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EXPLORING DISABILITY OUTCOMES AMONG AGING LATINOS IN THE  
UNITED STATES: A MIXED METHODS APPROACH

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## Introduction

Disability and bodily decline frequently accompany the aging process, and have significant implications for biological, psychological, and social well-being in old age. Disability has been defined as difficulty performing activities across any domain of life in a way that affects expected social roles (Altman, 2001; Crimmins, 2004). For older adults, this is often operationalized as difficulty with completing tasks of self-care. Also referred to as Activities of Daily Living (ADLs), these tasks include bathing, eating, getting dressed, transferring, and using the toilet. ADL disabilities (also called ADL limitations, or disabilities of self-care) are largely considered significant disabilities because of their impact on basic tasks of everyday life. Activities of daily living are generally physically demanding tasks, and are therefore also more indicative of physical decline.

Current estimates suggest that around 23% of the population over the age of 65 experience difficulty with activities of self-care, though these estimates vary dramatically by age, gender, and race/ethnicity (Melvin et al., 2014). The risk of ADL disability is higher for women, for racial/ethnic minorities, and for those at more advanced ages (Hayward et al., 2014). ADL disability is associated with an increased risk for recurrent hospitalization, greater use of outpatient care, and institutionalization (Guralnik, Fried, & Salive, 1996). Those who report any level of ADL disability have nearly doubled risk of 5-year mortality when compared to those without any level of disability (Manton, 1988). However, the extent to which ADL disability impacts older adults of different sociocultural groups remains underexplored, which will be a growing healthcare challenge given current demographic shifts in the United States. According to a CDC report, the population of Americans over the age of 65 will double during the next 25 years to about 72 million; this will account for roughly 20% of the U.S. population (Centers for

Disease Control, 2018). At the same time that the United States is growing older, it is also growing more diverse in terms of race and ethnicity. Although younger generations currently reflect more of this diversity than the older adult population, the youth of racial and ethnic minorities implies inevitable growth. In 2010, older Hispanics were 7% of the population over age 65, but by 2050 this percentage will nearly triple to 20% (ibid).

As we consider the future of aging and healthcare in America, it will be increasingly important to consider racial and ethnic differences, as all of these groups have divergent health trajectories in late life. Older African-Americans are disproportionately burdened by nearly every major age-associated disease, such as diabetes (Centers for Disease Control, 2013), frailty and disability (Fried et al., 2001), breast and lung cancer (Siegel, Naishadham, & Jemal, 2013), and dementia (Miles et al., 2001). The higher rates of chronic disease and disability for minority groups also reflect earlier onset of disease, greater severity, and worse survival rates (Williams & Sternthal, 2010). Early sociologist Du Bois (1899) first proposed that racial and ethnic differences in health are based in social and environmental inequality, and more recent work has reaffirmed that one of the most important determinants of health in late life is socioeconomic status (Hayward et al., 2000; Hummer, 1996). Though poverty and low educational attainment are predictors of poor health outcomes regardless of race and ethnicity, minority groups often face added burdens of discrimination. This discrimination can include structural segregation and racism, which contribute to vast differences in educational attainment, family income, and wealth (Hummer, 1996). Even after controlling for socioeconomic status, there are still racial differences in health at every level of education, suggesting that the added burdens of discrimination and social exclusion have significant health impacts (Williams & Collins, 2001).

However, the theorized connection between socioeconomic status and health outcomes has been troubled by observed patterns of health and mortality among Latinos. Despite similar socioeconomic status, Latinos have significantly longer life expectancies than African-Americans, and foreign-born Latinos have longer life expectancies than US-born whites (Abraido-Lanza, Chao, & Flórez, 2005). This phenomenon has been referred to as the Latino Mortality Paradox, termed such because it reflects the unexpected nature of Latinos' extended longevity despite an increase of mortality risk factors. Adding to the paradoxical is that Latinos have complex health profiles in late life that are often similar to those of African Americans, including higher burdens of disability (Markides et al., 2007). Even though Latinos are disproportionately burdened with disease and poor functioning in late life, their life expectancy as a group continues to be longer than expected. This has presented a real puzzle to scholars studying health and mortality trends. What might contribute to one group's extended longevity in the face of increased disease burden and decreased access to healthcare? Is this extension in life expectancy due to delayed onset of disease, or to increased resilience to mortality? As Latinos comprise the single largest growing group of older adults in the United States, understanding the experience of disability for Latinos will be increasingly relevant towards understanding the intersections of ethnicity, aging, and health.

### ***The Aging Body as a Sociocultural Experience***

While demography and epidemiology focus on questions of population-level health and mortality patterns, cultural gerontology and geroanthropology have traditionally attended to the ways in which understandings of the body and of the life course shape experiences and understandings of aging. The particular values and sociopolitical priorities of a community can

play a significant role in the meaning-making that accompanies late-life experiences. For example, in the now classic work *Number our Days*, anthropologist Barbara Myerhoff (1980) details the importance of ritual, tradition, narrative, and continuity for a community of Jewish elderly in Venice, California, many of whom were Holocaust survivors. Similarly, anthropologist Sharon Kaufman (1994) interviewed elderly Californians about their experiences of aging, and concluded that many older adults use motifs and themes from their past to articulate a continuity of the self. In the face of bodily changes and health declines, her participants consistently articulated that their essential self remained unchanged.

However, anthropologist Sarah Lamb (2014) suggests that it is precisely because of this "permanent personhood" that the process of aging can become stressful for older adults in the United States when the ability to exhibit individual agency and control, maintain productive activity, and live independently are challenged. As many older adults who report difficulty with activities of self-care also report a need for assistance, experiencing disability may challenge cultural values in the United States that prioritize independence and productivity at all stages of the life course. The "individualist personhood" that Lamb notes in the North American "successful aging" paradigm is echoed in Debbie Labilerte Rudman's work, who writes that these discourses of "successful" or "positive" aging push individuals "to govern the aging body in ways consistent with being a 'good' neoliberal citizen" (2015:100). Studies conducted in Western contexts consistently find that aging individuals actively work to resist or deny aging in the body, often in response to neoliberal priorities of individualism and responsibility (Calasanti, 2005; Lamb, 2014). Given strong preferences for independence and personal responsibility in the United States, experiencing bodily decline to the point of struggling with basic daily tasks of self-care could induce strain to an individual's identity and sense of self-worth, particularly if, as

Kaufman argues, those same individuals hope to maintain a continuity of the self. Indeed, a growing body of research has documented the relationship between ADL disability and depression in late life (Lin & Wu, 2011; Ormel et al., 2002). This tension may lead to a spiraling relationship between disabilities of self-care, poor mental health, and reduced social contact and support.

These findings about older adults in the United States are in contrast to findings of aging and the body in some non-Western contexts. In India, the centrality of the multigenerational family and focus on family caregiving gives rise to what Lamb (2013) terms “appropriate dependence”; experiencing decline in old age is expected and not a major stressor unless bodily needs are not cared for in the desired ways. Jordan Lewis (2011) writes that Alaska Natives have a much more holistic approach to aging that prioritizes the importance of community engagement, spirituality, and emotional well-being in the transition to elderhood. Sandra Torres (2006) writes that among aging Iranian immigrants in Sweden, some view aging as a health problem that should be combated, while others take a more harmonious approach that accepts bodily changes without fighting against them. In a multinational survey that asked elderly respondents to rank items that were important to aging well, Europeans prioritized remaining in good health until death, being able to take care of oneself, and feeling good about oneself as the most important, whereas Japanese respondents focused on good health outcomes and support systems. Latin Americans prioritized having friends and family present, being able to act according to one’s values, and being able to meet all of one’s needs (Fernández-Ballesteros et al., 2010). In a study that applied the same methodology to Latinos and non-Latino whites on the west coast of the United States, Latinos had very similar responses to those of Latin Americans, whereas non-Latino whites were more similar to western Europeans (Hilton et al., 2012). This

particular finding suggests that Latinos consider “aging well” similarly to their counterparts in their sending countries, and not in their receiving country.

In sum, these research findings all suggest that people have a general desire to maintain good health in old age. What remains unclear, however, is the extent to which members of these different groups conceptualize “good health” differently. Additionally, a major contrast lies in the emphasis to which different cultures place on communal support. As prior ethnographic research has repeatedly suggested that Latinos place a great deal of emphasis on interdependence and family support, how might ideas about “good health” in old age and expectations for social support interact to produce different disability outcomes?

### ***Narratives of Health, Aging, and the Body among Latinos***

Exploring impacts of disability among aging Latinos is critical not only because that subpopulation is growing in number, but also because previous research has highlighted the various ways in which experiences of health, illness, and aging vary cross-culturally. Latinos in the United States—particularly elderly Latinos—have divergent health outcomes and experiences from other racial and ethnic groups. Prior research has documented how certain common cultural values and practices among Latinos might be related to these differential health outcomes. These concepts include *familismo* (familism), *dignidad* (dignity), *respeto* and *simpatia* (respect and congeniality), *curanderismo* (folk healing), and religiosity (Padilla & Villalobos, 2007). Additionally, allocentrism and interdependence may be important mediators of responses to illness among Latinos (Zea, Quezada, & Belgrave, 1994). For example, many studies of aging and caregiving in the Latino community have documented the importance of familism and the accompanying expectation of family support in old age. Qualitative research has shown that

older Latina women view the decline of health in old age as natural and anticipated (McCarthy et al., 2004). They embody a more collectivist perspective in that health and illness are connected to an interdependence with family; elderly expect care from family as they become frailer. This is in contrast to a Western, neoliberal perspective in which loss of health is often perceived as loss of one's independence and becoming a burden on family. These qualitative findings are mirrored in quantitative social survey analysis; Latinos over the age of 65 are less than half as likely to live alone as non-Latino whites, and they are more likely to report more kin-centered social networks (Cornwell & Waite, 2009) and residence in multigenerational households (Cohen & Casper, 2002). Many scholars have argued that caregiving for older family members is often an expected outcome in Latino families, but this research has tended to focus on the burden this places on the caregiver, with significantly less attention paid to the stress this may cause the individual receiving care. Additionally, little empirical research exists to explore whether or not Latinos respond to the receipt of care in old age differently from their non-Latino peers, even if it does appear to be a more expected outcome.

While Latinos may very well have a different set of expectations about old age than non-Latino whites, it is also quite possible that these expectations vary by gender. Machismo and marianismo are well documented cultural norms that define gender expectations for many of Latino origin. Machismo identifies men as strong and protective and encourages them to be dominant in relationships and to demonstrate sexual virility (Cianelli, Ferrer, & McElmurry, 2008; Wentzell, 2013b). In her study of aging Mexican men, anthropologist Emily Wentzell examines how local understandings of masculinity change over time to accommodate changes in sexual ability. She writes that, “illness experiences and gendered selfhood are mutually

constituted”, requiring us to consider the role of gender in shaping experiences of and responses to an aging body (2013b:108).

Meanwhile, mariанизmo encourages women to be more passive and submissive in their roles as romantic partners and caretakers of the family (Cianelli et al., 2008). Marianismo is a particularly powerful force among those who are Catholic, as femininity and its performance is intimately linked with the sacrifice and suffering akin to that of the Virgin Mary. This may lead elderly Latinas who are caregivers to see their caregiving responsibilities as a sacrifice to be embraced as a sign of femininity (Arevalo-Flechas, 2008). Because of strong gender norms, the vast majority of caregivers for elderly individuals are women; typically, wives care for their husbands if they are able to, or a female child or other relative will provide caregiving (*ibid.*).

