and/or the financial means to pay for the service. On a person level, participants shared how they understood and managed the behaviors but what prominently surfaced as affecting this community particularly was this inability to have access to information and services that were culturally adequate.

c. *Theme: Caregiver Burden.*

According to the findings, an intersection of culture and caregiver burden is evident for this population. In a later section, I discuss the third research question that speaks about the burden that Latinas experience and touch upon this topic in more detail.

d. *Theme: Cultural Views.*

Participants prominently shared in their responses the cultural norms of gendered care expected to be done by the woman (*marianismo*) and family caring for family (*familismo*). Other cultural elements seemed to branch from these values. One such example included that "culturally," the Latina caregiver did not seek help from others given this notion that this was her responsibility and the expectation was that she should be able to fulfill this role accordingly while negotiating feelings of guilt and incompetence when the experience became challenging. Along those lines, seeking institutional care, especially permanent care such as nursing home care, was often not seen as a viable option. Moreover, the desire to have personable exchanges (*personalismo*) was significant in the findings, as all the participants spoke about the importance of feeling connected to others that understood their experience. In several accounts, feeling the connection was more relevant and than getting information from a trained professional, confirming that peer education as is implemented in the *Promotora de salud* model seemed like a promising practice with this population.

e. *Theme: Coping.*

There is much transition and loss that is experienced by the person living with ADRD as there is for the person providing care to that individual and other loved ones and family. The findings reflected much of the same forms of coping to deal with the emotions involved in the experience that are noted in the literature. Within the Latino community there is a noted reliance on religion and spirituality as a mechanism to cope with some of lifes most challenging situations. What was most culturally striking included the role as caregiver becoming a catalyst for self-discovery and transformation at times. In a patriarchal community as the Latino community is known to be, this sense of empowerment for women in these roles is significant.

Being placed in a situation where they were challenged, many times to the extreme, allowed for a deeper self-examination of who they were as a person and how they would develop the capacity to sustain in adversity. As a result of this personal development, there was then a desire to help others that were experiencing similar hardships and become a resource for others so they would not have to struggle as much as they had. This communal support that is common in Latino communities seemed to expend beyond family ties (*familismo*) to members in the community living through some of the same circumstance.

f. Theme: Social Support.

The participants shared experiences of needing or seeking social support from community-based entities, family and support groups, while institutional services were less prominent. The findings showed that although social supports were at times limited or nonexistent, caregivers understood the importance of these and were hopeful that if others shared resources that worked for them, they could take advantages of these as well when given the information. Culturally, word of mouth is one of the most effective ways to connect the Latino community to services and supports. Reliance on family for support was a nebulous situation. The participants expressed that family support many times was not an option due to the lack information on care needed, coping that was not fully developed to accept the situation, and conflicting schedules. Based on cultural norms of *familismo* this is a difficult place to be when there is an expectation that family will support family but that help is not available. There was much shared about the need and interest in having support groups. Participants reported that support groups as well as other community-based and institutional services such as adult day services were not readily available in their community or with a focus on the Latino community that provided linguistically and culturally sensitive services. Additionally, the lack of

information that prevails in the community even when the services do exist is a large barrier that the Latina caregivers face during this caregiving experience.

g. *Findings as they relate to what is already known.*

Central to the findings when considering culture for the adaptation were many of the values that have been prominent in the literature. The cultural values of *familismo, marianismo* and *machismo* were key in understanding the strong reliance on family and particularly women in the family to be the ones that are tasked to provide the care, many times single-handedly (Borrayo et al., 2007; Arévalo-Flechas et al., 2014; Friedmann & Buckwalter, 2014; Gelman, 2014; Mier, 2007; Ruiz, & Ransford, 2012). The theme of shifting family dynamics and tension developing when ADRD caregiving was required in Latino families seemed to be rooted in the expectation that family should be providing all the care, even if that meant only one family member. The mere thought of asking for help was described as a source of guilt, as others and they themselves may see it as a sign of not fulfilling this "duty" they felt was one for women in the family. Other members of the family not offering more support may feel that as long as someone in the family was taking on the care, that was sufficient. Not fully understanding the level of care is much more specialized and consuming than one single person could or should handle, and the overall lack of knowledge on the condition, the care and resources available are often referenced in the literature as an issue that is present in the Latino community (Borrayo et al., 2007; Neary & Mahoney, 2005; Gelman, 2014).

Structural barriers limiting availability, accessibility and acceptability of services and supports were identified as part of the experience for caregivers in the Latino community and therefore culturally relevant. My study supports the findings of Borrayo, Goldwaser, Vacha-Haase and Hepburn (2007) and Friedmann and Buckwalter (2014) who identified structural

limitations in health care, availability of services geographically and lower average income that could magnify the negative impact Latinas experience while providing care to their family member or loved one with ADRD. Some examples of limitations shared during the focus groups included the scarce availability of services in the suburbs, minimal Spanish-speaking and bicultural providers and services in the Chicagoland area, citizenship status, age requirements for the medical coverage that offers more supports (i.e., Medicare), income requirements for receiving a State-paid subsidy to pay adult day center services and lack of income to cover out-of-pocket costs for care. Lack of information about supports and services was commonly expressed in the focus groups and some participants felt there was a need to normalize the use of these including institutional care. These participants felt that acceptability of certain services such as assisted living or nursing homes, and other supports in general, may be greater if real scenarios were shared where others considered these as viable options and explained the process. Neary and Mahoney (2005) posit that nursing home placement is highly influenced by cultural values and even when caregivers decide to pursue placement because care needs and care recipient behaviors have exacerbated the caregiving experience, Latinos continue their routine of being vigilant and present at the nursing home to ensure the level of care is upheld to their standards.

3. How Do the Experiences of Burden Help Inform the Adaptation.

a. *Theme: Caregiver Burden.*

My findings captured some themes that described the experiences of burden of Latina family caregivers. In the analysis, the theme of "Caregiver Burden" covered various levels of burden expressed by the study participants. Providing care to a family member with Alzheimer's disease or related dementia (ADRD) universally seems to impact the caregiver's physical, mental

and financial wellbeing in some way. It is no different for Latinas in this role. What is different for these women is the baseline of health the community, as a whole, experiences even prior to providing ADRD care to a family member. Disparities in terms of physical and mental health, as well as fiscal security are prevalent in this population. Plagued by things like diabetes, hypertension, depression and poverty, the Latino community comes at the task of caregiving with substandard wellbeing. When one adds the caregiving factor into the equation, these disparities are exacerbated as compared not only to other populations but also as compared to other Latinas that are not providing ADRD care to a family member. The participants expressed an overall burden consisting of having too little time to take better care of themselves, difficulty managing the job outside of the home that is substantial to the livelihood of the caregiver and their family member, a diminishing supply of support from other family members. This finding was said to not only affect the physical aspect of providing care but also created an emotional burden that at times led to broken family ties, particularly shocking the communal aspect that is many times found in Latino communities. Additionally, these participants expressed that Latinas carried a heightened emotional sensitivity that affected them in the overall experience of caregiving through the entire trajectory. Cultural norms consisting of women as the innate caregivers and family members being the only ones trusted to care for their own family members sets Latinas at a prescribed position to be the sole caregivers of family members that are living with complex conditions such as ADRD, even though this task involves many roles and much time that is beyond the capacity of just one person. The following section discusses how this knowledge aligns with existing research.

   b. *Findings as they relate to what is already known.*

Emotions were central to the findings as participants described from beginning to end

what ADRD and caregiving meant to their lives, supporting Borrayo's et al. (2007) findings that

Latinas experience difficult emotions as one of the challenges in ADRD caregiving. Commonly

expressed by the participants was the need for human interaction and personal connection when

receiving information affirming with Richardson's et al. (2013) work that proposes ADRD

caregivers are at a high risk of experiencing social isolation and loneliness. Arévalo-Flechas et

al. (2014) examine the cultural values impacting the Latino community when caring for a family

member with ADRD and they suggest that lack of *personalismo* (personalism) can mean

underutilization of formal care or lack of trust to accept suggestions and treatment. The desire to

help and mentor other caregivers was commonly expressed and aligns with Arévalo-Flechas et

al.'s (2014) findings that *personalismo* includes the willingness to offer service and help others.

B.   Conceptual Model

In the previous section, the findings were contextualized in relation to the current

literature. This section will use the conceptual model to interpret the theoretical base in the

context of this study's findings. Themes derived during the analysis aligned with the constructs

found in The Revised Sociocultural Stress and Coping Model (Knight & Sayegh, 2010) and can

be compared by reviewing Figure 1 (see page 10) and Figure 3 (see page 51). Some elements

that proved to be prominent in the findings, which are not found in the original conceptual

model, included themes around lack of information, the views and process for obtaining an

ADRD diagnosis and the emotional complexity this experience is for Latinas. Participants in the

focus groups considered culture as a significant factor in the views on ADRD and the emotional

aspect of the caregiving experience for Latinas. Systems and practitioners have the duty of

continuing to find the best-practice options that consider the cultural aspects of the population

they are serving. Additionally, there is a need to see cultural values and practices as assets and

proactively find ways to support the Latina caregiving experience while addressing the existing health outcomes.

At the root of themes such as lack of information and processes of diagnosis as well as several sub-themes that were embedded within caregiver burden and social support particularly, are more structural implications and social determinants of health. Defined by the World Health Organization (2018), social determinants shape someone's health by where the person was born, grows, lives, works and ages, factoring in the distribution of money, power and resources globally, nationally and locally. There are obvious limitations in the environment and level of fiscal resources that are a part of the Latina ADRD caregiver experience, which further marginalizes their capacity for optimal health and well-being. Issues run the range of linguistically adequate and culturally responsive services to full access and availability of quality care. Although Aranda and Knight (1997) and Knight and Sayegh (2010) hint at the inequities ethnically/racially diverse caregivers are faced with, The Revised Sociocultural Stress and Coping Model they developed does not directly indicate these in its current version. For this population particularly, there is a need to understand the context of these social determinants of health and their place at the base of the full experience from the higher prevalence of ADRD in the community compared to the White majority, to the heightened disparities in health outcomes that are two-fold, as a Latina and as an ADRD caregiver. I propose the following image in Figure 4 (see page 102) to further assist in contextualizing the findings of this study where 'Social Determinants of Health' lie at the base informing all other constructs that should be considered when developing further practices, policies and research in this sector. As envisioned by Aranda and Knight (1997) then revisited by Knight and Sayegh (2010), the Revised Sociocultural Stress and Coping Model for Latina ADRD Caregivers follows the same major constructs and

interactions between them. When 'behavioral problems' arise in an individual with ADRD, there

is 'burden' for the caregiver that is mediated by the 'coping style' and 'social support' the

caregiver has in place (or not). These coping styles and social supports are moderated by the

'cultural values' of the caregiver. All these interactions ultimately define what the 'caregivers'

health' is while in the caregiving experience. Based on the findings of this study, Latinas

experience much of this process with an underlying impact of 'social determinants of health.'

Unequitable conditions in the environment for Latinas are a driving force in their caregiving

experiences. Matters of access, poverty, adequate and quality care in healthcare institutions,

among other things directly affect the level of care they can offer their family member with

ADRD and the level of health they themselves can achieve, particularly while in the caregiving

experience.
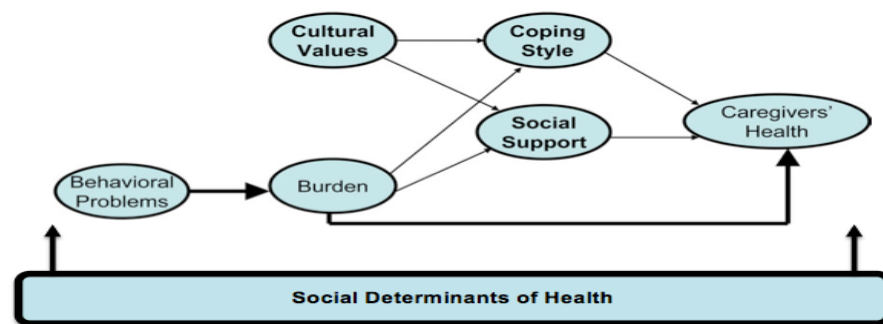
Figure 4. The Revised Sociocultural Stress and Coping Model for Latina ADRD Caregivers.

C.   Implications

The following section expands on the implications of the study findings for social work

practice, policy and future research.

1. Implications for Social Work Practice.

Based on the findings of this study, the following are recommendations for social work

practitioners working with Latinas who help in the care of a family member or loved one who is

living with Alzheimer's disease or related dementia (ADRD):

- **Conduct a thorough assessment on views and values around the condition and caregiving norms.** The findings suggest that participants have much to share and process about this condition and their experience with the ways it is impacting the family's life and well-being. During the focus groups, participants made mention of nursing home care not being an option considered for many reasons, including cultural expectations of elder care happening in the home. A coping mechanism that was shared in the focus groups related to faith in God during the caregiving experience. For practitioners, social work education considers the person in environment model as a prominent way to offer person-centered care (Brooker, 2006). It is critical to not only consider the identified problem when establishing a treatment plan but also to integrate the set of cultural views and values that play a significant role in informing the client's actions. Similarly, the client's worldview has an impact on the way information from a professional is being received by that client, and thus assessing in-depth what these views and values are initially and throughout the client-practitioner relationship may offer more effective ways to work with the client(s). There is no room for stereotypes when practicing in a culturally responsive manner, as there are variations that exist and unique circumstance including social determinants that are key in the lives of individuals, no matter their cultural affiliation.

- **Create an environment that is personable, free of judgment and power affirming for the client.** There was much talk during the focus groups about the importance of a human connection when seeking support and feeling like certain thoughts brought guilt just by thinking that way. The findings indicate it is highly

important for sustainable, positive outcomes to be possible, that building rapport moves beyond a business-like interaction and includes the flexibility and genuine interest of the practitioner to develop a more personal connection. This may mean starting sessions with some offerings of food and casual conversation; opening up sessions to having others (e.g., a neighbor, a church peer, friend etc.) attend that the client feels a close connection to; carrying out sessions at the client's home or locations familiar to the client; physical contact typically woman to woman or man to man such as extending your hand to greet or when saying good-bye (some Latina women greet other women with a hug and kiss on the cheek), putting an arm in a comforting manner around the shoulder of the person when the client becomes very emotional during a session. Moreover, it is essential to normalize the different feelings experienced in this process. In this safe space that is created for the client, there should be opportunities to process real life scenarios where the client can relate to the material being presented. Fundamental for culturally responsive practice, the practitioner should approach this work with an understanding that the client is the expert of her or his own situation and as such should be validated and acknowledged often. Practitioners should not make the mistake of thinking they hold the only correct methods for addressing identified problems. The power of the client and their cultural assets should be highlighted repeatedly and considered central to developing treatment options.

- **Serve as advocates, allies and companions.** Social work is founded on principles of social justice and as such the field and practitioners have the duty to uphold the power and voice of the most vulnerable and marginalized (NASW,

2017). The study findings relating to social determinants coming in the way of receiving services and supports, information, quality care and health outcomes even before the experience of caregiving call for a more just way of addressing the needs of this population. Whether that means advocating for agency and program processes that ensure access and availability of linguistically and culturally responsive services to all that are in the most need; seeking continuous training that expands anti-oppressive practices (Baines & Edwards, 2015); and/or offering services to increase the human capital of these communities in innovative ways. Volunteering time to offer respite to an ADRD family caregiver, supporting efforts of ADRD caregivers to build social networks, and/or having regular contact with local and national legislators to inform them of what is needed to continue supporting these families would all be great places to intervene in some of the structural gaps and disparities that exist for this community.

Although these recommendations offer a guide for practice with Latina ADRD family caregivers, there is a need for each setting to consider what are the sociocultural needs and structural context that govern supports and services, to determine what adaptations may be most important. With the current political climate and evolving needs to further support communities of color, there is a need for human sector fields like social work to continue expanding their efforts to train future generations of professionals in more anti-oppressive practices. Historically, there have been efforts to increase cultural competence in the field that is largely made up of White middle-class women practitioners serving poverty-stricken communities of color. There is an apparent need to shift the paradigm to one where practice is understood as culturally responsive and approached with humility rather than enforcing a power differential in the client-

practitioner relationship that is already visibly present. Equally important is the increasing demand for bilingual, bicultural practitioners, and thus creating mechanisms for existing providers to build their capacity based on the existing needs in communities where demand is greatest, as well as for members from these same underrepresented communities to be recruited and guaranteed equitable opportunities to become practitioners themselves.

2. Implications for Policy.

The findings of the study offer some explicit policy implications as well as others that were implied and will be expanded on in this section. Some concerning challenges expressed by participants included not obtaining a timely diagnosis nor sufficient information with or without a formal diagnosis to better understand the condition and care involved. An apparent need exists to establish more intentional training and professional standards of care in the health sector. Through technology and continued research, there is more knowledge becoming available regularly. Given the level at which society is aging, continuing professional development and overall health training should increase the content relevant to older adults and conditions such as ADRD that are most present in the aging population and require extensive care. Board testing and continuing education requirements should place a high standard on competency in these areas, to include how these intersect with cultural and structural implications. Additionally, another aspect that would address the stated concerns with the lack of information would be to incentivize healthcare institutions for supporting regular efforts to offer culturally responsive caregiver training and ADRD educational community forums. The intended target audience for these should be families that are experiencing ADRD through a family member and communities that experience higher prevalence of the condition as is the case with Latinos and African Americans. To attempt a more effective practice, the referral process can be streamlined so that

primary care providers and healthcare teams include this training and educational forum as part of the treatment plan that they offer to the family when signs and symptoms become apparent and definitely at time of a formal diagnosis. Now through the annual Medicare assessments being conducted with older adults, participation in trainings for family members and/or educational sessions on conditions like ADRD should be mandatory given the increased risk for ADRD after age 65 and much greater at 85 and older.

Participants in the focus groups shared challenges they faced in terms of not having available supports and services that were linguistically adequate and culturally responsive. The policy implication here is how readily available funding is for programs that target certain marginalized communities. Other than a budget issue and availability of fiscal resources, another policy driven issue is the complexity of regulations and associated fees that govern the implementation of structures like adult day centers. It is understood that these are set for guaranteeing the safety and security of an already vulnerable population but there is a need to expedite processes to ensure that funders and contractors can move forward with projects for building more centers just as quickly as other developments such as high-rises and expensive homes are built in places like affluent neighborhoods. Offering tax breaks and subsidies for land usage and building material would further enable this process. The return on investment might be apparent when less tax dollars are spent on long-term institutional care and repeated visits to the emergency room if the community elders have greater assets that allow for aging at home more efficiently.

Access was another issue that participants directly felt affected their caregiver experience. Factors like citizenship status, age requirements for the medical coverage that offers more supports (i.e., Medicare), income requirements for receiving a State-paid subsidy to pay

adult day center services and lack of income to cover out-of-pocket costs for care precluded them and or their family member from accessing benefits in programs and services that could alleviate much of the burden. The policy implications with regards to access calls for the following: (1) streamlining government services to be offered to those affected by progressively debilitating conditions such as ADRD regardless of legal status, age, income, etc.; and (2) allocating funding to community agencies so that supports such as adult day centers are free of charge for all older adults. Additionally, there is a scarcity of adult day programs in the city that offer more specialized services for those with ADRD who express more advanced behaviors seen as problematic to facilities serving the general older adult population. One participant expressed how he would have to look for permanent institutional care (e.g., assisted living facility, nursing home) if his father's current adult day center services would terminate as a result of some behavior issues the center staff identified. Consistent and specialized training to programs offering any kind of supports and services to families living with ADRD in the community are currently becoming a standard of care with recent local legislature passed. The enforcement of this though is not yet quite as rigorous as it should be since some sites that identify as dementia friendly or have a categorization of being a memory unit, particularly in nursing homes, have been known to terminate services if they identify certain behaviors as problematic. At that point, the family is left to take the family member back home to potentially a less adequate environment with even more limited supports and services than the family had prior to nursing home admission. That may have been the reason for nursing home placement initially. The third point that is an implication for policy given this last situation would be to have funding available for more skilled centers that offer support (e.g., home-based, institutional care) to families where the family member with ADRD is experiencing more advanced stages of the condition and

demonstrated behaviors that other services are not equipped to handle.

There were a few policy implications that were implied based on the information provided by the participants. The first was the lack of respite care available to families. According to this study's findings there is a high reliance and cultural expectation placed on care being offered by only family for this population. In this community, help-seeking practices are often thought to be low due to not wanting the support but these participants had considered supports such as adult day centers, assisted living facilities, and nursing homes. Having trusted individuals offer a recommendation for supports and services and more knowledge on the level of training of persons offering the care might increase the use of these services that would in turn offer relief to family caregivers, alleviating some of the burden being experienced. As a result, there is an apparent need for having more consistent, quality care in the form of respite care that is fully funded and sustainable, which would be available to families that have a family member with ADRD, regardless of legal status, age or income. Supports such as homemaker services that are subsidized by the state have strict income requirements and are offered in limited blocks of time for those who qualify based on very low or no income. The State of Illinois currently offers 80 hours of respite care per year for families that qualify. Having a family member with such a progressively debilitating condition such as ADRD requires much more than 80 hours of respite per year.

Another implied need these participants expressed included financial support. Those that were receiving supports and services were doing so through the support of state-based subsidies. Those that were not receiving supports and services were not receiving them due to not qualifying for the subsidized service but also could not afford to pay the out-of-pocket expense without having it affect other aspects of their financial stability. Policies to implement supports

such as a tax credit for families that offer care (e.g., physical, financial, etc.) to a family member living with ADRD and other forms of financial support including paid family leave have been considered in congress but not passed. For those families that qualify for homemaker services, a family member can serve as a paid family caregiver if that person signs up to become an employee of a homemaker care agency, is trained and follows through with any employee regulations and requirements. This is an obvious barrier for families where the caregiver is not documented, and thus not eligible to obtain a social security number and/or a work permit, directly affecting immigrant communities such as the Latino community.

Large gaps in access and eligibility for supports and services exist for Latino immigrant families where citizenship status is an issue for the care recipient and/or the family caregiver. Therefore, the last implied policy implication lays in reforming immigration policies that for centuries have fluctuated, often based on the labor force need in the U.S. There are millions of people that live in the country with a substandard quality of life and disparate health outcomes because their citizenship status precludes them from much needed access to basic needs such as wages that do not keep them in poverty, adequate housing that is closely tied to educational options, resources and quality health care. Current immigration policies coupled with the existing administration that is openly exacerbating anti-immigrant sentiment in the country makes for an urgency to establish a reform in legislature. There is a pressing need to ensure the safety and well-being of a population of individuals that for the most part have made this country their current home because international policies by this same country have been imposed on other nations and the economy, forcing circumstance to become so dire in their homeland that there is a need to seek slightly greater options and a safer environment elsewhere.

3. Implications for Future Research.

Findings of this study reveal some areas that merit further investigation. First, there is an obvious need to pilot the adaptation testing for feasibility and acceptability in the intended population of Latinas caring for a family member/loved one with Alzheimer's disease or related dementia. This study should additionally consider the collection of preliminary data that can further inform the relationship between participation in the intervention and health and well-being outcomes of Latina caregivers. After the findings of the pilot study are analyzed and the adaptation is further refined, there should then be a larger scale randomized control trial study that would further test the intervention's effectiveness. There is a definite gap that exists in evidence-based practice and health interventions, which are culturally adequate and responsive to the needs of Latina caregivers, and thus there is further research that would be required to continue testing this intervention for the purpose of achieving that standard of reliable outcomes.

Given the findings on the structural barriers that participants expressed, there is more extensive research needed on the implications of the social determinants of health that Latina family caregivers may be experiencing. This was a small sample, and thus this area would have to be tested further with a larger, more representative sample to see how applicable it is to the greater population. Identifying structural limitations can be key in informing social work practice, policy and education that may impact more sustainable change for marginalized communities who are constantly faced with inequitable circumstances and unjust distribution of resources.

D. Limitations

Some limitations existed with this study that I will address in this final section. To begin, there was a small sample size that participated in this study, limiting the opportunity of having a

wider range of perspectives. This population is hard to reach and therefore recruitment was done through various networks and established community agencies. These participants, given their circumstances, were given the flexibility to participate in one or multiple focus groups. Future research should look to have focus groups at various times of the year as winter months in Chicago may preclude more participation. Opportunities to participate remotely may be another consideration in future research to secure a larger sample.