While caregiving is a female-dominated domain in many societies, the tropes of religiosity and suffering among Latina women may uniquely shape the meanings that are ascribed to their particular caregiving (and care-receiving) experiences. Additionally, the cultural forces at work in shaping gendered identity not only influence gendered expectations of caregiving (and responses to caregiving burdens), but they also shape responses to aging bodies. Whereas Wentzell (2013b) writes that Mexican men often have to adjust their ideas about masculinity in old age, their aging female partners do not seem to experience such a disruption of gender and identity as they move through the life course and its accompanying changes in social roles. In sum, ideals of femininity and masculinity among traditional Latin cultures lead to divergent experiences of health, aging, and caregiving. However, few scholars have considered the ways in which these gender norms may also be reflected in gendered experiences of disability. Do Latino men and women respond differently to bodily decline in old age? Do they

employ different coping mechanisms upon experiencing physical decline, and what are the impacts on mental health and general well-being?

### ***Locating the Cultural in Ecological Models of Aging and Disability***

Psychologist M. Powell Lawton was one of the first to propose a model of aging and environment in what would come to be defined as the "general ecological model of aging" (Lawton, 1986). The primary argument is that human behavior and function result from the interaction between the competencies of the individual and the demands, or "press", of their environment. The relationship between individual competency and the environment is seen as a dynamic one, as both change throughout the life course and as part of the process of aging<sup>1</sup>. This model made an important first step towards considering the human-environment interaction as a critical component of aging, though the "environment" of this model is narrowly defined, and the macro and meso level factors contributing to individual competencies and environments are not considered.

A later model would expand how individual competencies come to be molded and shaped by environmental context. In 1994, Verbrugge and Jette published a sociomedical model of disability that would come to be at the theoretical foreground of the sociological imagination for the disability process in old age. Their model posits that pathology leads to impairments of the body, which lead to functional limitations, which lead to disability<sup>2</sup>. In their case, disability was characterized by difficulty in the performance of daily tasks including personal care, household management, and the maintenance of a healthy social life and its accompanying social roles. The model includes space for risk factors, such as predisposing demographic or behavioral

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<sup>1</sup> This relationship is summarized in the "Press-Competence Model", which is available in Appendix 1.

<sup>2</sup> Please see Appendix 2 for an extended view of the Verbrugge-Jette model.

characteristics, as well as an expanded view of internal and external environments. Their model of the disablement process was particularly important because it combined both functioning of the physical body with the personal and environmental factors that impact how physical decline is experienced in context. However, the Verbrugge-Jette model assumes that all ADL disability is a downstream result of biological pathology, leaving no room for individual experiences of the body and bodily change. Additionally, it separates extra-individual factors from intra-individual factors, suggesting that the two have no interaction. In reality, person-environment interactions are much more interdependent, as each builds upon and contributes to the other. Additionally, the cultural context cannot simply be placed into the realm of the extra-individual, as it plays an integral role in shaping internal scripts about wellness, coping mechanisms, and responses.

Traditionally, health studies literature has conceptualized culture as a single variable that can be captured in proxies such as race, ethnicity, language, or nationality. The unspoken assumption underneath such choices is that culture is either a risk factor or a protective factor for a particular outcome. In effect, this creates a simple cause-and-effect mechanism, which assumes that manipulating the cause (culture) results in distinct, clearly-defined outcomes. It neglects the influence that culture can have on perceptions of health, illness, and aging, such that the pathways are not so easily drawn. In other words, in health studies with categorical outcomes (ex: disabled or nondisabled, no cognitive impairment vs. mild cognitive impairment vs. dementia), it is implicitly assumed that the qualitative meaning of each outcome is equivalent across groups, and that merely changing the cultural background of an individual changes their relative risk factor of each outcome. This project considers how not only the cultural background of an individual is associated with health outcomes, but how those health outcomes are assigned separate meanings according to the cultural environment of the individual.

This dissertation therefore expands on the Lawton and Verbrugge-Jette models. I focus on the ways in which culture influences the perception of individual competence and structures the extra-individual and intra-individual environments. Instead of considering ADL disability as a static category with a uniform experience across ethnic groups, I instead use ADL disability as a proxy for experiences of bodily change and decline. ADL disability is measured by asking respondents whether or not they have difficulty with five separate activities of self-care: eating, bathing, dressing, getting in and out of bed, and toileting. Any reported degree of difficulty will be considered a sign of physical decline. In this dissertation, I explore the ways in which the sociocultural context of that decline can be a significant predictor of long-term health outcomes, care strategies and mental health consequences, and expectations for old age and “aging well”. As a substantial body of evidence suggests that the social environment may play a critical role in overall health and mortality outcomes in old age (Cornwell et al., 2008), I examine how aspects of the sociocultural environment vary by ethnicity and gender, and how these variations may impact ultimate health outcomes. This dissertation therefore has two principle goals: to describe the sociocultural environment of aging and disability among Latinos, and to characterize the relationship between that environment and the physical and psychological outcomes of disability and bodily decline among aging Latinos.

### ***Outline of the Dissertation***

The objective of this dissertation is to explore the ways in which the sociocultural context of Latinos with ADL disability may be different from their non-Latino peers, and how those differences may lead to divergent mental and physical health outcomes among older individuals who report disabilities of self-care. This dissertation also seeks to bridge the gap between

qualitative and quantitative literatures exploring disability and aging. In this project, the findings from prior qualitative research drive the hypothesis generation for the first two chapters, which are quantitative studies. Then, the third chapter details findings from a qualitative study designed to provide additional context and meaning to the findings from the prior two quantitative chapters. In total, I utilize data from two nationally representative, longitudinal social surveys and from 9 focus groups and 20 interviews conducted in Chicago. The use of mixed methods and supporting literature from a variety of disciplines will allow this project to not only map quantitative differences between groups, but also to attempt to find the meaning of those differences with qualitative data. All of these questions aim to elucidate the experience and meaning of disability and physical decline among Latinos, and how those experiences are shaped by the sociocultural environment.

The first chapter of this dissertation explores patterns of disability and mortality among Latinos, as well as the role of social environment in shaping those trajectories. It has been previously demonstrated that Latinos exhibit significantly longer life expectancies than their non-Latino counterparts, even in the face of increased risk factors, including higher prevalence rates of ADL disability (Hayward et al., 2014). Prior research has also established that high levels of social support may protect against adverse health outcomes among older adults, leading many scholars to hypothesize that the Latino survival advantage (also termed the Latino Mortality Paradox) may be due to more tightly connected, interdependent social networks. However, few have empirically tested whether Latinos do actually report more family-oriented, supportive social networks, nor whether those social networks confer protective benefit to older Latinos with disability. This study will therefore answer two key questions that remain at play in the literature on the Latino Mortality Paradox. Do elderly Latinos with ADL disability

empirically report significant differences in their social context from that of their non-Latino peers, and does ethnicity moderate the relationships between those measures of social context and risk for mortality?

The second chapter examines the relationship between personal care receipt, depressive symptoms, and ethnicity among the ADL-disabled. Older adults with ADL disability are significantly more likely to report increases in anxiety and depressive symptoms, and those who report receiving personal help in their daily tasks are at even higher risk for depressive symptoms. This study therefore explores whether these trends are different for the Latino subpopulation, as qualitative research in Latino communities has documented a higher emphasis on collectivism and interdependence among Latinos. Given this orientation towards interdependence, it is possible that care receipt is less stressful than for individuals from cultural contexts emphasizing independence at all stages of the life course. As such, this study examines whether disabled Latinos demonstrate similar relationships as non-Latinos between depression and the use of personal help. After exploring differences in that relationship by race/ethnicity, I then dive deeper into the disabled Latino subpopulation to explore how gender and marital status may shape the relationship between care receipt and depressive symptoms. This study will therefore contribute to the literature by examining how ethnicity, gender, and marital status can interact to produce distinct mental health responses to the use of personal care upon the onset of ADL disability. How does the use of personal help impact depressive symptoms among Latinos with ADL disability, and are these patterns different from their non-Latino peers? Do these patterns differ by gender and marital status?

The third study uses qualitative data collected from focus groups and interviews with older Latinos in the Chicagoland area. Prior research has documented that expectations of

caregiving, the body, and the family play a significant role in what Latinos consider to be "aging well" (McCarthy et al., 2004; Padilla & Villalobos, 2007). Given that the prior two studies of the dissertation examine the role of social networks and of personal care receipt in both mortality and mental health outcomes among Latinos with age-associated disability, these focus groups and interviews explore how these older adults envision their bodies in old age, and what expectations they have for handling physical decline. Prior literature has explored how Latinos conceptualize "aging well" or "successful aging" from a broad perspective, but little attention has been paid to the particularities of bodily decline and future care needs. In this case, this project contributes to the literature by exploring not only how physical decline is conceptualized in the context of aging, but also how individuals articulate ideal outcomes and scenarios when faced with physical challenges. How do older Latinos make sense of physical decline and its place in the life course, and how do they envision coping with such changes? What scenarios are seen as ideal and supportive, and which scenarios violate expectations of aging well? This study is designed to contextualize the findings from the first two chapters, and to explore any meaning-making processes among Latino older adults.

## **Chapter One. The social context of disablement and mortality outcomes: The role of ethnicity**

### ***Abstract***

Prior studies have established that older adult Latinos are more likely than non-Latinos to experience ADL disability, though they have reduced odds of mortality among the disabled subpopulation, even when adjusting for sociodemographic characteristics. This chapter explores whether variations in the social context by ethnicity are associated with the observed mortality differentials. Part A examines whether disabled Latinos and non-Latinos report significant differences in social well-being by comparing multiple measures of social context across three different racial/ethnic groups. In Part B, a moderation analysis is employed to examine to what extent the relationship between those measures of social context and 5-year mortality outcomes varies by ethnicity. The results show that Latinos report living in larger households and having denser social networks than their non-Latino counterparts. However, loneliness, perceived amounts of social strain, living alone, and social network size and composition were all found to have varying associations with mortality based on race/ethnicity. Race and ethnicity therefore play an important role not only in the objective structure of the social world, but also in how that social world is experienced and its association to health outcomes. Future research exploring the connection between health and social context among older adults should consider the ways in which race and ethnicity modify the connections between social context and health.

## ***Introduction***

Demographic research consistently documents a Latino advantage in adult mortality in the United States, wherein Latinos display mortality rates that are comparable to or lower than the non-Latino white population (Markides & Eschbach, 2011). However, the Latino mortality advantage does not also imply an advantage in health conditions. Prior research on minority health and aging has suggested that aging Latinos are more likely to report disabilities in completing activities of daily living (or ADL disability), yet still experience a significant survival advantage when compared to their similarly-disabled, non-Latino counterparts (Hayward et al., 2014; Mendes de Leon et al., 2005). Though controlling for sociodemographic and health-related characteristics may account for their increased odds of disability, their survival advantage within the disabled subpopulation persists even after controlling for those same factors. As social context can play a significant role in the trajectory of ADL disability, this study seeks to contribute to the literature on social context and health in old age by exploring the relationships between ethnicity, social context, and mortality among the disabled.

## ***Background***

### *ADL Disability among Latinos*

ADL disability is often measured by using a survey-based questionnaire to capture limitations in providing the self-care necessary for survival. Older adults are generally considered to be experiencing ADL disability if they have any difficulty bathing, eating, dressing, transferring in and out of bed, or toileting independently. ADL disability is of particular research interest because of its strong associations with increased health costs, elevated risks for other health conditions, and high risk of mortality (Altman, 2001; R. J. Angel, Angel, & Hill,

2015). For example, reporting difficulty completing between 1 and 3 of the above tasks is associated with a 40% increased risk for mortality in the next year (Stineman et al., 2012).

However, both prevalence rates and outcomes of ADL disability have been found to vary by race/ethnicity. Mendes de Leon and colleagues (2005) first documented a significant difference in rates of disability among members of different racial groups. Since then, similar disparities have been found between ethnic groups as well, wherein Latinos—both the native and foreign-born—have significantly higher rates of ADL disability than their non-Latino counterparts. However, Latinos also demonstrate a significant survival advantage among the disabled, leading to an extended period of disabled life expectancy (Hayward et al., 2014). Predisposing socioeconomic and health-related factors like age, gender, BMI, and educational attainment have been found to account for the elevated risk for ADL disability among Latinos relative to whites (Tennstedt & Chang, 1998; Zsembik, Peek, & Peek, 2000).

Though these predisposing factors may account for the increased risk of developing ADL disability among Latinos, there is heterogeneity within the Latino subpopulation. Though both native and foreign-born Latinos live significantly more years of disabled life when compared to non-Latino whites, the foreign-born have higher rates of ADL disability and also a longer life expectancy than the native-born (Crimmins, 2004). This is consistent with findings that foreign-born Latinos have lower all-cause mortality than their native-born counterparts (Markides & Eschbach, 2011). However, the age of arrival in the United States may be a more important predictor for health outcomes than nativity status (Fox, Thayer, & Wadhwa, 2017; Thomson & Hoffman-Goetz, 2009). Foreign-born Latinos who arrive in the United States during childhood have no mortality advantage over the native-born (Holmes, Driscoll, & Heron, 2015). This trend persists even though they are more likely to be English-dominant than Spanish-dominant, and

therefore have better access to healthcare (Abraido-Lanza et al., 2005). This suggests that foreign-born Latinos who arrived at young ages are more likely to be English-dominant than Spanish-dominant, and exhibit similar mortality profiles as the native-born (DuBard & Gizlice, 2008). Foreign-born Latinos who are Spanish-dominant are more likely to have arrived at later ages, and exhibit a significant mortality advantage when compared to the native-born despite their elevated risk for ADL disability.

In sum, both native-born and foreign-born Latinos exhibit elevated risk for ADL disability with a decreased risk for mortality, despite the strong connection between disability and mortality in the general population. This pattern is even more extreme for the foreign-born, particularly those who arrived in the United States after their childhood. However, though controlling for socioeconomic and health-related factors may account for the increased prevalence of ADL disability among Latinos, those same factors do not account for their survival advantage among the disabled subpopulation. This study looks to explore this pattern by considering the relationship between the social context of disablement and relative odds of mortality.

### *The Social Context of Disablement*

As older Latinos experience increased risk for ADL disability without an associated increased risk for mortality even after controlling for sociodemographic characteristics, this study explores the relationship between the social context in which ADL disability occurs and the risk for mortality among the disabled. The stress-buffering hypothesis suggests that access to supportive relationships can ameliorate the effects of illness and disability on both psychological and functional health, and that the absence of positive relationships can further exacerbate illness

or functional decline (S. Cohen, 2004; Warner & Kelley-Moore, 2012). In support of that hypothesis, research has found that being embedded in a large, dense network of diverse social relations is associated with a reduced risk of developing disability and better outcomes after its onset (Avlund et al., 2004; James et al., 2011). Marriage ties have been frequently associated with positive health behaviors among older adults (Seeman, 2000), though poor marital quality can significantly accelerate declines in functional health among older adults (Bookwala, 2005; Umberson et al., 2006). Living alone is also associated with increased risk for developing an ADL disability, though this may be mediated by feelings of loneliness (Perissinotto, Cenzer, & Covinsky, 2012).

Meanwhile, findings about functional aspects of the social world often highlight the double-edged sword of social life, as social ties present opportunity for both positive and negative impact on the quality of life. Older adults in particular may be more susceptible to the negative aspects associated with strained social relationships (Bookwala, 2005). Though social ties provide opportunities for emotional and instrumental support, they can also be a source of stress with a negative impact on health outcomes (Bulanda & Brown, 2007). Additionally, a large body of research has highlighted the negative impact that perceived isolation or feelings of loneliness can have on health outcomes, regardless of the structure of the social network (Chen & Feeley, 2014; Cornwell & Waite, 2009; Gerst-Emerson & Jayawardhana, 2015). Experiencing loneliness may be particularly predictive of rapid decline after the onset of ADL disability (Perissinotto et al., 2012). In contrast, having strong psychosocial support after the onset of a disability may be protective against further adverse outcomes by either slowing down decline in function or enabling recovery from a disabled state (Mendes de Leon et al., 2005; 2001).

### *Ethnicity and Social Context*

Though the social context of disablement can have significant implications for mortality outcomes, social context can vary significantly by race/ethnicity. Scholars of Latino studies have frequently documented a social world among Latinos that is marked by interdependent, kin-centered structures that place a high value on the social status of elders (Almeida et al., 2009; Marsiglia, Parsai, & Kulis, 2009; Molina & Alcántara, 2013; Padilla & Villalobos, 2007). As a result, many scholars of demography have hypothesized that older Latinos may experience larger, denser, more supportive social networks than their non-Latino counterparts, which may in turn contribute to their mortality advantage.

This hypothesis, termed the sociocultural hypothesis of the Latino Mortality Paradox, is based on findings in the general population wherein particular social structures are protective against adverse health outcomes. Prior research has documented that high degrees of social cohesion and large, supportive social networks are protective against adverse outcomes among older adults. However, most of this research has been conducted in North America and Western European countries, and it does not consider how the macrolevel cultural context may shape the formation and meaning of social ties (Bélanger et al., 2016; Berkman, Glass, Brissette, & Seeman, 2000a). As such, the hypothesis that the social context of Latinos may contribute to their survival advantage is based on health findings from non-Latino communities, without considering whether variations in cultural values and meaning-making also create divergent relationships between social context and health outcomes. Latinos may indeed have larger, more supportive social networks, but inasmuch as cultural values suggest that those ties are normative, their existence may not be as protective as they are for individuals who are not embedded in a highly interdependent cultural environment.

In support of this hypothesis, scholars of social epidemiology have theorized that the influence of social networks and social support on any individual's health status depends on the social and cultural context in which that individual lives (Kawachi & Berkman, 2000). Berkman and Glass (2000) argue that shape, nature, and meaning of social networks are conditioned by upstream sociocultural conditions, such as societal norms, politics, or socioeconomic factors. Those upstream cultural, economic, and political forces foster the environment in which social networks are constructed. The structure and characteristics of those social networks, in turn, provide individuals with opportunities for social support, social engagement, and access to resources or material goods. As a great deal of research has been devoted to exploring the ways in which members of different racial or ethnic group experience differing sociocultural contexts, it is quite possible that social networks are structured, and thereby interpreted, in distinct ways.

In sum, the relationship between social context and mortality outcomes among the disabled is tightly linked, but social context and how it is experienced may vary significantly by race/ethnicity. Therefore, this study asks two important questions that remain unanswered in the literature. Part A of this study explores a significant assumption of the sociocultural hypothesis of the Latino Mortality Paradox as it relates to disability by asking whether disabled Latinos report any significant differences in their social context when compared to their non-Latino counterparts. A key premise of the sociocultural hypothesis argues that the Latino health advantage is at least partly due to a higher degree of social cohesion and family support among Latinos, suggesting that we should expect Latinos to report higher social support and lower social strain, larger household sizes and more kin-centered social networks, and higher social network density.

Part B then explores whether the relationships between multiple aspects of social context and mortality risk vary by race/ethnicity. For this section, there are two major competing theories. The Berkman and Glass theory of social integration and health argues that the relationship between social context and health outcomes depends on the ethnicity of the individual in question. If the Berkman and Glass theory holds with the ADL-disabled subpopulation, then we should find that ethnicity is a significant modifier of the social context-health pathway, such that differing aspects of the social world are differentially associated with mortality risk by race/ethnicity. However, prior research in the relationships between social context and health has assumed homogeneity across different ethnic groups, leading to the development of the sociocultural hypothesis of the Latino Mortality Paradox. These assumptions suggest that we should not find any significant differences in the relationship between social context and health by race/ethnicity, and that Latinos should benefit from high amounts of social support and network density in similar ways to their non-Latino counterparts. The findings in Part B will therefore provide evidence-based insight to two competing theories about the relationship between social context and health outcomes.

## **Data and Measures**

This study uses data from Waves 1, 2, and 3 of the National Social Life, Health, and Aging Project (NSHAP). NSHAP is a longitudinal, nationally representative study of community dwelling individuals between the ages of 57 and 85 at Wave 1. African-Americans, Hispanics, men, and individuals between 75 and 84 years of age were oversampled. Wave 1 was conducted from July 2005 to March 2006 and featured in-home interviews, biospecimen collection, and respondent-completed questionnaires (n=3,005). The same types of data were collected in Wave

2 (August 2010 to May 2011). Wave 2 included 2,261 returning Wave 1 respondents, 161 Wave 1 eligible respondents who were not interviewed in Wave 1, and 955 spouses or cohabitating romantic partners. Individuals from Wave 1 who were not interviewed in Wave 2 included those who were either deceased, moved away, or whose health was too poor to participate in Wave 2. The overall weighted response rate was 75.5% and 76.9% for Waves 1 and 2, respectively (O’Muircheartaigh et al., 2009; 2014).

The analytic subsample for this study was comprised of three subgroups: 1) Wave 1 respondents who reported any degree of ADL disability (described below) and had mortality data in Wave 2, 2) new respondents to the survey in Wave 2 who reported any degree of ADL disability and had mortality data in Wave 3, and 3) returning respondents who reported a new ADL disability in Wave 2 and had mortality data in Wave 3. In total, 750 Wave 1 respondents reported ADL disability, 212 new respondents in Wave 2 reported ADL disability, and 247 returning Wave 2 respondents reported the onset of ADL disability. The total sample size was 1,176 after accounting for missing mortality data.

#### *Dependent Variable: Mortality Outcomes among the ADL-disabled Subpopulation*

In order to assess disability status, respondents were asked whether they had no difficulty, some difficulty, much difficulty, or were unable to independently perform any of the following tasks: eating, bathing, dressing, getting in and out of bed, and toileting. Respondents who reported any level of difficulty with any of the five ADLs were assigned to the ADL-disabled subpopulation. These respondents were then assessed five years later as either survivors or deceased.

### *Covariates*

All models controlled for age, gender, race/ethnicity, educational attainment, year of survey, and language in which the survey was administered. Age was a continuous measure centered at the sample mean, and was considered by race/ethnicity in order to account for previously documented variations in age trajectories of ADL disability (M. Hayward et al., 2014; Mendes de Leon et al., 2005). To measure race/ethnicity, respondents were separately asked for their race (White/Black/Other), and whether or not they were of Latino origin. These measures were combined and respondents were classified as either non-Latino white, non-Latino black, or Latino. Non-Latinos who reported “other” as their race were dropped from the sample due to low sample size. Gender and educational attainment were reported by the respondent as well. Educational attainment was treated as a categorical variable with four options: less than high school completion, high school completion or equivalent, some college or vocational training, and the completion of a 4-year bachelor’s degree or higher.