Given the time needed to review the original intervention, the interview guide used seemed limiting. The individual experiences of the participants in relation to caregiving could have been more in-depth with other probing questions and more time to dialogue in the focus groups. Future research might consider conducting in-depth individual interviews to supplement the accounts offered briefly during the focus groups. Existing literature on the views and experiences of Latina caregivers are typically from other regions of the country, and thus there is a need to better understand narratives that are pertinent to Latina caregivers in the Midwest. Some variations in experiences may exist based on country of origin, migration story, resources available, and social determinant panorama among other factors. Additionally, testing for further modifications needed of the intervention, as well as dissemination of the findings in the form of peer-reviewed publications and reports shared with the community would be recommended.

Participants may have been those who feel more confident and willing to seek information and involvement in the subject matter, and thus not necessarily representing the views and experiences of the varying perspectives of Latina ADRD family caregivers. For future research, there may be a need to expand the recruitment plan to include other locations in the community such as more faith-based institutions, local shopping plazas, Laundromats, grocery stores and beauty salons. There might be a need to be a part of various activities around the city

where more visibility is possible and trust is built such as in health fairs, community festivals,

town hall meetings and other major events with high attendance.

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APPENDICES

Phase I Focus Groups Interview Guides – English-language

Interview Guide: Caregiver Focus Groups (1, 2, and 3)

Introduction: Thank you for agreeing to participate in this group discussion. Your participation is completely voluntary. Please feel free to take a break or stop your participation in the discussion at any time. Our discussion today will last about two hours. The discussion will be about your thoughts on what is important for Latinas that help take care of a family member or loved one with Alzheimer's disease or related dementia (ADRD). This discussion will happen over three different 2-hr sessions and will be used to create a program for Latinas that helps them take better care of themselves as they are caring for the other person. This group discussion will be audio recorded so that I can go back and listen to your responses when I am making the manual for the program. I also have my colleague helping to take notes in case anything goes wrong with the audio recordings. In order to keep your privacy, I ask that we do not use each other's actual names out loud during the discussion while the session is being recorded. We can use a different name that we write on the cards I am about to give you, if you would like to use a name at all. Also, in order to respect each other's privacy, I ask that what is discussed in this group or who is present in the meeting is not shared outside of this meeting. Are there any questions for me before we start?

1) Please tell us a little about yourself and how you know about taking care of persons with ADRD.

2) I am passing out a manual for a program that was made for mothers of children and adults with intellectual and developmental disabilities like Autism, Down Syndrome, etc. We will review the manual together and I would like you to take notes at each page

where you think changes need to be made to make this fit to a Latina taking care of a

family member/loved one with ADRD. We will talk about your notes as a group and then

I will collect these manuals to have a record of your thoughts about the manual.

3) Based on your notes and your thoughts, what changes are needed?

4) Do you think this program, if we make the changes you are suggesting, would be helpful

for Latinas taking care of a family member or loved one with ADRD?

5) Is there anything that you would like to add that we have not discussed yet?

Closing: I would like to thank you for your time today and look forward to keeping you informed

about how this project is coming along in the future. All the information you provided today is

very important and will be very helpful in creating the best possible manual for this project.

To assess interest in participating in member check: After I finish these group discussions and

review the results of what we discussed, I would like to check back with anyone who is willing

to talk to me again so that together we can review what I came up with in my analysis to make

sure it matches what people shared with me during this group discussion. Talking with me after

these focus groups have finished to discuss what I found is completely voluntary. I would not be

providing $20 like I did for our group discussion today. If you would like me to contact you a

second time to speak about what I learned from these group discussions, please write down your

name and number on the back of the manual I will collect back from you at this time. Thank you

again for all the valuable time you are willing to give to this project.

Interview Guide: Other Stakeholder Focus Groups (1 and 2)

Introduction: Thank you for agreeing to participate in this group discussion. Your participation is completely voluntary. Please feel free to take a break or stop your participation in the discussion at any time. Our discussion today will last about two hours. The discussion will be about your thoughts on what is important for Latinas that help take care of a family member or loved one with Alzheimer's disease or related dementia (ADRD). This discussion will happen over two different 2-hr sessions and will be used to create a program for Latinas that helps them take better care of themselves as they are caring for the other person. This group discussion will be audio recorded so that I can go back and listen to your responses when I am making the manual for the program. I also have my colleague helping to take notes in case anything goes wrong with the audio recordings. In order to keep your privacy, I ask that we do not use each other's actual names out loud during the discussion while the session is being recorded. We can use a different name that we write on the cards I am about to give you, if you would like to use a name at all. Also, in order to respect each other's privacy, I ask that what is discussed in this group or who is present in the meeting is not shared outside of this meeting. Are there any questions for me before we start?

1) Please tell us a little about yourself and how you know about taking care of persons with ADRD.

2) I am passing out a manual for a program that was made for mothers of children and adults with intellectual and developmental disabilities like Autism, Down Syndrome, etc. We will review portions of the manual together and I would like you to take notes at each page where you think changes need to be made to make this fit to a Latina taking care of

a family member/loved one with ADRD. We will talk about your notes as a group and

then I will collect these manuals to have a record of your thoughts about the manual.

3) Based on your notes and your thoughts, what changes are needed?

4) Do you think this program, if we make the changes you are suggesting, would be helpful

for Latinas taking care of a family member or loved one with ADRD?

5) Is there anything that you would like to add that we have not discussed yet?

Closing: I would like to thank you for your time today and look forward to keeping you informed

about how this project is coming along in the future. All the information you provided today is

very important and will be very helpful in creating the best possible manual for this project.

To assess interest in participating in member check: After I finish these group discussions and

review the results of what we discussed, I would like to check back with anyone who is willing

to talk to me again so that together we can review what I came up with in my analysis to make

sure it matches what people shared with me during this group discussion. Talking with me after

these focus groups have finished to discuss what I found is completely voluntary. I would not be

providing $20 like I did for our group discussion today. If you would like me to contact you a

second time to speak about what I learned from these group discussions, please write down your

name and number on the back of the manual I will collect back from you at this time. Thank you

again for all the valuable time you are willing to give to this project.

Phase I Focus Groups Interview Guides – Spanish-language

Interview Guide: Caregiver Focus Groups (1, 2, and 3)

Introduction: Gracias por aceptar el participar en este diálogo en grupo. Su participación es completamente voluntaria. Por favor siéntase con la libertad de tomar un receso o detener su participación en este diálogo en cualquier momento. Nuestro diálogo durara aproximadamente como dos horas el día de hoy. El diálogo será sobre sus opiniones en cuanto a lo que es importante para las mujeres latinas que ayudan en el cuidado de un familiar o ser querido con Alzheimer o demencia. El diálogo se llevara acabo en **tres sesiones de dos horas cada sesión**. La información recolectada se usara para crear un programa para mujeres latinas para intentar ayudarlas en su propio cuidado mientras cuidan a su familiar o ser querido. Este diálogo en grupo será audio grabado para que yo pueda regresar a escucharlo cuando este creado el manual para el programa. (También tengo a mi colega tomando notas por si llega a pasar algo con la grabación.) Para mantener su privacidad les pido que no usen sus nombres actuales durante el diálogo mientras estamos grabando la sesión. Podemos usar diferentes nombres que escribiremos en las tarjetas que estoy repartiendo, si es que desean usar un nombre durante el diálogo. También, como respeto a la privacidad de los demás les pido que lo que se diga en este grupo o información sobre quien este presente en la reunión no sea compartida fuera de este reunión. ¿Hay alguna pregunta antes de comenzar?

6) Por favor díganos brevemente algo sobre usted y cómo es que sabe de el cuidado a un ser querido/pariente con Alzheimer o demencia.

7) Estoy distribuyendo un manual de un programa cual fue creado para madres latinas de niños y adultos con discapacidades intelectuales y del desarrollo tal como autismo,

síndrome de Down, etc. Repasaremos porciones del manual juntas/os y me gustaría que en cada página donde usted siente que cambios son necesarios para que esto sea adecuado para mujeres latinas que cuidan de pariente/ser querido con Alzheimer o demencia. Platicaremos sobre sus opiniones en grupo y luego recogere los manuales y notas para tener por escrito lo que han dicho sobre el manual.

8) De acuerdo con sus notas y opiniones, ¿qué cambios son necesarios?

9) ¿Usted piensa que este programa, haciendo los cambios que usted sugiere, ayudaría a mujeres latinas que cuidan a familiar/ser querido con Alzheimer o demencia?

10) ¿Hay algo más que le gustaría mencionar que todavía no ha compartido?

Conclusion: Me gustaría agradecer su tiempo el día de hoy y espero mantenerme en contacto para informarle como va este programa en el futuro. Toda la información que me han dado el día de hoy es muy valiosa y me ayudará bastante para desarrollar el mejor manual posible para este proyecto.

To assess interest in participating in member check: Después de haber terminado los grupos de enfoque y repasado los resultados de lo que se diálogo, quisiera reunirme con quien este de acuerdo para platicar conmigo y repasar lo que he encontrado basado en sus respuestas para asegurar de que yo este entendiendo lo que se compartió durante los grupos de enfoque. Platicar conmigo después que se hayan terminado estos grupos de enfoque es completamente voluntario. En esa reunión opcional no estaria proporcionando $20 por su tiempo como lo estoy haciendo para estos grupos. Si le gustaría que me comunique con usted para esa conversación opcional por favor anote su nombre y número de teléfono en la hoja que voy a pasar en el último grupo de enfoque. Muchas gracias nuevamente por su tiempo valioso y lo que ha aportado a este proyecto.

Interview Guide: Other Stakeholder Focus Groups (1 and 2)

Introduction: Gracias por aceptar el participar en este diálogo en grupo. Su participación es completamente voluntaria. Por favor siéntase con la libertad de tomar un receso o detener su participación en este diálogo en cualquier momento. Nuestro diálogo durara aproximadamente como dos horas el día de hoy. El diálogo será sobre sus opiniones en cuanto a lo que es importante para las mujeres latinas que ayudan en el cuidado de un familiar o ser querido con Alzheimer o demencia. El diálogo se llevara acabo en **dos sesiones de dos horas cada sesión**. La información recolectada se usara para crear un programa para mujeres latinas para intentar ayudarlas en su propio cuidado mientras cuidan a su familiar o ser querido. Este diálogo en grupo será audio grabado para que yo pueda regresar a escucharlo cuando este creado el manual para el programa. (También tengo a mi colega tomando notas por si llega a pasar algo con la grabación.) Para mantener su privacidad les pido que no usen sus nombres actuales durante el diálogo mientras estamos grabando la sesión. Podemos usar diferentes nombres que escribiremos en las tarjetas que estoy repartiendo, si es que desean usar un nombre durante el diálogo. También, como respeto a la privacidad de los demás les pido que lo que se diga en este grupo o información sobre quien este presente en la reunión no sea compartida fuera de este reunión. ¿Hay alguna pregunta antes de comenzar?

1) Por favor díganos brevemente algo sobre usted y cómo es que sabe de el cuidado a un ser querido/pariente con Alzheimer o demencia.

2) Estoy distribuyendo un manual de un programa cual fue creado para madres latinas de niños y adultos con discapacidades intelectuales y del desarrollo tal como autismo, síndrome de Down, etc. Repasaremos porciones del manual juntas/os y me gustaría que

en cada página donde usted siente que cambios son necesarios para que esto sea adecuado para mujeres latinas que cuidan de pariente/ser querido con Alzheimer o demencia. Platicaremos sobre sus opiniones en grupo y luego recogere los manuales y notas para tener por escrito lo que han dicho sobre el manual.

3) De acuerdo con sus notas y opiniones, ¿qué cambios son necesarios?

4) ¿Usted piensa que este programa, haciendo los cambios que usted sugiere, ayudaría a mujeres latinas que cuidan a familiar/ser querido con Alzheimer o demencia?

5) ¿Hay algo más que le gustaría mencionar que todavía no ha compartido?

Conclusion: Me gustaría agradecer su tiempo el día de hoy y espero mantenerme en contacto para informarle como va este programa en el futuro. Toda la información que me han dado el día de hoy es muy valiosa y me ayudará bastante para desarrollar el mejor manual posible para este proyecto.