Additionally, total reported level of ADL severity (ranging from 1-5 total ADL disabilities) was also controlled for. To further account for variation in outcome due to other health conditions, a modified version of the Charlson Comorbidity Index was also included, as previously verified and used by Vasilopoulos et al. (2014). The comorbidity scale is designed to account for any elevated risk for mortality due to comorbid conditions. The scale assessed 1 point each for history of heart attack, congestive heart failure, coronary artery disease, emphysema, Alzheimer’s disease or dementia, stroke, and diabetes. 2 points were given for a history of cancer, and 6 points for whether or not that cancer had spread. The result was comorbidity scale ranging from 0 to 15 (Vasilopoulos et al., 2014), with a maximum observed value in the analytic subsample of 12.

Finally, all analyses also controlled for the language in which the survey was administered. Respondents who were Spanish-dominant could choose to complete the survey in Spanish. Though immigration status is significantly associated with health outcomes, many scholars have argued that the concept of “acculturation” is a much more significant predictor of health outcomes, as it indicates the degree to which an individual is able to access resources available to the dominant cultural group is (DuBard & Gizlice, 2008). Immigrants who are fully fluent in English are more likely to have arrived at younger ages, and generally have health profiles that are more similar to the native-born (Lebrun, 2012), whereas those who remain Spanish-dominant are more likely to have immigrated in young adulthood or later, remain more culturally tied to their native countries than English-speakers, and have a stronger mortality advantage than English-speakers. Thus, language of the survey was controlled for in all models to account for significant variations in mortality outcomes among the Latino subpopulation.

#### *Independent Variables: Measures of Social Context*

NSHAP has a particularly rich set of measures aimed to capture the social worlds of its respondents. These includes measures of perceived quality of social interactions, living arrangements, and social network characteristics.

- Perceived Quality of Social Interactions

Social strain, social support, and loneliness were separately measured to evaluate multiple dimensions of the perceived quality of social interactions. To measure perceived social support, respondents were asked a series of six questions. They were asked, "How often can you open up to members of your family if you need to talk about your worries?" and "How often can

you rely on them for help if you have a problem?". The same two questions were asked about the respondent's friends and spouse. Responses ranged from "never" (0) to "often" (2). Perceived amounts of social support was therefore assessed on a scale from 0-12.

To assess perceived social strain, respondents were asked "how often does your spouse criticize you?" and "how often does your spouse make too many demands?". The same questions were asked about friends and family as well. Response options were the same as for social support. Responses were scored the same way as they were for perceived social support, such that perceived social strain was also assessed on a scale from 0-12.

Additionally, a modified version of the UCLA loneliness scale was utilized (Russell, Peplau, & Cutrona, 1980). For use in large surveys, Hughes and colleagues (2004) shortened the original 20-item scale to three questions with a simplified set of response categories. Respondents were asked how often they felt they lacked companionship, how often they felt isolated from others, and how often they felt left out. Answers ranged from "hardly ever or never" (1) to "often" (3). As previously used and verified by Hawkley and Kocherginsky (2018), respondents were assigned to the "lonely" category if their mean response was greater than 1.5, corresponding to a frequency of "occasionally/some of the time" for at least 2 items or "often" for at least 1 item.

- Living Arrangements

Respondents were asked who else resided in the household. A dichotomous variable for living alone was constructed. For those who are not living alone, two additional dummy variables were constructed for living with a spouse/partner and living with children. "Child" here refers to a child of the respondent, not necessarily a minor coresident. Additionally, the total number of reported coresidents was summed to measure the total household size.

- Social Network Characteristics

Four total variables were included to measure the size, composition, and connectedness of the social network. First, respondents were asked: "From time to time, most people discuss things that are important to them with others. For example, these may include good or bad things that happen to you, problems you are having, or important concerns you may have. Looking back over the last 12 months, who are the people with whom you most often discussed things that were important to you?" Respondents could name up to five people; thus, the network size variable ranges from 0-5. Network density measures the proportion of network members that know each other. Finally, the percentage of listed network members who are kin of the respondent and the percentage of network members who are coresidents with the respondent were each calculated as well.

Table 1 provides a full description of each of the independent variables described here, as well as the mean of each variable in the analytic subsample.

Table 1. Description of independent variables

	Variable	Coding	Sample Range	Sample Mean (SE)
Quality of Social Interactions	Social Support	Respondents were asked "how often can you open up to your friends? Your family? Your spouse?" Response options ranged from "never" (0) to "often" (2). Responses were summed into a continuous scale measure ranging from 0-12.	0-12	7.168 (0.081)
	Social Strain	Respondents were asked "How often do your friends/family/spouse criticize you? Make demands of you?" Response options ranged from "never" (0) to "often" (2). Responses were summed into a continuous scale measure ranging from 0-12.	0-9	1.659 (0.051)
	Loneliness	Respondents were asked how often they felt they lacked companionship, how often they felt isolated from others, and how often they felt left out. Answers ranged from "hardly ever or never" (1) to "often" (3). A dichotomous measure of loneliness was created by assigning respondents with a mean response greater than 1.5 to the "lonely" category.	Binary	0.382 (0.016)
Living Arrangements	Living Alone	Dichotomous measure for living alone.	Binary	0.310 (0.014)
	Live with Partner	Dichotomous measure for living with a partner or spouse.	Binary	0.549 (0.015)
	Live with Child	Dichotomous measure for living with a child of the respondent.	Binary	0.182 (0.012)
	Household Size	A continuous measure documenting the total number of coresidents in the household, including minor children.	0-7	1.275 (0.036)
Network Characteristics	Network Size	Respondents were asked to list the individuals with whom they discuss important matters. Respondents could name up to 5 people for a continuous variable ranging from 0-5.	0-5	3.574 (0.042)
	% Kin	Respondents were asked to identify their relationship with each identify on their network roster. The percentage of the total number of network members was calculated.	Proportion, 0-1	0.686 (0.009)
	% Coresident	The percentage of the total number of network members who co-resided in the same household was calculated.	Proportion, 0-1	0.258 (0.009)
	Density	Respondents were asked to identify which members of their network roster knew each other.	Proportion, 0-1	0.814 (0.009)

### ***Analytic Strategy***

All models controlled for age, gender, race/ethnicity, educational attainment, language of survey, year of survey, total number of reported ADL disabilities, and the modified Charlson Comorbidity Index. In Part A, race/ethnicity was regressed on each measure of social context to see whether or not there are significant differences by race/ethnicity in the relevant measure. In Part B, a logistic regression approach was employed to examine whether the relationship between each measure of social context and odds of mortality varies by race/ethnicity.

## **Results**

### *Descriptive Results*

Among all respondents in Waves 1 and 2, 27.39% of Latinos reported any degree of ADL disability, compared to 22.20% of the non-Latino white respondents and 24.63% of the non-Latino black respondents. Table 2 demonstrates the distribution of covariates among the total ADL-disabled subpopulation. The mean age was 71.99 (SE 0.24), and 57.6% of the subpopulation was female. The mean modified Charlson Comorbidity Index was 1.93 (SE 0.06). The average number of reported ADL limitations was 2.04 (SE 0.04).

Latinos and non-Latino blacks were younger on average than their non-Latino white counterparts, and they also reported more ADL disabilities. However, non-Latino whites had higher comorbidity scores on average. Table 3 provides further descriptive results for the comorbidities included in the comorbidity index, and demonstrates that non-Latinos reported much higher rates of stroke and cancer, but lower rates of diabetes. Significant disparities in educational attainment were observed across all racial/ethnic groups, with 73.38% of the disabled subpopulation of Latinos achieving less than a high school education compared to

17.34% of non-Latino whites. In total, 90 surveys were completed in Spanish. Among Latinos (n=139), 63.31% (n=88) completed the survey in Spanish.

Table 2. Distribution of covariates among ADL-disabled by race/ethnicity				
	Latino (N=139)	non-Latino white (N= 813)	non-Latino black (N= 231)	Overall (N=1183)
<b>Mean Age (SE)</b>	70.662 (0.664)	72.615 (0.298)*	70.675 (0.544)	71.941 (0.241)
<b>% Female (SE)</b>	0.546 (0.042)	0.571 (0.017)	0.628 (0.032)	0.576 (0.014)
<b>Educational Attainment</b>				
% < hs	73.38	17.34	41.56	28.52
% HS Completion	8.63	30.01	22.08	25.89
% Some College/ Vocational	12.95	31.37	29	28.77
% Bachelors+	5.04	21.28	7.36	16.82
<b>mean # of ADL limitations (SE)</b>	2.424 (0.124)	1.902 (0.041)*	2.290 (0.086)	2.037 (0.036)
<b>mean Charlson Comorbidity Index score (SE)</b>	1.877 (0.113)	2.493 (0.066)*	2.130 (0.110)	2.347 (0.051)
<b>% Deceased 5 Years Later (SE)</b>	0.178 (0.033)	0.273 (0.016)*	0.271 (0.029)*	0.261 (0.013)

\*indicates significant difference from Latinos with p<0.05

Table 3. Contributing comorbidities to Charlson Comorbidity Scale by race/ethnicity among the ADL-disabled subpopulation (%, SE)

Comorbidity	Latino	non-Latino white	non-Latino black	Overall
Heart Attack	0.173 (0.032)	0.151 (0.012)	0.158 (0.024)	0.154 (0.010)
Congestive Heart Failure	0.204 (0.039)	0.177 (0.015)	0.236 (0.033)	0.190 (0.013)
Coronary Artery Disease	0.172 (0.033)	0.205 (0.014)	0.143 (0.024)	0.189 (0.011)
Emphysema	0.137 (0.029)	0.224 (0.015)	0.147 (0.023)	0.198 (0.011)
Alzheimer's/Dementia	0.014 (0.010)	0.027 (0.005)	0.026 (0.010)	0.026 (0.005)
Stroke	0.046 (0.020)	0.202 (0.015)*	0.261 (0.030)*	0.201 (0.012)
Diabetes	0.439 (0.042)	0.262 (0.015)*	0.374 (0.032)	0.304 (0.013)
History of Cancer	0.101 (0.026)	0.374 (0.017)*	0.095 (0.019)	0.289 (0.013)
Metastasized Cancer	0.041 (0.012)	0.119 (0.028)	0.158 (0.086)	0.114 (0.024)

\*indicates significant difference from Latinos with  $p<0.05$  after adjusting for age, gender, educational attainment, language use

Table 4 provides the coefficients for the covariates-only model, and indicates that Latinos exhibit a significant survival advantage over non-Latinos, even when controlling for age, gender, educational attainment, language and year of survey, total number of reported ADL limitations, and the Charlson Comorbidity Index. Among the subpopulation with ADL disability, non-Latino whites were 2.56 times as likely to be deceased 5-years later as Latinos, and non-Latino blacks were almost 3 times as likely to be deceased 5 years later. Age was a significant predictor of mortality for both non-Latino whites and Latinos, but not for non-Latino blacks. Worsened health status (as measured by number of ADL limitations and the Charlson Comorbidity Index) was negatively associated with survival odds. Having a higher educational attainment was positively associated with survival. Language of the survey was not found to have any significant impact on mortality after accounting for race/ethnicity. In other words, both Spanish and English-speaking Latinos demonstrated reduced odds of mortality relative to non-Latinos.