To assess interest in participating in member check: Después de haber terminado los grupos de enfoque y repasado los resultados de lo que se diálogo, quisiera reunirme con quien este de acuerdo para platicar conmigo y repasar lo que he encontrado basado en sus respuestas para asegurar de que yo este entendiendo lo que se compartió durante los grupos de enfoque. Platicar conmigo después que se hayan terminado estos grupos de enfoque es completamente voluntario. En esa reunión opcional no estaria proporcionando $20 por su tiempo como lo estoy haciendo para estos grupos. Si le gustaría que me comunique con usted para esa conversación opcional por favor anote su nombre y número de teléfono en la hoja que voy a pasar en el último grupo de enfoque. Muchas gracias nuevamente por su tiempo valioso y lo que ha aportado a este proyecto.

Phase I Member Check Follow-up

Member Check: Invitation Phone Script

(for both caregivers and institutional stakeholders)

Hello, this is Judith Rocha calling from the University of Illinois at Chicago. Thank you again for participating in the group discussion on _____ (specify date of the focus group). The information that you provided was very helpful for my project.

At the group discussion, you provided your contact information so that we could speak again after I reviewed the responses of the group discussions to help me make sure that what I came up with in my analysis is the same as what was shared in the group discussion. Speaking with me about this is completely voluntary, and I would not be providing $20 like I did for the group discussion. Are you still interested in speaking with me this time?

If no: Not a problem at all. I really appreciate all of the time that you have given to this project.

If yes: Thank you so much for accepting to help with this. Would you prefer to meet individually or would you be willing to meet in a small group?

For those requesting individual meetings: When and where would be convenient for you to meet?

For those requesting group meetings: I am planning to hold a group meeting at either _____ or _____ (give two meeting time options) at _____(add location). Which of these times would be most convenient for you?

Member Check: Individual Session Interview Guide

(for both caregivers and institutional stakeholders)

Introduction: Thank you for your time today to meet with me about the results of my analysis. Your decision to speak with me is completely voluntary, and I will not be providing $20 like I did at our group discussion. Do you have any questions for me before we get started?

1) Here are the results of my analysis: _____ (I will provide a brief oral summary of my findings).

2) Do you have any questions about the results of my analysis?

3) Do these results reflect what was shared during the group discussion?

    If yes:

    a) Is there any other feedback about these results that you would like to share?

    If no:

    a) What is missing and/or needs to be changed?

    b) Is there any other feedback about the results that you would like to share?

Closing: I really appreciate that you met with me again today. The information that you provided is very important and helps me make sure that I understand the information form the group discussion correctly. Thank you for all the valuable time you have given me for this project.

Member Check: Group Session Interview Guide

(for both caregivers and institutional stakeholders)

Introduction: Thank you for your time today to meet with me about the results of my analysis. Your decision to speak with me is completely voluntary, and I will not be providing $20 like I did at our group discussion. In order to respect each other's privacy, I ask that what is discussed in this group or who is present in the meeting is not shared outside of this meeting. Do you have any questions for me before we get started?

1) Here are the results of my analysis: _____ (I will provide a brief oral summary of my findings).

2) Do you have any questions about the results of my analysis?

3) Do these results reflect what was shared during the group discussion?

    If yes:

    a) Is there any other feedback about these results that you would like to share?

    If no:

    a) What is missing and/or needs to be changed?

    b) Is there any other feedback about the results that you would like to share?

Closing: I really appreciate that you met with me again today. The information that you provided is very important and helps me make sure that I understand the information from the group discussion correctly. Thank you for all the valuable time you have given me for this project.

APPENDIX C

LATINA FAMILY CAREGIVER FOCUS GROUP CONSENT

Informed Consent Form: English-Language Form

**The University of Illinois at Chicago
Research Information and Consent
Permission for Participation in Social Behavioral Research
Caring of Caregivers Organically (CoCO)**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title:	Judith S. Rocha, LCSW – Doctoral Candidate
Department and Institution:	University of Illinois at Chicago (UIC)
	Jane Addams College of Social Work
Address and Contact Information:	1040 W. Harrison St., M/C 309, Chicago IL 60607
	Phone: 773-580-3302
Sponsor/funder:	Midwest Roybal Center for Health Promotion and
	Translation

Why am I being asked?
You are being asked to be a subject in a research study that will evaluate an educational program designed to help Latinas who care for a family member/loved one with Alzheimer's disease or related dementia care for their own health. You have been asked to participate in the research because you are a woman, of Latin American decent, and the caregiver of a family member/loved one with Alzheimer's disease or related dementia.

Your participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago or with any organization that may have given you the information for this study. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

What is the purpose of this research?
Latinas that help in the care of a family member/loved one with Alzheimer's disease or related dementia spend much of their energy caring for that person, often ignoring their own health care

needs. The purpose of our study is to assess an educational program which aims to help those Latinas that help in the care of a family member/loved one with Alzheimer's disease or related dementia to develop health and wellness knowledge and skills. Our objective is to offer suggestions and methods to improve the quality of their health and general well-being, which may benefit these Latinas and their family.

What procedures are involved?

Your participation in this research study will last approximately one month and will include: **3** focus groups held at the UIC Disability, Health, and Social Policy Building (DHSP) located at 1640 W. Roosevelt Rd., Chicago, IL or the Pilsen Satellite Senior Center located at 2021 S. Morgan St., Chicago, IL. The location that is most convenient to the group is the one that was selected for the focus groups.

Focus Group 1-3:

➢ If you agree to participate, you will need to go to the UIC DHSP or Pilsen Senior Satellite Center, whichever site that was confirmed with you prior to the meeting dates. You will be asked to sign this consent form.

➢ A researcher will facilitate the three (3) focus group discussions with you and 4-6 more people about an existing health education program to gather your views on how that program can be adapted for Latinas that care for a family member/loved one with Alzheimer's disease or related dementia. Each focus group will take about two (2) hours to complete. The discussions will be audio-recorded and then transcribed. Your name will not be included on the transcription.

➢ The researcher will also conduct an optional focus group or individual discussion (session 4) after the three (3) focus groups have been completed. You will be contacted by phone for scheduling. You will be asked to review with the researcher if the information gathered is what you feel was what the group shared. That focus group or individual discussion will be led by Judith S. Rocha, and last about 60 to 90 minutes. The discussion will be audio-recorded and then transcribed. Your name will not be included on the transcription.

What are the potential risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. The focus groups may include discussion of sensitive issues, such as your experience caring for your family member/loved one with Alzheimer's disease or related dementia. You do not have to discuss anything that makes you feel uncomfortable.

Another risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information). All study staff are trained in the importance of confidentiality to protect you from this risk.

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you personally. Our goal is to develop a health education program that will offer suggestions and methods to improve the health and healthy habits of Latinas caring for a family member/loved one with Alzheimer's disease or related dementia. We hope that the information learned from this study will benefit other families in the future.

What other options are there?
You have the option to not participate in this study and can stop at any time.

What about privacy and confidentiality?
The people who will know that you are a research subject are members of the research team and other participants in the focus group. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law. Although all participants will be asked to respect each other's privacy and not repeat what is said at the focus group, this level of confidentiality cannot be guaranteed.

Study information, which identifies you and the consent form signed by you may be looked at and/or copied for checking up on the research by: UIC Office for the Protection of Research Subjects (OPRS) and State of Illinois Auditors.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

To protect your confidentiality, we will not record your name on any of your responses during the focus groups. You will be asked to use a pseudonym or no name at all for yourself and others in the focus group during the audio-recordings. An identifying number will be used on any written documents. Judith S. Rocha, the researcher, will maintain a file with your name, address, phone number and study ID number which will be stored on a different secured electronic drive. This file will be destroyed when the study is completed. Your contact information will be kept until the study is complete in case we need to re-contact you during analysis of the study data if we find that there is any missing or unclear information. Audio recordings will be destroyed after they have been transcribed, verified and analyzed. Forms and transcription of the audio-recordings that do not include identifying information will be kept in locked files indefinitely.

If the researchers learn that you, your family member/loved one with Alzheimer's disease or related dementia, or someone else is in serious danger or at risk of being harmed, they may make disclosures to the appropriate authorities necessary to protect you and/or other persons. If concerns arise about the welfare of you, your family member/loved one or other family members, the researchers will make every effort to talk with you before disclosing the information.

What are the costs for participating in this research?
There are no costs to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?
You will receive $20 in cash after completing each focus group session (Focus Group 1, 2, and 3). You will NOT receive any money if you decide to participate in the optional focus group/individual session (session 4) that will be conducted after the three (3) focus groups. If you complete all three (3) focus groups, you will receive a total of $60.

Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent or permission and discontinue participation at any time without penalty.

The Researcher also has the right to stop your participation in this study without your consent if they believe it is in your best interest or determines that you are not eligible for the study.

In the event you withdraw or are asked to leave the study, you will still be compensated as described above.

Who should I contact if I have questions?
Contact the principal investigator, Judith S. Rocha at 773-580-3302 or email address:
jrocha2@uic.edu
- if you have any questions about this study or your part in it; and/or
- if you have questions, concerns or complaints about the research.

For questions, concerns or complaints you may also contact the faculty sponsor of this study, Dr. Chang-ming Hsieh at chsieh@uic.edu or 312-996-0041.

What are my rights as a research subject?
If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember:
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or any organization that may have given you the information for this study. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Optional Participation in Future Research Studies (please initial):
We would like to contact you again in the future to see if you would be interested in participating in other research studies about families of persons with Alzheimer's disease or related dementia. This is optional and will not affect your participation in this study if you do not wish to be contacted. If you agree, your contact information will be securely stored in a separate database and maintained under password protection on a computer at 1640 W. Roosevelt Rd., Room 705 (with access limited to only Judith S. Rocha) for 5 years after the study is completed upon which time it will be destroyed.

_____ I agree to be contacted for future studies about caregivers of persons with Alzheimer's disease or related dementia.
_____ I do **not** agree to be contacted for future studies caregivers of persons with Alzheimer's disease or related dementia.

Signature of Subject

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

_____   _____

Signature of Subject   Date

_____

Printed Name of Subject

_____   _____

Signature of Person Obtaining Consent   Date (must be same as subject's)

_____

Printed Name of Person Obtaining Consent

APPENDIX C (continued)

Informed Consent Form: Spanish-Language Form

Universidad de Illinois en Chicago
Información y consentimiento de participación en un estudio de conducta social
CuidandO de Cuidadores Organicamente (CoCO)
Consentimiento para grupo de enfoque de mujeres latinas que cuidan a un ser
querido/familiar con Alzheimer o demencia

Se le ha pedido que participe en un estudio de investigación. Los investigadores tienen la obligación de suministrarle un formulario de consentimiento como el que tiene en sus manos para comentarle en qué consiste el estudio de investigación, explicarle que toda participación es voluntaria, describir los riesgos y ventajas de participar, y ayudarle a tomar una decisión informada. No dude en consultar con los investigadores cualquier duda que pueda tener

Nombre y cargo del investigador principal:	Judith S. Rocha, LCSW –Candidata del Doctorado
Departamento e Instituto:	University of Illinois at Chicago (UIC)
	Jane Addams College of Social Work
Dirección e información de contacto:	1040 W. Harrison St., M/C 309, Chicago IL 60607
	Teléfono: 773-580-3302
El patrocinador/fuente de financiamiento:	Midwest Roybal Center for Health Promotion and Translation

¿Por qué se me pide participar?
Se le ha pedido que participe como sujeto en un estudio de investigación que evaluará un programa diseñado para ayudar a mujeres latinas que cuidan a un ser querido/familiar con Alzheimer o demencia para que cuiden de su propia salud y bienestar. Se le ha pedido que participe en el estudio porque usted es una mujer de decendencia latino americana y cuida a un ser querido/familiar con Alzheimer o demencia.

Su participación en este estudio de investigación es voluntaria. Tanto si decide participar como si no, su relación actual o futura con la Universidad de Illinois en Chicago o con cualquier organización que le dio la información del estudio no se verá afectada por dicha decisión. **Si decide participar, es libre de retirarse en cualquier momento sin que ello afecte dicha relación.**

¿Cuál es el objetivo de esta investigación?

APPENDIX C (continued)

de sus energías cuidando a su pariente/ser querido, a menudo ignorando sus propias necesidades de salud. El propósito de nuestro estudio es evaluar un programa educacional cuyo propósito es ayudarle a estas latinas desarrollar habilidades y conocimientos de salud y el bienestar. También proporcionaremos sugerencias y estrategias que puedan mejorar la calidad de su salud y bienestar, lo cual podrá beneficiarle a ella y a su familia.

¿Qué procedimientos integran el estudio?
Su participación en el estudio de investigación durará aproximadamente un mes e incluirá:
3 grupos de enfoque que se llevaran acabo en el edificio de UIC de discapacidad, salud, y poliza social (DHSP por sus siglas en ingles) ubicado en el 1640 W. Roosevelt Rd., Chicago, IL o en el centro de personas de la tercera edad de Pilsen (Pilsen Satellite Senior Center) ubicado en 2021 S. Morgan St., Chicago, IL. La ubicación que sea más practica para el grupo sera el lugar elegido para llevar a cabo los grupos de enfoque.

Grupos de Enfoque 1-3:
- ➢ Si decide participar, usted necesitará venir a UIC DHSP o al Pilsen Senior Satellite Center, cualquiera de los sitios que fue confirmado con usted antes de las fechas para las citas. Se le pedirá firmar este formulario de consentimiento.
- ➢ La investigadora llevara a cabo el diálogo de los tres (3) grupos de enfoque con usted y 4-6 personas más sobre un programa de salud para recolectar sus opiniones de como este programa puede ser adaptado para mujeres latinas que cuidan de un familiar/ser querido con Alzheimer o demencia. Cada grupo de enfoque durara aproximadamente dos (2) horas. Los diálogos seran audio-grabados y seran transcritos. Su nombre no sera incluido en las transcripciones.
- ➢ La inverstigadora también llevara a cabo un grupo de enfoque opcional o conversación individual (sesión 4) después de que los tres (3) grupos de enfoque se hayan terminado. Se le llamara por teléfono para programar esa sesión opcional. Se le pedira platicar conmigo y repasar lo que he encontrado basado en sus respuestas para asegurar de que yo este entendiendo lo que se compartió durante los grupos de enfoque. Ese grupo de enfoque o sesión individual será dirigido por Judith S. Rocha, y durara aproximadamente 60 a 90 minutos. El diálogo será audio-grabada y luego transcrita. Su nombre no se incluirá en la transcripción.

¿Cuáles son los posibles riesgos y molestias?
A nuestro conocimiento, las cosas que usted tendrá que hacer no acarrean un riesgo o daño mayor que el habitual de la vida cotidiana. Los grupos de enfoque pueden incluir una discusión de temas sensibles como su experiencia cuidando de su familiar/ser querido con Alzheimer o demencia. Usted no tiene que compartir nada que la haga sentir incomoda.

Un riesgo de esta investigación es la pérdida de privacidad (el poner en conocimiento de otras personas que usted está participando en este estudio) o de la confidencialidad (la divulgación de información sobre usted a otras personas que no cuentan con su permiso para ver esta información). Todo personal del estudio está entrenado en la importancia de la confidencialidad

para protegerla a usted de este riesgo.

¿Cuáles son los beneficios de participar en el estudio de investigación?
Tomar parte en este estudio de investigación tal vez no la beneficie personalmente. Nuestro objetivo es ofrecer sugerencias y métodos que puedan mejorar la calidad de mujeres latinas que cuidan de un familiar/ser querido con Alzheimer o demencia. Esperamos que la información que aprendemos de este estudio beneficiará a otras familias en el futuro.

¿Qué otras opciones existen?
Tiene la opción de no participar en este estudio o retirarse en cualquier momento.

¿Cómo se tratará la privacidad y la confidencialidad?
Las personas con conocimiento de su participación como sujeto en la investigación son los miembros del equipo de investigación y las otras participantes del grupo de enfoque. Por lo demás, la información sobre usted únicamente se divulgará a otras personas con su permiso por escrito, o si fuera necesario para proteger sus derechos o bienestar, o en cumplimiento de la ley. Aunque, como respeto a la privacidad de los demás se le pide a todos los participantes que lo que se diga en este grupo no sea compartida fuera de esta reunion, este nivel de confidencialidad no se podría garantizar.

Datos del estudio que le identifican individualmente y el formulario de consentimiento firmado por usted serán examinados o copiados para analizar la investigación por: UIC Oficina para la Protección de los Seres Humanos en la Investigación (OPRS) y Auditores del Estado de Illinois.

En el caso en que los resultados de la investigación se publiquen o comenten en congresos, no se incluirá ninguna información que pudiera revelar su identidad.

Para proteger su confidencialidad, nosotros no notaremos su nombre en ningún cuestionario o con ninguna de sus respuestas durante los grupos de enfoque. Se le pedira usar un nombre que no sea el suyo o no usar nombre durante la audio-grabación de los grupos de enfoque. Se usará un número de identificación. Judith S. Rocha, la investigadora, mantendrá un archivo con su nombre, dirección, teléfono y número de identificación del estudio en otra unidad electrónica asegurada. Este archivo será destruido después de la terminación del estudio. Su información de contracto se mantendra hasta que se termine el estudio en caso de que necesitemos comunicarnos con usted nuevamente durante el análisis de la información recolectada del estudio si encontramos que hay información incompleta o confusa. Audio-grabaciones seran destruidas después de ser transcritas, verificadas, y analisadas. Formularios que no incluyan información de identificación y las transcripciones de audio (que no incluirá identificadores directos como su nombre) serán mantenidas bajo llave indefinidamente.

Si la entrevistadora percibe que usted, su pariente/ser querido con Alzheimer o demencia, o alguien más está en peligro o en riesgo de ser herido o sufrir algún daño, ella podrá revelar la información que sea necesaria para protegerla a usted o a otras personas. Si existen dudas acerca del bienestar de usted, su familiar/ser querido u otro miembro de la famila, la entrevistadora hará

todos los esfuerzos posibles para hablar con usted antes de revelar dicha información.

APPENDIX C (continued)

¿Cuáles son los costos de participar en esta investigación?
No hay costos para usted por participar en esta investigación.

¿Se me reembolsarán algunos de mis gastos o se me pagará por mi participación en este estudio de investigación?

Recibirá $20.00 después de completar cada grupo de enfoque (Grupo de Enfoque 1, 2, y 3). NO recibirá dinero si decide participar en la conversación opcional (sesión 4) que ser llevara a cabo después de los tres (3) grupos de enfoque. Si participa en los tres (3) grupos de enfoque usted recibirá un total de $60.

¿Puedo retirarme o ser eliminado del estudio?
Si decide participar, es libre de retirar su consentimiento y dejar de participar en cualquier momento sin ninguna penalización.

La investigadora tiene también derecho a interrumpir su participación en este estudio sin su consentimiento si cree que es lo más conveniente para usted o si determinan que usted no es elegible para el estudio.

En el caso que usted se retire o que se le pida que abandone el estudio, seguirá siendo compensado tal como se ha descrito anteriormente.

¿A quién debo contactar si tengo preguntas?
Póngase en contacto con la investigadora principal, Judith S. Rocha llamando al 773-580-3302 o por correo electrónico: jrocha2@uic.edu
- si tiene preguntas acerca de este estudio o de su participación en él,
- si tiene preguntas, preocupaciones o quejas sobre la investigación.

Para preguntas, preocupaciones, o quejas también se puede comunicar con my professor y supervisor en este estudio, Dr. Chang-ming Hsieh por correo electrónico chsieh@uic.edu o llamando al 312-996-0041.

¿Cuáles son mis derechos como sujeto de investigación?
Si cree que usted no ha sido tratada de acuerdo con las descripciones de este formulario, o si tiene preguntas sobre sus derechos como sujeto de investigación, preocupaciones, quejas, o para darnos su opinión, puede llamar a la Oficina para la Protección de los Seres Humanos en la Investigación (OPRS, Office for the Protection of Research Subjects) al 312-996-1711 o 1-866-789-6215 (llamada gratuita) o enviar un mensaje por correo electrónico a la OPRS a uicirb@uic.edu

Recuerde:
Su participación en esta investigación es voluntaria. Su decisión sobre su participación no afectará a su relación actual o futura con la universidad o con cualquier organización que le dio

información sobre este estudio. Si decide participar, es libre de retirarse en cualquier momento sin que esto afecte dicha relación.

APPENDIX C (continued)

Participación opcional en futuros estudios de investigación (por favor marque con sus iniciales):

Quisiéramos comunicarnos con usted en el futuro para ver si usted estaría interesada en participar en otras investigaciones sobre familias que tienen a un ser querido/pariente con Alzheimer o demencia. Esto es opcional y no afectará su participación en este estudio si no desea ser llamada después. Si esta de acuerdo, su información de contacto sera guardada con contraseña en un sistema de datos en un computador que estará bajo llave en el edificio ubicado en el 1640 W. Roosevelt Rd., Salon 705 (con acceso a Judith S. Rocha solamente) por 5 años despues que termine el estudio en cual momento la información será destruida.

_____ Estoy de acuerdo en que se comuniquen conmigo para estudios en el futuro sobre personas que proveen cuidado a un familiar/ser querido con Alzheimer o demencia.

_____ **No estoy de acuerdo** en que se comuniquen conmigo para estudios en el futuro sobre personas que proveen cuidado a un familiar/ser querido con Alzheimer o demencia.

Firma del sujeto o del representante legalmente autorizado

He leído (o alguien me ha leído) la información anterior. He tenido oportunidad de hacer preguntas, y éstas se han contestado a mi entera satisfacción. Acepto participar en esta investigación. Se me entregará una copia de este formulario firmado y fechado.

_____   _____

Firma   Fecha

_____

Nombre en letra de molde

_____   _____

Firma de la persona que obtiene el consentimiento   Fecha (debe ser la misma que la del sujeto)

_____

Nombre de la persona que obtiene el consentimiento en letra de imprenta

APPENDIX C (continued)

OTHER STAKEHOLDERS FOCUS GROUP CONSENT

Informed Consent Form: English-Language Form

The University of Illinois at Chicago
Research Information and Consent
Permission for Participation in Social Behavioral Research
Caring of Caregivers Organically (CoCO)

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Judith S. Rocha, LCSW – Doctoral Candidate
Department and Institution: University of Illinois at Chicago (UIC)
                                 Jane Addams College of Social Work
Address and Contact Information: 1040 W. Harrison St., M/C 309, Chicago IL 60607
                                 Phone: 773-580-3302
Sponsor/funder: Midwest Roybal Center for Health Promotion and
                                 Translation

Why am I being asked?
You are being asked to be a subject in a research study that will evaluate an educational program designed to help Latinas who care for a family member/loved one with Alzheimer's disease or related dementia care for their own health. You have been asked to participate in the research because you are a service provider, organization/community leader, academic, researcher, and/or content area expert that understands Latino aging, Alzheimer's disease or related dementia, and/or work with Latino families in the Chicagoland area.

Your participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago or with any organization that may have given you the information for this study. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

What is the purpose of this research?
Latinas that help in the care of a family member/loved one with Alzheimer's disease or related dementia spend much of their energy caring for that person, often ignoring their own health care

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needs. The purpose of our study is to assess an educational program which aims to help those

Latinas that help in the care of a family member/loved one with Alzheimer's disease or related dementia to develop health and wellness knowledge and skills. Our objective is to offer suggestions and methods to improve the quality of their health and general well-being, which may benefit these Latinas and their family.

What procedures are involved?
Your participation in this research study will last approximately one month and will include:
2 focus groups held at the UIC Disability, Health, and Social Policy Building (DHSP) located at 1640 W. Roosevelt Rd., Chicago, IL or the Pilsen Satellite Senior Center located at 2021 S. Morgan St., Chicago, IL. The location that is most convenient to the group is the one that was selected for the focus groups.