Table 4. Multivariate logistic regression predicting 5-year mortality among ADL-disabled, covariates only

Covariate	Odds of 5-year mortality	Standard Error	p-value
<b>Age X Ethnicity<sup>1</sup></b>			
Latino	1.103	0.047	0.023
White	1.073	0.015	<0.001
Black	1.029	0.026	0.241
<b>Female</b>	0.679	0.127	0.039
<b>Education<sup>2</sup></b>			
HS/Equivalent	0.938	0.234	0.799
Vocational/Some College	0.665	0.167	0.105
Bachelor's +	0.269	0.091	<0.001
<b>Wave 2 Onset</b>	2.684	0.684	0.101
<b>Survey done in Spanish</b>	1.029	0.64	0.963
<b>Total # of reported ADL Limitations</b>	1.295	0.094	<0.001
<b>Charlson Comorbidity Index</b>	1.352	0.067	<0.001
<b>Race/Ethnicity<sup>3</sup></b>			
White	2.563	1.015	0.049
Black	2.869	1.621	0.037

1. Measures the effect of age for each racial/ethnic group separately

2. Reference category is less than a high school education.

3. Reference category is Latino.

*Part A. Do Latinos with ADL disability report any significant differences in their social context?*

Table 5 provides the unadjusted means for each measure of social context by race/ethnicity, with indicators for significant differences from Latinos after adjusting for the full set of covariates. When compared to all non-Latinos, Latinos report living in significantly larger households and having significantly denser social networks. When compared to non-Latino blacks, Latinos are more likely to live with a partner or spouse, less likely to live alone, and

report a higher proportion of kin in their social networks. In sum, they report no significant differences in perceived quality of social interactions, and modest differences in objective measures of the social network structure.

		Table 5. Unadjusted mean scores for independent variables by race/ethnicity among ADL-disabled (Mean, SE)			
		Variable	Latino	non-Latino white	non-Latino black
Quality of Social Interactions	Social support	6.824 (0.243)	7.437 (0.098)	6.419 (0.171)	
	Social Strain	1.550 (0.162)	1.585 (0.059)	2.00 (0.131)	
	Loneliness	0.439 (0.047)	0.357 (0.018)	0.453 (0.041)	
Living Arrangements	Lives Alone	<b>0.175 (0.037)</b>	0.309 (0.018)	<b>0.402 (0.034)**</b>	
	Lives with partner	<b>0.592 (0.047)</b>	0.594 (0.019)	<b>0.368 (0.034)*</b>	
	Lives with child	0.296 (0.044)	0.135 (0.013)	0.268 (0.031)	
	Household size	<b>1.556 (0.012)</b>	<b>1.183 (0.039)*</b>	<b>1.415 (0.100)*</b>	
Network Characteristics	Network Size	3.309 (0.119)	3.657 (0.049)	3.442 (0.100)	
	% Kin	<b>0.791 (0.024)</b>	0.672 (0.011)	<b>0.673 (0.022)*</b>	
	% Coresident	0.317 (0.028)	0.257 (0.011)	0.225 (0.019)	
	Density	<b>0.907 (0.021)</b>	<b>0.800 (0.011)*</b>	<b>0.752 (0.015)*</b>	
*indicates significant difference from Latinos after accounting for the full set of covariates with p<0.05					
**indicates significant difference from Latinos after accounting for the full set of covariates with p<0.01					

*Part B. Does ethnicity moderate the relationship between social context and mortality among the disabled?*

Table 6 demonstrates the results of 11 different models, each examining the impact of a different aspect of the social context on odds of mortality among the disabled. Each line of the

table represents its own model, where the relevant measure of social context is interacted with race/ethnicity in a multivariate logistic regression predicting odds of mortality. The odds ratio for mortality and its associated p-value is reported for each racial or ethnic group. For example, Latinos who report being lonely are almost twice as likely to be deceased 5 years when compared to Latinos who are not lonely (p=0.002), though reporting loneliness was not significantly associated with mortality outcomes for either of the other two racial/ethnic groups.

Table 6. Association between individual measures of social context and odds of 5-year mortality among the ADL-disabled, by race/ethnicity

		Latinos		non-Latino white		non-Latino black	
Quality of Social Interactions	Variable <sup>1</sup>	OR	p-value	OR	p-value	OR	p-value
	social support	0.897	0.306	<b>0.875</b>	<b>0.008</b>	0.990	0.925
	social strain	<b>1.443</b>	<b>0.044</b>	<b>0.773</b>	<b>0.009</b>	<b>0.749</b>	<b>0.093</b>
	Lonely	<b>1.968</b>	<b>0.002</b>	1.076	0.480	0.996	0.983
Living Arrangements	Lives Alone	2.963	0.253	<b>1.834</b>	<b>0.032</b>	<b>0.341</b>	<b>0.027</b>
	Lives with partner	0.829	0.828	0.395	0.404	1.863	0.283
	Lives with child	0.488	0.404	0.880	0.540	2.348	0.250
	Household size	0.852	0.572	0.969	0.822	1.226	0.223
Network Characteristics	Network Size	1.152	0.542	<b>0.725</b>	<b>&lt;0.001</b>	<b>0.723</b>	<b>0.065</b>
	% Kin	<b>0.411</b>	<b>0.024</b>	0.954	0.784	1.031	0.874
	% Coresident	0.554	0.294	1.065	0.685	1.546	0.102
	Density	0.317	0.146	0.726	0.619	4.669	0.220

1. Each measure of social context represents its own model.

Table 6 indicates that social support is significantly associated with moderately reduced odds of mortality for non-Latino whites only, although social strain is significantly associated with mortality for all racial/ethnic groups. However, the direction of that relationship varies. For

Latinos, perceiving higher amounts of social strain reduces odds of survival, whereas high social strain increases odds of survival for non-Latinos. Living alone is significantly associated with mortality odds for non-Latinos, but the direction of that relationship also varies with race. For disabled non-Latino whites, those who live alone have increased odds of mortality, though for non-Latino blacks, living alone is associated with reduced odds of mortality. Finally, having a larger reported social network is significantly associated with reduced odds of mortality for non-Latinos, but not for Latinos. Instead, Latinos who report a larger proportion of kin in their social network have a reduced risk for mortality, though there is no significant relationship between the composition of the social network and mortality for non-Latinos.

## **Discussion**

Consistent with prior qualitative literature, older Latinos with disability do report living in larger households and having denser social networks than their non-Latino counterparts. They also report a lower likelihood of living alone and a higher likelihood of living with a spouse than do non-Latino blacks, which is consistent with prior research in marital trends by race/ethnicity (Bulanda & Brown, 2007). They also report having more kin-centered social networks than non-Latino blacks. However, they do not report larger social networks, nor do they report receiving more social support than their non-Latino counterparts. Taken together, these findings suggest that the objective social world—as measured by household structure and social network characteristics—may indeed be significantly different for older Latinos than non-Latinos. However, the functional aspects of that social world—as measured by their perceptions of social support, social strain, and loneliness, do not differ. Though Latinos may report larger household sizes and denser social networks, this does not correspond to increases in perceptions of social

support, for example. These findings suggest modest support for a key assumption of the sociocultural hypothesis of the Latino Mortality Paradox. Latinos do indeed report some significant differences in aspects of social context that are associated with reduced risk for adverse health outcomes, particularly when compared to non-Latino blacks. However, while Latinos do report some structural differences in their social context, those differences do not extend to any functional differences in how the social context is experienced.

Though their reports of perceptions of strain, support, and loneliness do not differ significantly, the association of each of these measures with mortality differed significantly by race/ethnicity. Reporting higher amounts of social support was associated with reduced odds of mortality for non-Latino whites, though this same benefit did not extend to other racial/ethnic groups. Being lonely nearly doubled the risk of mortality for Latinos, but was not significantly associated with mortality outcomes for others. As Latinos are often documented to live in dense, family-centered social networks, the experience of loneliness may be particularly distressing to them, and also indicate a profound lack of adequate caregivers and/or other supportive social relationships. Because loneliness is a particularly problematic experience for Latinos in terms of mortality outcomes, it may have the most significant implications for potential interventions. As Latinos with ADL disability who report feelings of loneliness are at an even higher risk for adverse outcomes, community-level interventions that include group activities designed to foment social support, physical activity, and positive mental health may have significant impact on well-being, health, and even recovery from disability.

Additionally, social strain was found to be associated with mortality outcomes for every racial/ethnic group, but the direction of that relationship varied. Figure 1 provides a graphical representation of that relationship.

Figure 1. Relationship between perceived amounts of social strain and odds of 5-year mortality among the ADL-disabled, by race/ethnicity

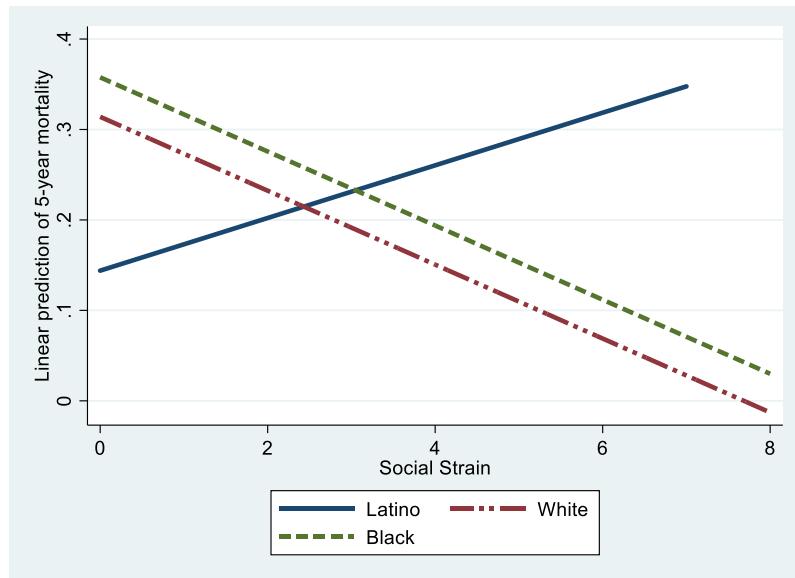


Figure 1 demonstrates that Latinos who report higher amounts of social strain have increased odds of mortality, whereas for non-Latinos, higher amounts of social strain is associated with increased odds of survival. These results highlight both the double-edged sword of social relationships as they relate to health, as well as the ways in which the social world may vary in its relationship with health outcomes according to race/ethnicity. For Latinos, perceiving high amounts of criticism and demands may be a source of stress that correlates with deviations from expectations for caregiving and/or family support in old age. As other scholars have noted that cultural norms of caregiving and support can be quite strong among Latinos, experiencing criticisms or demands may be particularly stressful to them, or indicate a particularly non-supportive social environment.

For non-Latinos, however, social strain may actually indicate that the individual is receiving adequate care. The “nagging” spouse or child may actually be ensuring that their loved

one is complying with medical orders, for example. It may also be the case that individuals of different racial/ethnic groups perceive social strain quite differently. What may be “demanding” for one group may simply be supportive to another group, to the point that the threshold for perceived social strain for Latinos is much higher. Social strain for Latinos may indicate a relationship that is non-supportive and detrimental to overall well-being, whereas strain for others may indicate an irritation that is actually supportive. Future research could utilize cognitive interviewing techniques to understand how members of different sociocultural groups understand and answer questions about negative social interactions. How is social strain felt and experienced by members of different racial/ethnic groups? The answer to that question could have important implications for the ways in which social stress operates to produce health outcomes.