Focus Group 1-2:
  ➢ If you agree to participate, you will need to go to the UIC DHSP or Pilsen Senior Satellite Center, whichever site that was confirmed with you prior to the meeting dates. You will be asked to sign this consent form.
  ➢ A researcher will facilitate the two (2) focus group discussions with you and 4-6 more people about an existing health education program to gather your views on how that program can be adapted for Latinas that care for a family member/loved one with Alzheimer's disease or related dementia. Each focus group will take about two (2) hours to complete. The discussions will be audio-recorded and then transcribed. Your name will not be included on the transcription.
  ➢ The researcher will also conduct an optional focus group or individual discussion (session 3) after the two (2) focus groups have been completed. You will be contacted by phone for scheduling. You will be asked to review with the researcher if the information gathered is what you feel was what the group shared. That focus group or individual discussion will be led by Judith S. Rocha, and last about 60 to 90 minutes. The discussion will be audio-recorded and then transcribed. Your name will not be included on the transcription.

What are the potential risks and discomforts?
To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. The focus groups may include discussion of sensitive issues such as your own experiences of caring for a family member/loved one with Alzheimer's disease or related dementia and/or those of others you have come in contact with in your professional/personal life. Although this is not specifically asked about in the focus group, the conversation may include conversation around this subject. You do not have to discuss anything that makes you feel uncomfortable.

Another risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information). All study staff are trained in the importance of

confidentiality to protect you from this risk.

Are there benefits to taking part in the research?
Taking part in this research study may not benefit you personally. Our goal is to develop a health education program that will offer suggestions and methods to improve the health and healthy habits of Latinas caring for a family member/loved one with Alzheimer's disease or related dementia. We hope that the information learned from this study will benefit other families in the future.

What other options are there?
You have the option to not participate in this study and can stop at any time.

What about privacy and confidentiality?
The people who will know that you are a research subject are members of the research team and other participants in the focus group. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law. Although all participants will be asked to respect each other's privacy and not repeat what is said at the focus group, this level of confidentiality cannot be guaranteed.

Study information, which identifies you and the consent form signed by you may be looked at and/or copied for checking up on the research by: UIC Office for the Protection of Research Subjects (OPRS) and State of Illinois Auditors.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

To protect your confidentiality, we will not record your name on any of your responses during the focus groups. You will be asked to use a pseudonym or no name at all for yourself and others in the focus group during the audio-recordings. An identifying number will be used on any written documents. Judith S. Rocha, the researcher, will maintain a file with your name, address, phone number and study ID number that will be stored on a different secured electronic drive. This file will be destroyed when the study is completed. Your contact information will be kept until the study is complete in case we need to re-contact you during analysis of the study data if we find that there is any missing or unclear information. Audio recordings will be destroyed after they have been transcribed, verified and analyzed. Forms and transcription of the audio-recordings that do not include identifying information will be kept in locked files indefinitely.

If the researchers learn that you, your family member/loved one with Alzheimer's disease or related dementia, or someone else is in serious danger or at risk of being harmed, they may make disclosures to the appropriate authorities necessary to protect you and/or other persons. If concerns arise about the welfare of you, your family member/loved one or other family members, the researchers will make every effort to talk with you before disclosing the information.

What are the costs for participating in this research?

There are no costs to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?
You will receive $20 in cash after completing each focus group session (Focus Group 1 and 2).
You will NOT receive any money if you decide to participate in the optional focus
group/individual session (session 3) that will be conducted after the two (2) focus groups. If you
complete all two (2) focus groups, you will receive a total of $40.
Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent or permission and discontinue
participation at any time without penalty.

The Researcher also has the right to stop your participation in this study without your consent if
they believe it is in your best interest or determines that you are not eligible for the study.

In the event you withdraw or are asked to leave the study, you will still be compensated as
described above.

Who should I contact if I have questions?
Contact the principal investigator, Judith S. Rocha at 773-580-3302 or email address:
jrocha2@uic.edu
- if you have any questions about this study or your part in it; and/or
- if you have questions, concerns or complaints about the research.

For questions, concerns or complaints you may also contact the faculty sponsor of this study, Dr.
Chang-ming Hsieh at chsieh@uic.edu or 312-996-0041.

What are my rights as a research subject?
If you feel you have not been treated according to the descriptions in this form, or if you have
any questions about your rights as a research subject, including questions, concerns, complaints,
or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-
996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember:
Your participation in this research is voluntary. Your decision whether or not to participate will
not affect your current or future relations with the University or any organization that may have
given you the information for this study. If you decide to participate, you are free to withdraw at
any time without affecting that relationship.

Optional Participation in Future Research Studies (please initial):
We would like to contact you again in the future to see if you would be interested in participating
in other research studies about families of persons with Alzheimer's disease or related dementia.
This is optional and will not affect your participation in this study if you do not wish to be
contacted. If you agree, your contact information will be securely stored in a separate database
and maintained under password protection on a computer at 1640 W. Roosevelt Rd., Room 705
(with access limited to only Judith S. Rocha) for 5 years after the study is completed upon which

time it will be destroyed.

_____ I agree to be contacted for future studies about caregivers of persons with Alzheimer's disease or related dementia.

_____ I do **not** agree to be contacted for future studies caregivers of persons with Alzheimer's disease or related dementia.

<u>Signature of Subject</u>

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

Signature of Subject	Date

Printed Name of Subject

Signature of Person Obtaining Consent	Date (must be same as subject's)

Printed Name of Person Obtaining Consent

CoCO
Phase I Focus Group
Phone Screening

(Use screener with response sheet)

ID#:___ ___ ___

Dates/Times of calls and response:

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

(Use additional contact sheet form)

Start here for making calls to families who returned a response sheet:

HELLO, THIS IS (your name) FROM THE JANE ADDAMS COLLEGE OF SOCIAL WORK AT THE UNIVERSITY OF ILLINOIS AT CHICAGO. **DO YOU PREFER SPANISH OR ENGLISH** TO CONTINUE? I'M CALLING BECAUSE YOU EXPRESSED INTEREST IN OUR STUDY *CARING OF CAREGIVERS ORGANICALLY (COCO)*. I WANT TO BRIEFLY TELL YOU ABOUT THIS STUDY. IS THIS A GOOD TIME TO TALK?

FIRST, LET ME ASK YOU: HOW DID YOU LEARN ABOUT THE STUDY?

_____

_____

DID YOU RECEIVE A FLYER/BROCHURE WITH INFORMATION ABOUT THE STUDY?

_____ (0) no **(If no, read the script in the box below)**   _____ (1) yes **(continue)**

For those who did not receive a brochure:

I HAVE A FLYER/BROCHURE THAT COMPLIMENTS THE INFORMATION I WILL TELL YOU. I WILL MAIL THAT TO YOU TODAY. YOU CAN EXPECT TO RECEIVE IT IN THE NEXT COUPLE OF DAYS.
　　　(date brochure sent :_____)

I WOULD LIKE TO BRIEFLY TELL YOU ABOUT THE RESEARCH STUDY. LATINAS THAT CARE FOR A RELATIVE/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA OFTEN SPEND TIME TAKING CARE OF THEIR FAMILIES, BUT IGNORE THEIR OWN HEALTH NEEDS. THE PURPOSE OF THE STUDY IS TO ASSESS AND ADAPT AN EDUCATIONAL PROGRAM THAT AIMS TO HELP THESE LATINAS DEVELOP HEALTH AND WELLNESS KNOWLEDGE AND SKILLS. MY OBJECTIVE IS TO OFFER SUGGESTIONS AND METHODS TO IMPROVE THE QUALITY OF THESE WOMEN'S HEALTH AND GENERAL WELL-BEING FOR THEM AND THEIR FAMILY.

DOES OUR STUDY SOUND LIKE SOMETHING YOU ARE INTERESTED IN PARTICIPATING IN?

　　　　　(If yes:)   Continue with the script page
　　　　　(If no:)   Go to page 6, Reluctant to participate

I WILL EXPLAIN A LITTLE MORE ABOUT THE STUDY AND WHAT WE NEED YOU TO DO, BUT FIRST I WOULD LIKE TO ASK YOU A FEW QUESTIONS TO FIND OUT IF YOU MEET OUR STUDY CRITERIA. WOULD THAT BE ALL RIGHT IF I ASK YOU A FEW QUESTIONS? IT SHOULD ONLY TAKE ABOUT 10 MINUTES TO COMPLETE.

Oral Consent provided: Yes ☐   No ☐
Date: _____
Research staff initials: _____

Eligibility Questions

THE FOCUS OF OUR STUDY IS ON WOMEN THAT HELP CARE FOR A FAMILY MEMBER/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA WHO ARE OF LATIN AMERICAN DESCENT AND LIVE IN THE U.S.

　　1.　ARE YOU A LATINA THAT HELPS CARE FOR A RELATIVE/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA?

　　　　_____ (0) no　　　　　　　_____ (1) yes

　　OR

2. ARE YOU SOMEONE THAT IS VERY FAMILIAR WITH INFORMATION ABOUT CARING FOR OLDER ADULTS WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA, SUPPORTS AND SERVICES FOR LATINO FAMILIES, AND/OR HEALTHY AGING?

_____ (0) no   _____ (1) yes

3. CAN YOU ATTEND MEETINGS AT: the UIC Disability, Health and Social Policy Building located at 1640 W. Roosevelt Rd., Chicago, IL 60608 or at the Pilsen Satellite Senior Center located at 2021 S. Morgan St., Chicago, IL 60608? (**Circle location preferred**)

_____ (0) no   _____ (1) yes

(If a Latina Caregiver:)   Continue with the #4
(If an Other Stakeholder:)   Continue with the #10
(If not a Latina Caregiver, Other Stakeholder and/or cannot attend meetings in Chicagoland area:)   Continue with the (*) after #4

For Caregivers only

4. HOW WOULD YOU CATEGORIZE YOUR ETHNIC BACKGROUND?

___(1) Mexican/Mexican-American/Chicano
___(2) Puerto Rican
___(3) Cuban/Cuban-American
___(4) Other Latino (specify)_____
___(5) Latino and non-Latino ethnicity (specify)_____
___(6) Non-Latino (specify)_____

*If a Caregiver responds non-Latino, does not indicate a Latin American country of origin or ancestry or if the person is neither a Latina Caregiver or Other Stakeholder, say:

THANK YOU FOR YOU TIME AND INTEREST IN OUR STUDY. RIGHT NOW, THE FOCUS IS ON LATINA CAREGIVERS LIVING IN THE CHICAGOLAND AREA BECAUSE THEY ARE UNDERREPRESENTED IN RESEARCH ABOUT FAMILIES AND ALZHEIMER'S DISEASE OR RELATED DEMENTIA. THANK YOU FOR CONSIDERING PARTICIPATION.

If person meets ethnicity criteria, continue:

ONE OF THE PREFERENCES OF THE STUDY IS THAT THE WOMEN BE 50 YEARS OLD OR OLDER. THIS IS BECAUSE I AM INTERESTED IN LEARNING ABOUT HOW

MIDLIFE AND OLDER CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA CAN IMPROVE THEIR HEALTH GIVEN THEY HAVE MORE HEALTH RISKS. IF YOU ARE NOT 50 YEARS OLD OR OLDER THAT DOES NOT DISQUALIFY YOU FROM THE STUDY.

5. IF YOU DON'T MIND ME ASKING, HOW OLD ARE YOU, AND WHAT IS YOUR DATE OF BIRTH?

_____

NEXT I HAVE A FEW QUESTIONS ABOUT THE FAMILY MEMBER/LOVED ONE THAT YOU HELP CARE FOR.

6. DOES YOUR RELATIVE/LOVED ONE HAVE A DIAGNOSIS OF ALZHEIMER'S OR SOME TYPE OF DEMENTIA?

_____ (0) no   _____ (1) yes

7. **(if yes:)** WHAT IS THE PERSON'S PRIMARY DIAGNOSIS?

_____

8. **(if no:)** WHAT SYMPTOM(S) DOES YOUR FAMILY MEMBER/LOVED ONE HAVE THAT MAKE YOU BELIEVE S/HE HAS ALZHEIMER'S DISEASE OR RELATED DEMENTIA?

_____

9. WHAT KINDS OF THINGS DO YOU HELP WITH WHEN PROVIDING CARE FOR YOUR FAMILY MEMBER/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA?

_____

For Other Stakeholders only

10. OUT OF THE AREAS MENTIONED: CARING FOR OLDER ADULTS WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA, SUPPORTS AND SERVICES FOR LATINO FAMILIES, AND/OR HEALTHY AGING; WHAT IS YOUR AREA OF EXPERTISE OR WHAT DO YOU KNOW ABOUT SPECIFICALLY/WHAT ARE YOU FAMILIAR WITH?

_____

11. HOW/WHERE HAVE YOU GAINED THIS KNOWLEDGE?

_____

If participant meets criteria of study:

GREAT! YOU HAVE MET ALL THE CRITERIA FOR OUR STUDY.

NOW I WOULD LIKE TO TELL YOU MORE ABOUT THE STUDY AND YOUR PARTICIPATION.

YOUR PARTICIPATION WILL HELP US ASSESS AND ADAPT AN EDUCATIONAL PROGRAM WHICH AIMS TO HELP LATINAS CARING FOR A FAMILY MEMBER/LOVED ONE DEVELOP HEALTH AND WELLNESS KOWLEDGE AND SKILLS.

IF YOU CHOOSE TO PARTICIPATE IN THE FOCUS GROUPS, YOUR PARTICIPATION IN THE STUDY WILL LAST NO MORE THAN ONE MONTH AND WILL INCLUDE:

(FOR LATINA CAREGIVERS) THREE (3) FOCUS GROUPS /
(FOR OTHER STAKEHOLDERS) TWO (2) FOCUS GROUPS

AT the UIC Disability, Health and Social Policy Building located at 1640 W. Roosevelt Rd., Chicago, IL 60608 or at the Pilsen Satellite Senior Center located at 2021 S. Morgan, Chicago, IL 60608.

AT THE START OF YOUR FIRST FOCUS GROUP WE WILL REVIEW AND SIGN A CONSENT FORM. THE CONSENT FORM EXPLAINS MORE ABOUT THE STUDY, THE BENEFITS AND RISKS, AND YOUR RIGHTS. YOU CAN DECIDE TO PARTICIPATE BY SIGNING THE CONSENT FORM. THAT PROCESS WILL TAKE ABOUT 15 MINUTES AT THE START OF THE YOUR FIRST FOCUS GROUP. EACH FOCUS GROUP ITSELF WILL TAKE TWO (2) HOURS TO COMPLETE FOR A TOTAL OF:

(FOR LATINA CAREGIVERS) SIX (6) HOURS SPLIT INTO THREE (3) DIFFERENT FOCUS GROUPS/
(FOR OTHER STAKEHOLDERS) FOUR (4) HOURS SPLIT INTO TWO (2) FOCUS GROUPS.

ALSO, DURING THE WEEK FOLLOWING THE LAST OF THE FOCUS GROUPS YOU WILL BE INVITED TO TAKE PART IN AN OPTIONAL SESSION WHERE I WOULD REVIEW WITH YOU THE RESULTS OF THE FOCUS GROUPS TO MAKE SURE THAT MY INTERPRETATION OF THIS INFORMATION IS WHAT YOU UNDERSTAND TO BE CORRECT. THIS WILL TAKE BETWEEN 60 TO 90 MINUTES.

DO YOU HAVE ANY QUESTIONS?

APPENDIX D (continued)

ARE YOU INTERESTED IN PARTICIPATING?

If yes, proceed to scheduling the informed consent process and review focus groups dates/times.

<u>SCHEDULING INFORMED CONSENT/FOCUS GROUP LOCATION/DAYS AND TIME PREFERENCES</u>

IN THINKING ABOUT THE FOCUS GROUPS:

(FOR LATINA CAREGIVERS) THREE (3) FOCUS GROUPS /
(FOR OTHER STAKEHOLDERS) TWO (2) FOCUS GROUPS;

TWO (2) HOURS EACH – WHAT DAYS AND TIMES USUALLY WORK BETTER FOR YOU (WEEKDAY/WEEKEND, AM/PM)?

WHAT LOCATION WORKS BETTER FOR YOU?

_____ UIC Disability, Health and Social Policy Building located at 1640 W. Roosevelt Rd. in Chicago

_____ Pilsen Satellite Senior Center located at 2021 S. Morgan St. in Chicago

I WILL ALSO ASK THE OTHER PEOPLE PARTICIPATING IN THE FOCUS GROUPS AND TRY TO COME UP WITH A REASONABLE SCHEDULE. I WILL CALL YOU BACK AND PROVIDE THE INFORMATION OF THE DATES, TIMES AND LOCATION OF THE FOCUS GROUPS.

DO YOU PREFER TO REVIEW PRINTED MATERIAL IN:

_____Spanish   _____English

   THANK YOU SO MUCH FOR YOUR TIME TODAY. I'M LOOKING FORWARD TO OUR MEETING. GOOD-BYE.

(Record all scheduling information. Keep all sheets in the interview folder.)

If not interested, update the information below.

Would the respondent like a call back/is reluctant?   _____ no   _____ yes

(If yes: date of call back :_____)

Did the respondent agree to participate after callback? _____ no (fill out box below)
_____ yes (fill out Part 2)

If Reluctant to Participate

DO YOU HAVE ANY QUESTIONS I CAN ANSWER TO CLARIFY THE STUDY AND WHAT WE ARE ASKING YOU TO DO? I REALIZE I GAVE YOU A LOT OF INFORMATION AT ONCE.

If still hesitant:
WOULD YOU LIKE US TO CALL YOU BACK IN 2 OR 3 WEEKS AFTER YOU'VE THOUGHT ABOUT IT SOME MORE?

(If yes, say:)   THAT WOULD BE GREAT. THANK YOU FOR YOUR TIME, AND WE'LL CALL YOU BACK IN A COUPLE OF WEEKS. GOOD-BYE.

(If no, say:)   I AM SORRY YOU HAVE DECIDED NOT TO PARTICIPATE. THANK YOU FOR YOUR TIME. GOOD-BYE.

Answer if the Respondent Does Not Want to be Interviewed

Reason:_____

_____

(Part 2 - Interview information)

ID#:_____

Interviewer: _____

1. Type of Interview (circle one):   in office   in home

Dates/Times of calls and response for interview scheduling:
Date/Time:

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

_____   _____

Interview date & time: _____

****

CARING of CAREGIVERS
ORGANICALLY
(CoCO)
RESEARCH PROJECT

Leave box empty – For official use only

ARE YOU A LATINA THAT HELPS TO CARE FOR A FAMILY MEMBER/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA?

**IF YOU ANSWERED YES TO THE QUESTION,
YOUR HELP IS NEEDED!**

**PLEASE CONTACT:
JUDITH S. ROCHA, LCSW (Social Worker)
(773) 580-3302
jrocha2@uic.edu**

**COME BE A PART OF A SERIES OF 3 FOCUS GROUPS, EACH LASTING 2 HOURS, THAT WILL HELP DEVELOP A PROGRAM FOR KEEPING LATINAS HEALTHY AND WELL AS THEY CARE FOR A FAMILY MEMBER/LOVED ONE WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA. THE FOCUS GROUPS WILL BE AUDIO RECORDED.
YOU WILL RECEIVE $20 FOR EACH FOCUS GROUP ATTENDED.**

CuidandO Cuidadores
Organicamente
(CoCO)
Proyecto de Investigación

Leave box empty – For official use only

¿ES USTED UNA MUJER LATINA QUE AYUDA EN EL CUIDADO DE UN FAMILIAR/SER QUERIDO CON ALZHEIMER O DEMENCIA?

SI USTED CONTESTÓ SÍ A ESTA PREGUNTA ¡NECESITAMOS SU AYUDA!

FAVOR DE COMUNICARSE CON:
JUDITH S. ROCHA, LCSW (Trabajadora Social)
(773) 580-3302
jrocha2@uic.edu

VENGA Y FORME PARTE DE UNA SERIE DE 3 GRUPOS DE ENFOQUE, CADA UNO DURA 2 HORAS QUE AYUDARAN A DESARROLLARA UN PROGRAMA SOBRE LA SALUD Y EL BIENESTAR DE LATINAS QUE AYUDAN EN EL CUIDADO DE UN FAMILIAR/SER QUERIDO CON ALZHEIMER O DEMENCIA. LOS GRUPOS SERÁN AUDIO GRABADOS. USTED RECIBIRÁ $20 POR CADA GRUPO DE ENFOQUE QUE ASISTA.

ALIVIO MEDICAL CENTER
An Active Presence for a Strong Community

August 10, 2016

Dear UIC Institutional Review Board,

I met Judith S. Rocha last fall when she was attending a fundraiser hosted by the Latino Alzheimer's & Memory Disorders Alliance (LAMDA). Her mother was diagnosed with Alzheimer's disease ten years ago and Judith and her older sister currently provide the care that their mother needs in the home. She and her sister are participants of the LAMDA the support group hosted at Alivio Medical Center's Pilsen Satellite Senior Center located at 2021 S. Morgan St. in Chicago.

Alivio Medical Center is a community health center, serving the largely Latino population of Chicago's southwest side and the suburban communities of Cicero, Berwyn and Stickney for more than 27 years. The Senior Center is part of Alivio's commitment to the health and well-being of all the people in our community. The Senior Center serves more than 3000 older adults and their families in the Pilsen neighborhood and surrounding areas. The center continuously seeks to expand the support it provides to seniors and their families by engaging in local and regional projects that address the issues related to the issues these individuals and their families are experiencing. We provide culturally and linguistically appropriate resources, services and support to the Latino community and have tremendously expanded our efforts. We have many organizational partners and participants that receive our support that would serve well in Judith's efforts to explore Latina/o caregiver needs, recruit study participants, and disseminate significant findings to the community.

Judith has expressed to me her interest in furthering the research and resources relevant to Latina/o family caregivers of person with ADRD and I fully support her in this commitment. I find her willingness to create additional support that is evidence-based commendable and would welcome opportunities to collaborate with these efforts. I anticipate working on various projects with Judith and I am pleased to know that her personal experiences have motivated her to alleviate some of the caregiving issues that others will endure as well.

I fully support Judith's efforts and will provide a private class or conference room for hosting group meetings in connection with the Caring of Caregivers Organically (CoCO) Study. Please contact me via e-mail svega@aliviomedicalcenter.org or phone (312) 743-0493 as needed.

Respectfully yours,

Sue Vega
Get Covered Illinois and
Senior Programs Manager

Rush Alzheimer's Disease Center   Tel: 312.942.2028
Rush University Medical Center   www.rush.edu
600 S. Paulina St., Ste. 1022
Chicago, IL 60612

ⓒ RUSH

Rush Memory Clinic
600 S. Paulina St.,
Ste. 130
Chicago, IL 60612
Tel: 312.942.3333

RADC Laboratory
1735 W. Harrison St.,
Ste. 436
Chicago, IL 60612
Tel: 312.563.3574

August 12, 2016

Judith S. Rocha
University of Illinois at Chicago
Jane Addams College of Social Work
1040 W. Harrison St., (MC 309)
Chicago, IL 60607

Dear Ms. Rocha:

This letter is in support of your request to collaborate with the Rush Alzheimer's Disease Center for recruitment of participants for your study titled, "CuidandO Cuidadores Organicamente (COCO)." The research project will adapt and pilot a culturally responsive caregiver health education intervention for Latina Alzheimer's disease caregivers. The study seeks to develop a novel health behavior change intervention to promote adaptive aging for Latina family caregivers, age 50 and older, of persons with Alzheimer's disease or related dementia (ADRD), with a focus on positive health behaviors and well-being.

The Rush Alzheimer's Disease Center will collaborate with this project by contacting individuals who have consented to take part in our Rush Memory Clinic Data and Specimen Repository and who have agreed to be contacted about future research studies. Our staff will provide a basic overview of the study and inquire if they would like to learn more. If they agree to participate, we will obtain verbal consent to share their name and contact information with you and document such permission in our records. The Repository's recruitment support procedures and processes are approved by the Rush University Medical Center Institutional Review Board.

Sincerely,

Raj C. Shah, MD
Associate Professor, Family Medicine and
Rush Alzheimer's Disease Center

Rush is a not-for-profit health care, education and research enterprise comprising Rush University Medical Center, Rush University, Rush Oak Park Hospital and Rush Health.

APPENDIX G

IRB APPROVAL LETTER

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC-672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response to Modifications)

October 10, 2016

Judith Rocha, BSW, MSW
Jane Addams College of Social Work
1040 W. Harrison St
M/C 309
Chicago, IL 60607
Phone: (773) 580-3302

RE: Protocol # 2016-0831
"**Caring of Caregivers Organically (CoCO): Health Education for Latina Alzheimer's Family Caregivers**"

Dear Ms. Rocha:

Your Initial Review application (Response to Modifications) was reviewed and approved by the Expedited review process on October 5, 2016. You may now begin your research.