Results were similar when examining the relationship between living alone and mortality outcomes. For non-Latino whites, living alone was associated with increased odds of mortality, whereas it was associated with decreased odds of mortality for non-Latino blacks. These findings likely reflect divergent trajectories of health in old age, and the role of the family. As this is not a causal study, it may be the case that older non-Latino blacks are more likely to move in with family as their functional health declines, such that those who are living alone are less likely to be deceased as they are in better health. Non-Latino whites however may continue to live independently even as their health declines. Those with significant functional challenges who continue to live alone have less access to instrumental care, and may not have anyone in the immediate vicinity in the case of medical emergency. This finding may provide opportunity for clinical intervention; living alone after functional decline increases risk for negative health outcomes, and non-Latino whites are particularly likely to be in that situation.

Finally, the findings for social network structure suggest that there may be divergent priorities or preferences in the social context by race/ethnicity. For Latinos, having a higher percentage of kin was protective against mortality, though this was not significant for non-Latinos. However, non-Latinos who reported larger social network sizes also reported lower odds of mortality. Taken together, this suggests that for Latinos the size of the social network is not as important as its composition, while for non-Latinos the quantity of social relationships is more important than the type of social relationships. This may echo the findings for social strain; non-Latinos benefit from a larger social network, which also increases opportunity for social strain. At the same time, Latinos benefit from a kin-centered social network, wherein they expect to receive instrumental and emotional support—not strain. In a multinational study of social support and health outcomes among older adults, Bélanger and colleagues (2016) found that South Americans placed more emphasis on support from children for their well-being than did North Americans. This cultural value may extend to Latinos living in the United States such that having a smaller percent of kin in your network may indicate a reduced amount of support from children, which is subsequently associated with reduced quality of life. Additionally, having a focus on kin-relationships may indicate more availability for caregiving and instrumental support, which may extend life as well.

As these findings are complex, researchers in health outcomes among Latinos should be careful to neither romanticize nor essentialize the experience of social life among Latinos. Though many have hypothesized that the emphasis placed on interdependence and *familismo* among Latinos may contribute to their extended longevity, these findings suggest that Latinos do not actually demonstrate such a pattern. Though they do have more family-centered networks, the quality of their relationships does not seem to differ from that of other groups. However, the

ways in which those relationships are experienced does impact mortality outcomes. Latinos may have a baseline expectation for kin-centered social worlds in their old age, and the lack of such a social system may be additionally stressful. They may also have certain expectations for social engagement in their old age, such that experiencing loneliness and/or social strain may be particularly detrimental to them. This is in contrast to findings for non-Latinos, who receive a protective benefit from larger social networks and higher amounts of social strain, suggesting that the quantity of social contact is more important than its content. Taken together, these findings suggest that meeting expectations for social life is more important than any objective measure of the social world; violating these expectations may induce a stress response that elevates the risk of mortality.

As this analysis was limited to long-term mortality outcomes among individuals who already report disability, it did not consider risk factors for the onset of disability. Future research could also address whether or not these measures of social context are similarly related to the prevention or delayed onset of disability. Exploring which factors of social context are associated with the onset of disability could have important implications for interventions designed to prevent disability in the first place.

Finally, this same analysis could also be applied to explore within-group differences among Latinos. A large body of literature has documented differences in the ways Latino men and women understand their social worlds (Viruell-Fuentes & Schulz, 2009), and how social context changes generationally among Latinos (Molina & Alcántara, 2013). Do these measures of social context have equal impact for both men and women? Is there any difference in the relationship between social context and mortality outcomes for individuals of different countries or regions of origin? How does nativity status impact these relationships?

All together, these research findings suggest that social context may impact mortality outcomes not only through the provision of instrumental support, but also through deviation of expectations. The pathways between stress in the environment and health outcomes—a persistent topic in the interdisciplinary social sciences—may be shaped by sociocultural norms and expectations. These findings suggest that what qualifies as a stressor varies by group, and the impact of that stressor varies by group as well, thereby supporting the theory put forth by Berkman and Glass that the relationship between social networks and health outcomes depends on the sociocultural environment in which an individual is embedded (F. Berkman & Glass, 2000). It is therefore important to not only examine heterogeneity in social context, but also heterogeneity in the impact of that social context on health outcomes. Future qualitative research could explore the ways in which expectations for aging are set among Latinos, and how deviations from those expectations impact both mental and physical health.

## **Chapter Two. Depressive symptomology and care receipt among older adults with ADL disability: The roles of gender, marital context and ethnicity**

### ***Abstract***

Prior research has shown that older adults with ADL disability are more likely to be depressed than others, and the receipt of personal care further elevates risk for depression. This chapter explores whether there is any variation in this trend by race/ethnicity, and then explores further variation among the Latino subpopulation by considering the roles of both gender and marital status. Data come from Rounds 11, 12, and 13 of the Health and Retirement Study. In Part A, I examine the relationship between care receipt status and total reported number of depressive symptoms by race/ethnicity. In Part B, I divide the disabled Latino subpopulation by gender and explore the interaction effect between care receipt status and marital status on total number of reported depressive symptoms. Findings indicate that disabled Latinos report higher baseline depressive symptoms than disabled non-Latinos. However, Latinos who receive personal care report fewer depressive symptoms than Latinos who do not receive care, whereas receiving care is associated with more reported depressive symptoms among non-Latinos. This trend among Latinos may be driven by single women and married men, however. They report fewer depressive symptoms when they receive care than when they do not, whereas married women and single men report more depressive symptoms when receiving care. These findings highlight the importance of considering multiple social categories and their role in shaping psychological responses to physical health declines.

## ***Introduction***

In the previous chapter, I argued that older Latinos with ADL disability report only modest differences from non-Latinos in their social context, but that there may be variations in how the social world is experienced, regardless of its objective reality. These differences in perception or priorities in turn produce divergent relationships between social context and health outcomes by race/ethnicity. Specifically, social strain was associated with increased odds of mortality for Latinos but decreased mortality odds for others, and the composition of the social network may be more important than its size for Latinos, but that trend is reversed for non-Latinos. Disabled Latinos with more kin-centered social networks have reduced mortality risk than others, suggesting that there may be differences by race/ethnicity in both the availability and preference of care arrangements in the social networks of older adults with disability.

This chapter continues exploring the role of ethnicity in the experience of ADL disability among older adults by considering how ethnicity may influence the relationship between the receipt of personal, intimate care and psychological well-being, and what role gender and marital status may play in that relationship among Latinos. Specifically, I begin by comparing patterns of depressive symptoms and care receipt among Latino, non-Latino white, and non-Latino black adults with ADL disability. Then, I dive deeper in to the social world of Latinos by considering whether the relationship between receipt of personal care and depressive symptoms depends on both gender and marital context. These two research questions aim to provide insight to the complex dynamics at play in health, aging, intimate personal care, and sociocultural context. Ultimately, I argue that cultural forces shape expectations for aging and care receipt among older adults, and that alignment among those expectations has critical implications for mental well-

being. These expectations not only differ by racial or ethnic group, but also for men and women, and for the married and unmarried, such that considering the intersections of multiple social categories is important towards understanding risk for poor psychological health co-occurring with the onset of ADL disability.

## **Background**

### *ADL Disability and Psychological Well-Being*

While disability has clear healthcare implications for older adults, the psychosocial impact can be equally devastating. Research in the experience of disability in old age has documented a well-established link between depressive symptomology and disability (Bruce, 2001; Downer et al., 2016; Ormel et al., 2002). This association is often bidirectional; some longitudinal studies have suggested that depressive symptoms can lead an individual to report higher difficulty with basic activities, and difficulty with basic activities can lead to the development of depressive symptoms (Ormel et al., 2002). Ultimately, the two can begin to reinforce one another. Regardless of which occurs first, experiencing disabilities of self-care can have significant impacts on mental well-being that can lead to a downward trend for both overall well-being and levels of independent functioning. This suggests that bodily decline can be a significant stressor for older adults, such that older adults with physical disabilities report more depressive symptoms (Bierman & Statland, 2010; Yang, 2006), lower self-esteem (Reitzes & Mutran, 2006), and lower life satisfaction (Ducharme, 1994).

This lower psychosocial well-being may reflect both unmet social needs and reduced sense of independence and self-determination. Functional limitations can restrict the abilities of older adults to perform desired social roles (Verbrugge & Jette, 1994) and negatively impact the

quality of social relations, leading to less perceived social support (Taylor & Lynch, 2004). As social ties are important for socioemotional wellbeing (S. Cohen, 2004), functional limitations that threaten social relationships can be significant stressors in the lives of older adults. This may lead to cascade of negative consequences for mental health and well-being (Bookwala, 2005).

By challenging routine functioning, disablement may also result in a loss of autonomy (Korporaal et al., 2008). Older adults who are beginning to struggle with the completion of basic tasks may fear worsening symptoms, and those that require personal help and intimate care may face a particularly high risk for reduced psychological well-being as their sense of independence and adulthood is immediately challenged. Particularly in a cultural context where autonomy is highly valued, experiencing dependence can have a profound effect on one's sense of self (Lamb, 2014).

The relationship between reduced functional health and poor psychological health can be further exacerbated for adults who receive personal care to complete basic tasks. Prior research has established that older adults that require personal care assistance with the completion of activities of daily living have even further elevated risk for depression (Agree, 1999). While a large body of research has documented the negative effects of caregiving on the caregiver, receiving help can also be burdensome and challenging to the care recipient. When using personal help, older adults face additional stressors on top of their declining health and function, such as needing to accommodate the caregiver's schedule, yielding decision power to the caregiver, and increased risk for negative social interactions with the caregiver (Liang, Krause, & Bennett, 2001; Newsom & Schulz, 1998). Additionally, the receipt of highly visible and explicit forms of support can further amplify the negative side effects of stressful health declines (Bolger, Zuckerman, & Kessler, 2000; Bolger & Amarel, 2007). For example, in a study of married

couples where one partner provided care for the other, nearly 40% of care recipients reported emotional distress in response to the care they received, and reporting that distress was found to predict depression as much as one year later, even if the initial need for care had been resolved (Newsom & Schulz, 1998). This suggests that there may be long term effects to receiving care that outlast even the disability itself.

### *Ethnicity, Depression, and Personal Care Receipt*

Though the receipt of personal care and increased risk for depressive symptoms have a well-documented correlation among older adults with disabilities of self-care, this pattern is not necessarily homogeneous across different social groups. Being minority, female, and married is positively associated with the use of personal help (Agree, 1999; Agree & Freedman, 2003; Scherer, Craddock, & Mackeogh, 2011), and older adults who are minorities, women, and/or unmarried tend to have lower positive affect, self-realization, and self-efficacy than their respective counterparts (Chen & Feeley, 2014; Shiovitz-Ezra & Litwin, 2015) . Minorities, women, and the married are more likely to receive personal help. While married individuals tend to have better psychological health than their unmarried counterparts, both women and minorities are at increased risk for reporting poor psychological health relative to men and non-Latino white individuals. While a growing body of research has documented the risk factors for both receiving personal help and depressive symptoms, few studies have explored how such demographic factors may interact to produce unique relationships between personal care receipt and depressive symptoms. As such, this study focuses on the interactions between gender, marital status, and race/ethnicity as they relate to patterns of depressive symptoms and care receipt among the disabled.

In the case of race and ethnicity, culture—that is, the shared beliefs, values, and behaviors of a community—plays an important role in health outcomes and responses to illness (Helman, 2000). For older adults with ADL disability, the cultural environment may play a significant part in both odds of receiving personal, informal care upon the onset of ADL disability and the relationship between care receipt and depressive symptoms. A large body of research documents that individuals of different races and ethnicities not only follow different trajectories and accumulate different resources over the life course, but are also exposed to differing cultural beliefs and norms (Jackson, Goria, & Sellers, 2011). As older adults of different racial or ethnic groups are exposed to differing cultural or political forces across the life course, this may in turn foster differences in older adults' ability and preferences to adopt personal care as a coping strategy for disability.

In support of this theory, scholars have found that members of different racial/ethnic groups utilize personal care at different rates. Both Latino and African American older adults are more likely than non-Latino white older adults to use long term informal care (Bradley et al., 2004; Tennstedt & Chang, 1998), and Latinos report receiving more hours of weekly informal care than their counterparts (Weiss, González, Kabeto, & Langa, 2005). In a study comparing African American and white older adults, African Americans were more likely to intend to use long-term informal care, though social norms concerning family caregiving mediated the relationship between race and the intention of long-term informal care use. Taken together, these findings suggest that minority groups are more likely to utilize informal care, and that cultural norms and expectations around family caregiving may be a critical predictor for the adoption of informal care. As Latinos have also been documented to have a highly family-centered social

world, they may also have expectations for family caregiving in old age, making the transition to receiving personal care from family a more common and less stressful outcome.

Cultural values and norms may also influence the extent to which an older adult can accept the stigma of lost independence that generally accompanies the use of personal care (Agree et al., 2005; Cornman & Freedman, 2008). For adults in communities that prioritize independence and productivity at all stages of adulthood, the inability to care for one's basic needs may be a more significant stressor than it is in communities where interdependence is a more salient cultural value (Lamb, 2014). Prior researchers have documented that Latinos tend to report a high degree of social support that is marked by kin-centered social networks. Respect for elders and expectations of caregiving have significant impact on aging experiences for elder Latinos (Padilla & Villalobos, 2007). Additionally, Latinos may place more value on interdependence in old age, such that functional decline and reliance on others is experienced differently from their non-Latino counterparts in the United States (McCarthy et al., 2004). For this reason, disabled Latinos may not necessarily show the same patterns of increase in depressive symptoms upon receiving personal care as have been found in the general population. For example, one study found that strong identification with and attachment to family members (or *familismo*) is significantly correlated with reduced burden among Latino caregivers (Losada et al., 2006). However, this study focused on caregiver burden and did not explore whether or not familism also reduces burden on the care recipient. The previous chapter of this dissertation demonstrated that Latinos with ADL disability may benefit from a densely kin-centered social network; this chapter furthers that research by asking whether Latinos who *receive* care also experience reduced burden relative to non-Latinos.

### *The Role of Gender and Marital Status in Health Outcomes*

Race/ethnicity and gender are separate social constructs that jointly and simultaneously structure health outcomes and experiences in the United States, including those of disability (Warner & Brown, 2011). As such, this chapter begins by considering solely the role of ethnicity in the relationship between care receipt and depressive symptoms, but then adopts an intersectional approach to consider how race/ethnicity and gender are not separate and additive dimensions of the social structure, but instead are mutually defining and reinforcing across the life course. While many studies of health and aging consider race/ethnicity and gender separately, both are key factors of how health and illness are experienced, including disability. Women and minority groups are more likely to experience both disability and depression, but the intersection of those identities can have important implications for who gives and who receives care, and how care receipt impacts mental health. Additionally, I also consider marital status, as the presence of a marital relationship plays a key role in how and when care is received, as well as the relationship of the caregiver to the care recipient.

The stress-buffering hypothesis suggests that access to supportive relationships can ameliorate the effects of illness and disability on both psychological and functional health, and that the absence of positive relationships can further exacerbate illness or functional decline (S. Cohen, 2004; Warner & Kelley-Moore, 2012). In support of this hypothesis, a large body of research has consistently documented the protective benefit of marriage in health across the life course (Bélanger et al., 2016; Boerner et al., 2014). Older adults who are married tend to have better health outcomes across numerous domains, including all-cause mortality (Johnson et al., 2000) and mental health (Cornwell & Waite, 2009; Umberson et al., 2006; Warner & Kelley-Moore, 2012). There are two dominant explanations for this so-called “marriage benefit”: social

selection and social causation. The social selection hypothesis proposes that healthy and financially secure people are more likely to marry and remain married over the life course, thus accounting for the association between marital status and health. Meanwhile, the social causation hypothesis argues that marriage provides economic and psychosocial benefits that directly enhance health across the life course, particularly for older adults. Marriage is often argued to operate as a key form of social control, as married people are less likely to smoke, drink excessively, and engage in risky behaviors like not wearing seat belts (Tucker & Anders, 2001; Umberson & Montez, 2010). Spouses, especially wives, may also help their partner with health-enhancing behaviors, such as regular visits to the doctor, exercise, healthy eating, and complying with medication regimens (Schone & Weinick, 1998).

Marital status and social context are of particular importance in the experience of disability, as disability is typically defined as the difficulty or inability to perform activities across any domain of life in a manner that affects one's ability to perform expected social roles (Crimmins, 2004). This necessarily defines disability as both a biological and a social condition. While experiencing disability can put significant strain on an older adult's social life, having a spouse may be of particular benefit, as a spouse is often available to provide instrumental and emotional support, and the spousal relationship may offer a stabilizing presence in the face of age-related changes. As such, disabled older adults report a preference to receive support from a spouse before others (Noël-Miller, 2010), and the spousal relationship is less vulnerable to declines in relationship quality upon the onset of functional decline (Carr & Moorman, 2011). The long-term commitment, stability, and routinized social interactions among older married adults may also make the marital relationship particularly well-suited to moderate the

psychosocial stresses and consequences of disability, consistent with the stress buffering hypothesis (Cutrona, 1996; Unger, Johnson, & Marks, 1997).

Nonmarried older adults, however, do not have access to the potential benefits of marriage when faced with significant health declines. In addition to not having a partner to provide immediate care like their married counterparts, physical disability may produce changes to the relationships with non-spouse family and friends to the extent that challenges to routine functioning and autonomy make maintaining such relationships more difficult or less fulfilling (Korporaal et al., 2008; Verbrugge & Jette, 1994). Prior research has suggested that older adults typically have a hierarchy of preferred caregivers, which typically place the spouse and adult children at the top, though more distant relatives, friends, and formal helpers are substitutes when those sources are unavailable (Cantor, 1979). If a child becomes a caregiver though, a parent may find the parent-child relationship suddenly reversed, causing an increase in stress and feelings of burden. Prior studies have found that increased nonmarital support from social network members may actually exacerbate worsening mental health among older adults. For example, receipt of instrumental support and care from non-spouse relationships was associated with greater depression among older adults with severe vision impairment (Reinhardt, Boerner, & Horowitz, 2006) and diabetes (Penninx et al., 1996).

Though marriage generally confers significant protection against adverse health outcomes to its members, gender plays an important role in this relationship. Marital role expectations—and the structure and content of social relations more broadly—differ for men and women (Moen, 2001). A large body of research has argued that men and women experience marriage differently due to gendered spousal expectations (Bernard, 1982; Boerner et al., 2014). This holds particularly true for current cohorts of older adults, whose expectations for both

gender and marriage developed within a broader and more rigid set of gender norms wherein men were seen as autonomous providers and women as nurturing caregivers (Ridgeway, 2009). Men tend to rely more heavily on marriage to provide emotional support, companionship, and caregiving, whereas women tend to have a more diverse set of social contacts and support (Cutrona, 1996; Spitz & Ward, 2000; Warner & Adams, 2016). Indeed, compared to women, men are more likely to rely exclusively on their spouses for support (Antonucci, Ajrouch, & Birditt, 2014; Umberson & Montez, 2010) and report that they would be less likely to rely on non-kin if ill (Fischer & Beresford, 2015). Additionally, the lifelong expectation that wives provide instrumental and emotional support to their husbands and children, but not husbands to their wives (Spitz & Ward, 2000) results in men being less effective caregivers to their wives when called to do so (Thomeer, Umberson, & Pudrovska, 2013). This may also contribute to why wives are only a third as likely as their husbands to list their spouse as their preferred primary caregiver upon facing health setbacks (Allen, Goldscheider, & Ciambrone, 1999).

Gender is also of importance when considering the relationships between mental health and functional health in old age, as women are more likely to report both depression and ADL disability. Additionally, care receipt patterns differ for men and women. Women are more likely to receive personal, informal care than men and receive it from more diverse sources, whereas men who receive personal intimate care tend to receive that care from wives (Penning & Strain, 1994; Spitz & Ward, 2000). These patterns are particularly strong among Latinos, where traditions of *machismo* and *marianismo* may be at work. *Machismo* and *marianismo* are well documented cultural norms that define gender expectations for many of Latino origin. *Machismo* identifies men as strong and protective and encourages them to be dominant in relationships and to demonstrate sexual virility (Cianelli et al., 2008; Wentzell, 2013b). Meanwhile, *marianismo*

encourages women to be more passive and submissive in their roles as romantic partners and caretakers of the family (Cianelli et al., 2008). The result is that the vast majority of caregivers for elderly individuals in many Latino communities are women; typically, wives care for their husbands if they are able to, or a female child or other relative will provide caregiving (*ibid.*). As such, women who are used to using their bodies to provide care may find the need to receive care in old age a more troubling experience. Meanwhile, these cultural trends result in competing hypotheses about how care receipt may be experienced in old age among aging men. Some married men may be more able to accept intimate care from their wives, as wives provide care in many forms throughout the life course. Alternatively, as men are socialized to be autonomous providers, experiencing functional disability—and the accompanying disruption to life's routines—may have a more profound effect on men's mental health than it does for women, who find less distress at bodily decline (Ormel et al., 2002).

In sum, ideals of femininity and masculinity among traditional Latino cultures lead to divergent experiences of health, aging, and caregiving. However, few scholars have considered the ways in which these gender norms may also be reflected in gendered experiences of disability. Taken together, these findings suggest that both gender and ethnicity play an important role in relationships of care across the life course, as does the marital context of disability. As disability is both a physical and a social experience, the social context in which disability occurs can also have significant implications for outcomes of that disability. This chapter therefore examines to what extent ethnicity moderates the relationship between personal care receipt and depressive symptoms, and what roles gender and marital context play in those pathways.

### *Research Questions*

This study is divided into three parts. Part A explores whether members of different racial/ethnic groups report significantly different amounts of depressive symptoms and/or significantly different odds of receiving personal help. As Latinos have been documented to live in more interdependent, kin-centered social worlds than their non-Latino counterparts, I anticipate that Latinos will report fewer depressive symptoms upon the onset of ADL disability, and a higher likelihood of utilizing personal help as part of their compensation strategy. This hypothesis rests on prior findings that Latinos approach aging as a more natural process than their non-Latino counterparts, and that familism plays a key role in shaping eldercare arrangements in Latino families. Part B examines how the relationship between receiving personal help and depressive symptoms varies by race/ethnicity. Prior research would suggest that Latinos should report fewer depressive symptoms when utilizing personal care than members of other ethnic groups who receive personal care. Finally, Part C explores the role of gender and marital status in shaping the relationship between receipt of personal care and depressive symptoms among Latinos with ADL disability. I anticipate that married men who receive care will report fewer depressive symptoms than their nonmarried counterparts, as the cultural trope of machismo suggests that married men receive care and support from their wives, but offer that support to their children. Care receipt that subverts these traditional caregiving pathways may be additionally stressful. For women however, prior research suggests that receiving care may be a stressful experience for them regardless of marital status, as they have often spent a lifetime in a caregiver role—not a care receiving role. As such, care receipt from either a spouse or a child may challenge their views of their role within the family.