Please note the following information about your approved research protocol:

> Please note that only Phase I of this research has been reviewed and approved by the Board. Kindly remember to submit revised and new documents necessary for subsequent phases of this research via amendment prior to initiating those research activities.

> Please note that subject zip codes cannot be retained for future research or for service provision unless or until the consent document is revised or a consent addendum requesting the retention of such data is submitted and approved.

> Please remember to submit a copy of the completed transcription agreement with a non-UIC transcriptionist with your next continuing review application packet.

> Please note that stamped and approved .pdfs of all recruitment and consent documents will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain these emailed documents for your files for auditing purposes.

Protocol Approval Period: October 5, 2016 - October 5, 2017
Approved Subject Enrollment #: 14
Phone: 312-996-1711   http://www.uic.edu/depts/ovcr/oprs/   FAX: 312-413-2929

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<u>**Additional Determinations for Research Involving Minors:**</u> These determinations have not been made for this study since it has not been approved for enrollment of minors.

<u>**Performance Sites:**</u>	UIC, Rush Alzheimer's Disease Center, Pilsen Satellite Senior Center (Alivio Medical Center)
<u>**Sponsor:**</u>	UIC Roybal Center
<u>**PAF#:**</u> –	Not applicable
<u>**Grant/Contract No:**</u>	Not applicable
<u>**Grant/Contract Title:**</u>	Not applicable

<u>**Research Protocol:**</u>

    a) Caring of Caregivers Organically: Health Education for Latina Alzheimer's Family Caregivers; Version 2; 09/12/2016

<u>**Recruitment Materials:**</u>

    a) Caregiver Focus Group Flyer for CoCO Study (English); Version 2; 09/12/2016

    b) Caregiver Focus Group Flyer for CoCO Study (Spanish); Version 2; 09/12/2016

    c) Phase I Focus Group Phone Screening for CoCO Study (English); Version 2; 09/12/2016

    d) Stakeholders Focus Group Flyer for CoCO Study (Spanish); Version 2; 09/12/2016

    e) Phase I Member Check Follow-up for CoCO Study (English); Version 2; 09/12/2016

    f) Stakeholders Focus Group Flyer for CoCO Study (English); Version 2; 09/12/2016

<u>**Informed Consents:**</u>

    a) Caregiver Focus Group Consent for CoCO Study (English); Version 2; 09/12/2016

    b) Stakeholder Focus Group Consent for CoCO Study (English); Version 2; 09/12/2016

    c) A waiver of documentation of consent (verbal consent/no written signature obtained) and an alteration of consent has been granted for eligibility screening only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; data for potential subjects who decline or are ineligible will be destroyed immediately)

    d) A waiver of consent has been granted for the release of potential subject contact information from the Rush University data repository, under repository guidelines, under 45 CFR 46.116(d)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

<u>**Please note the Review History of this submission:**</u>

Receipt Date	Submission Type	Review Process	Review Date	Review Action
08/17/2016	Initial Review	Expedited	09/07/2016	Modifications Required
09/13/2016	Response To Modifications	Expedited	10/05/2016	Approved

Please remember to:

☐ Use your <u>**research protocol number**</u> (2016-0831) on any documents or correspondence with the IRB concerning your research protocol.

☐ Review and comply with all requirements on the OPRS website under:

    <u>**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**</u>

APPENDIX G (continued)

(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014.

> Sincerely,
> Sandra Costello
> Assistant Director, IRB # 2
> Office for the Protection of Research Subjects

Please note that stamped and approved .pdfs of all recruitment and consent documents listed below will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain these emailed documents for your files for auditing purposes.

Enclosures:
1. **Informed Consent Documents:**
   a) Stakeholder Focus Group Consent for CoCO Study (English); Version 2; 09/12/2016
   b) Caregiver Focus Group Consent for CoCO Study (English); Version 2; 09/12/2016
2. **Recruiting Materials:**
   a) Caregiver Focus Group Flyer for CoCO Study (English); Version 2; 09/12/2016
   b) Caregiver Focus Group Flyer for CoCO Study (Spanish); Version 2; 09/12/2016
   c) Phase I Focus Group Phone Screening for CoCO Study (English); Version 2; 09/12/2016
   d) Stakeholders Focus Group Flyer for CoCO Study (Spanish); Version 2; 09/12/2016
   e) Phase I Member Check Follow-up for CoCO Study (English); Version 2; 09/12/2016
   f) Stakeholders Focus Group Flyer for CoCO Study (English); Version 2; 09/12/2016

cc: Creasie Hairston, Jane Addams College of Social Work, M/C 309
        Chang-Ming Hsieh (faculty advisor), Jane Addams College of Social Work, M/C 309
        OVCR Administration, M/C 672

Education

Ph.D.	University of Illinois, Chicago Jane Addams College of Social Work, 2019
MSW	University of Illinois, Chicago Jane Addams College of Social Work, 2005
BSW	University of Illinois, Chicago Jane Addams College of Social Work, 2001

Research Interests / Research Profile

• Health of Latinx/a/o family caregivers of persons with Alzheimer's disease or related dementia;
• Quality of life of Latinxs/as/os dealing with Alzheimer's disease or related dementia and their families;
• Cultural responsiveness of services, practice, policies and research affecting Latinxs/as/os; and
• Latinx community investment, enhancement and preservation of protective cultural factors.

Research Experience

Project Coordinator/Research Assistant, Department of Disability and Human Behavior – College of Applied Health Sciences, University of Illinois, Chicago, Illinois
Summer 2016 – May 2018

> • *By Caring for Myself, I Care for Them Better – project coordinator of pilot study exploring the use of technology (e.g., accelerometer and text messages), 24-hr food intake recall, and self-report measures to test the feasibility and acceptance of a health education intervention with Latina mothers age 35 and older, of children and adults with intellectual and developmental disabilities*

Research Assistant, Department of Kinesiology and Nutrition – College of Applied Health Sciences, University of Illinois, Chicago, Illinois
Fall 2014 – Summer 2015

> • *The Influence of Multicomponent Factors in the Experience of the Latino Caregiver – co-investigator of qualitative study exploring factors that influence care provided by Latina/o family caregivers of persons with Alzheimer's disease or related dementia and the effect of caregiving and cultural factors on perceived health and health behaviors*

Research Assistant, Center for Social Policy and Research, Jane Addams College of Social Work, University of Illinois, Chicago, Illinois
Fall 2013

> • *Illinois Commission to End Disparities Facing the African American Community – Health and Healthcare Disparities report provided to the Commission*

Research Assistant, Chicago Historical Society, Chicago, IL
Fall 1998 – Spring 1999
> • *Neighborhoods Research project – town hall meeting data gathered and analyzed for report compilation*

Teaching Experience/Conference Presentations

Presenter: The Arc National Convention, San Diego, California, November 2017
> • *By Caring for Myself: A Promotora Intervention for Latino Families of Children with Intellectual and Developmental Disabilities. In R. Shaffert (Chair), Family support spotlight: Supporting caregivers, expressive art and parents with disabilities.*

Instructor: Aging Populations Course (SOCW 521), University of Illinois, Chicago, Illinois, Fall 2017 Guest Lecturer
> • *Latina/o Older Adults in the U.S.*

Instructor: The Mexican Experience in Chicago: Structural Social Work and a Transnational Examination of Social Justice Course (SOCW 527), University of Illinois, Chicago, Illinois, Spring 2017
> • *Developed a graduate level course with two colleagues in Summer 2015*

Presenter: Latin American Studies Association Conference, Pontificia Universidad Católica del Perú, Lima, Peru, April 2017
> • *Caring of Caregivers Organically (CoCO): Health Education for Latina Family Caregivers of Persons with Alzheimer's Disease or Dementia – Phase I Findings*

Instructor: Critical Social Work in a Multicultural Society Course (SOCW 411), University of Illinois, Chicago, Illinois, Spring 2016 Guest Lecturer
> • *Latinidad: Deconstructing Identity While Building Community*

Presenter: Society of Social Work and Research Conference, Renaissance Hotel, Washington, DC January 2016
> • *Predictors of Depression in Latina Mothers of Youth and Adults with Intellectual and Developmental Disabilities: An Overview of Baseline Data for a Health Promotion Intervention*

Instructor: Disability in Latino Communities Course (DHD 403), University of Illinois, Chicago, Illinois, Fall 2015 & Fall 2016 Guest Lecturer
> • *Latina/o Older Adults in the U.S.*

Presenter: Latino Social Work Organization Conference, University of Illinois, Chicago, Illinois, October 2016
> • *Caring of Caregivers Organically (CoCO): Health Education for Latina Family Caregivers of Persons with Alzheimer's Disease or Dementia*

Presenter: Latino Social Work Organization Conference, University of Illinois, Chicago, Illinois, October 2014
> • *Practice with Latinos: What's in a Framework – co-presenter*

Instructor: Social Security Claims Authorizer Training Course, Chicago, Illinois, Fall 2012 – Spring 2013
> • *Trained through course packet, case examples and case processing, newly promoted Claims Authorizers on factors of beneficiary entitlement, claim/appeal adjudication, and record maintenance.*

Presenter: Latino Social Work Organization Conference, University of Illinois, Chicago, Illinois, Spring 2011
> • *US/Mexico Border Immigration: Increasing understanding and awareness as we attempt to walk in their shoes: A theological perspective panel discussion*

Community Involvement / Administrative Activity

• Latinas/os con Alzheimer Buscando Refugio y Optimismo Cuando Hacen Arte – *LA BROCHA – The Paintbrush* Collective co-founder, 2016 – present;
• University of Illinois Jane Addams Student Government Ph.D. Liaison, 2016 – 2017;
• Society for Social Work and Research Member, 2015 – present;
• University of Illinois Graduate Student Council Member, 2015 – 2017;
• University of Illinois Latina/o Graduate Student Association Member, 2015 – present, President 2017 – Spring 2018;
• University of Illinois Chancellor's Committee on the Status of Latinos Member, 2015, Executive Committee 2017 – present;
• Council on Social Work Education Member, 2015 – present;
• American Society on Aging Member, 2014 – present;
• Gerontological Society of America Member, 2014 – present;
• Association for Gerontology Education in Social Work Member, 2014 – present;
• Latina/o Alzheimer's Coalition for Advocacy, Research & Education, 2013 – present;
• Jane Addams College of Social Work Alumni Association Board Member, 2011 – 2017, Board President 01/2017 – 11/2017, Board Secretary 2011 – 2013;
• Latino Social Work Organization Member, 2005 – present, Conference Committee 2005 and 2014;
• National Association of Social Workers, Illinois Chapter Member, 2005 – present;
• University of Illinois Alumni Association Member, 2005 – present; and
• Toylend Lekotek Program of United Cerebral Palsy Advisory Board Member, 2005 – 2008, Board Secretary 2005 – 2008.

Awards / Fellowships / Honors

• 2014 Association for Gerontology Education in Social Work (AGE SW) Gerontological Social Work Pre-Dissertation Initiative Award
• 2015-2016 University of Illinois at Chicago Martin Luther King Jr. Service Scholarship
• 2015-2016 University of Illinois at Chicago Graduate Student Council Certificate of Appreciation for Performance and Lasting Contribution

• 2015-2016 & 2017-2018 University of Illinois at Chicago Chancellor's Student Service & Leadership Award
• 2016 University of Illinois at Chicago Midwest Roybal Center for Health Promotion and Translation Doctoral Pilot Dissertation Award

Academic Publications

- Magaña, S. M., & **Rocha, J. S.** (2016, March 1). Aging in a Latino World [Review of the book *Latinos in an Aging World: Social, Psychological and Economic Perspectives*, by R. J. Angel & J. L. Angel]. *The Gerontologist, 56*(2), 372-374. doi:10.1093/geront/gnw041

- O'Grady, C., & **Rocha, J. S.** (2016). Social work practice with Latinos: A review of the literature. *TS Cuadernos de Trabajo Social No 15*. Retrieved from http://www.tscuadernosdetrabajosocial.cl/index.php/TS/article/view/95