## **Data and Measures**

Data come from rounds 11, 12, and 13 of the Health and Retirement Study (HRS). These data were collected in 2012, 2014, and 2016, respectively. The HRS is a longitudinal panel study funded by the National Institutes on Aging (NIA U01AG009740) that interviews a nationally representative sample of approximately 20,000 older adults every two years. In this chapter, I examine only individuals who report the onset of a new ADL disability, as the onset of disability is more tightly linked to increases in depressive symptoms (Ormel et al., 2002). As such, all respondents who had complete outcome data (CES-D score, described below) and reported ADL disability for the first time in 2014 or 2016 were included in the study. Data from 2012 were only utilized to establish baseline presence of ADL disability. ADL disability was defined as the self-report of any degree of difficulty in independently completing any of the five ADL measures of interest: bathing, eating, dressing, transferring in and out of bed, and toileting. In other words, ADL disability was measured by the reported presence of any difficulty with independently completing an ADL task, and was measured at baseline in 2012. Respondents who reported the onset of ADL disability in either 2014 or 2016 were included in the study sample. All covariates and dependent variable measures were derived from the relevant year in which a respondent reported the onset of disability. The total sample size was 2,623.

### *Covariates*

To account for confounding between depressive symptoms and odds of receiving help, all analyses controlled for relevant sociodemographic characteristics, including the mean-centered age and self-reported gender of the respondent. To measure educational attainment, a categorical variable with four options was created: less than high school completion, high school diploma or

equivalent, some college or vocational training, or a bachelor's degree or higher. Respondents were also asked to report their race (white/black/other), and whether or not they were Latino. To consider the race/ethnicity of respondents, a new variable was created with three categories: Latino, non-Latino white, and non-Latino black. Respondents who identified their race as "other" and who were not Latino were dropped from the sample due to both heterogeneity<sup>3</sup> and small sample size (N=75).

Individuals with more severe or pervasive disability are more likely to be both depressed and require personal help; the impact of personal help on depressive symptoms is therefore confounded by the degree of disability. To account for confounding between these two outcomes of interest (odds of receiving help and number of depressive symptoms), all analyses controlled for the total number of reported ADL disabilities (1-5). Additionally, a comorbidity scale was constructed to capture the presence of other comorbid conditions that increase risk for depression and/or receiving personal help with daily tasks. Respondents were given 1 point each for a history of hypertension, diabetes, Alzheimer's/dementia, cancer, stroke, heart disease, emphysema/lung disease, and arthritis for a scale ranging from 0-8. Each of these comorbidities is associated with increased odds of both depression and receiving personal care, with a higher total comorbid burden significantly associated with higher odds of negative outcomes (Stenholm et al., 2015).

Finally, respondents were also asked if the primary language spoken in the home was English. A dichotomous variable was constructed where a value of 1 indicates that the respondent speaks a foreign language in the home. Prior research has found that health outcomes vary significantly between English-dominant and Spanish-dominant Latinos, where the English-

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<sup>3</sup> Respondents in the "non-Latino other" group could have been from widely heterogeneous backgrounds, including both Asian and Native American descent.

dominant are more likely to be either native-born or childhood arrivals, and correspondingly have better access to health care and healthcare resources. However, Spanish-dominant Latinos, who are almost exclusively foreign-born, have a longer life expectancy despite their health disadvantages. Controlling for language spoken in the home therefore accounts for heterogeneity within the Latino population.

### *Independent Variables*

To measure receipt of personal help, respondents who reported any difficulty with a particular ADL task were asked if they received personal help with completing that task. The measure was dichotomized among respondents with any ADL disability to separate individuals who have difficulty with a task but complete it independently from those who receive personal help from another individual to complete the task. To measure marital status, a dichotomous variable was created to separate individuals who are married from those who are single. The "single" category includes those who were never married, divorced, widowed, or separated. Those who reported widowhood occurring in the last two years (N=85) were eliminated from the sample in order to minimize the confounding of bereavement with both functional decline and depressive symptoms.

### *Dependent Variable*

A single depression indicator was constructed by using a score from the Center for Epidemiologic Studies Depression (CES-D) scale. The CES-D score is the sum of six "negative" indicators minus two "positive" indicators. The negative indicators measure whether the respondent experienced the following sentiments all or most of the time: depression, everything is an effort, sleep is restless, felt alone, felt sad, and could not get going. The positive indicators

measure whether the respondent felt happy and enjoyed life, all or most of the time. The result is a scale ranging from 0 to 8, where higher scores indicate the self-report of more depressive symptoms. The CES-D scale was designed for inclusion in surveys and measures a continuum of psychological distress, but does not determine the absence or presence of clinical depression (Radloff, 1977). It has been used with many ethnic and linguistic minority groups, including Korean immigrants, Chinese-Americans, American Indians, Guatemalans, African-Americans (Guarnaccia, Angel, & Worobey, 1989; Prescott et al., 1998; Ying, 1988). It has also been used with specific subpopulations suffering from physical health complaints: chronic pain patients, hospitalized physically-ill patients, persons with rheumatoid arthritis, and stroke survivors (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997). It is important to note however that there are many ways in which the CES-D questions do not match the DSM (Diagnostic and Statistical Manual) criteria for depressive disorders. The questions do not address duration and intensity, which are important components for a diagnosis of disorder. Still, the CES-D scale has consistently been shown to be highly correlated with clinical diagnoses of depression, even among diverse populations (Morin et al., 2011; Van Dam & Earleywine, 2011; Zhang et al., 2012). Table 7 provides a list of all variables used in this chapter, with descriptions of the variable and basic summary measures of the variable in question.

Table 7. Independent variable descriptions (N=2655).

Variable	Type	Description	Range	Mean (SE)
<b>Age</b>	continuous	Self-reported age, mean-centered	55-102	73.08 (0.18)
<b>Gender</b>	binary	Self-reported gender, 1=female	0-1	0.61 (0.01)
<b>Race/Ethnicity</b>	categorical	Self-reported race and ethnicity questions combined to create three categories: Latino, non-Latino white, non-Latino black	N/A	N/A
<b>Educational Attainment</b>	categorical	Self-reported educational attainment transformed into four categories: less than high school attainment, high school attainment or equivalent, some college/technical school, bachelor's degree or higher	N/A	N/A
<b># comorbidities</b>	continuous	Scale score assigning one point each for history of hypertension, diabetes, Alzheimer's/dementia, cancer, stroke, heart disease, lung disease, and arthritis	0-8	2.89 (0.02)
<b># ADLs</b>	continuous	Scale score assigning one point each for any degree of reported difficulty with eating, bathing, transferring, dressing, and toileting	1-5	1.72 (0.02)
<b>Language preference</b>	binary	Self-report for whether or not English is spoken in the home; 1=foreign language spoken	0-1	0.13 (0.01)
<b>Receipt of personal care</b>	binary	Respondents who report receiving help with any of the ADLs with which they report difficulty are considered to receive personal help; 1= receives help	0-1	0.40 (0.01)
<b>Marital Status</b>	binary	Respondent assigned 0 if never married, widowed >2 years ago, divorced, or separated; assigned 1 if married	0-1	0.50 (0.01)
<b>CES-D score</b>	continuous	The sum of six "negative" indicators minus two "positive" indicators. The negative indicators measure whether the respondent experienced the following sentiments all or most of the time: depression, everything is an effort, sleep is restless, felt alone, felt sad, and could not get going. The positive indicators measure whether the respondent felt happy and enjoyed life, all or most of the time.	0-8	2.69 (0.04)

## **Analytic Strategy**

In Part A, a multiple linear regression was used to examine whether there are significant differences in number of reported depressive symptoms by race/ethnicity after adjusting for age, gender, educational attainment, number of comorbidities and ADL disabilities, and language spoken in the home. Then, a multiple logistic regression with the same covariates was used to examine whether there are differences in odds of reporting the receipt of personal care by race/ethnicity. In Part B, a fully-adjusted multiple linear regression was utilized to examine the presence of interaction effects between race/ethnicity and receipt of personal care on the number of reported depressive symptoms. In Part C, the sample of Latinos with ADL disability was divided by gender. Then, a multiple linear regression predicting depressive symptoms was utilized in each of the two subpopulations to examine interaction effects between marital status and receipt of personal care.

## **Results**

### *Descriptive Findings*

Table 8 summarizes basic descriptive statistics for all covariates and outcome measures by race/ethnicity.

Table 8. Distribution of covariates among the ADL-disabled, by race/ethnicity

Covariate	Latino (N=410)	White (N=1641)	Black (N=572)	Overall (N=2623)
<b>Age</b>	66.75 (0.54)	75.22 (0.28)**	67.50 (0.46)	72.14 (0.23)
<b>% Female</b>	0.61 (0.02)	0.59 (0.01)	0.65 (0.02)	0.61 (0.01)
<b>Educational Attainment</b>				
< High School	56.10	17.87	31.12	26.75
High School or Equivalent	23.90	40.12	30.77	35.55
Some College	14.63	24.09	27.45	23.34
Bachelor's +	5.37	17.93	10.66	14.38
<b>Foreign Language Spoken at Home</b>	0.63(0.02)	0.04 (0.004)**	0.05 (0.01)**	0.14 (0.01)
<b>Comorbidities (0-8)</b>	2.50 (0.07)	2.99 (0.03)	2.92 (0.06)*	2.89 (0.03)
<b># ADLs (1-5)</b>	1.72 (0.05)	1.65 (0.03)**	1.69 (0.04)	1.67 (0.02)
<b>CES-D Score (0-8)</b>	3.59 (0.13)	2.44 (0.06)**	2.86 (0.10)**	2.73 (0.05)
<b>% Receiving Personal Help</b>	0.41 (0.02)	0.38 (0.01)*	0.38 (0.02)	0.38 (0.01)
<b>% Married</b>	0.62 (0.02)	0.52 (0.01)	0.41 (0.02)**	0.51 (0.01)

\*significant difference from Latinos after adjusting for other covariates with p<0.05

\*\* significant difference from Latinos after adjusting for other covariates with p<0.01

Latinos with ADL disability were significantly younger than non-Latino whites, thereby supporting prior research (Warner & Brown, 2011). They also reported significantly lower levels of educational attainment than their non-Latino counterparts ( $\chi^2=274.63$ ,  $p<0.001$ ). They also reported fewer comorbidities than non-Latinos, but slightly more ADL disabilities than non-Latino whites. They were also more likely to be married than non-Latino blacks, which closely follows marital trends identified in prior research (Bulanda & Brown, 2007). Around 63% of the Latino subsample reported speaking a language other than English in the home, which is highly correlated with immigration status (Pew Research Center, 2017). Finally, Latinos reported significantly higher scores on the CES-D scale than non-Latinos, and were more likely to report receiving personal help than non-Latino whites.

Table 9. Distribution of comorbid conditions among the ADL-disabled, by race/ethnicity

Comorbidity	Latino	White	Black	Overall
<b>Hypertension</b>	0.74 (0.02)	0.70 (0.01)**	0.84 (0.02)	0.73 (0.01)
<b>Diabetes</b>	0.45 (0.02)	0.28 (0.01)**	0.41 (0.02)	0.33 (0.01)
<b>Alzheimer's/Dementia</b>	0.07 (0.01)	0.11 (0.01)	0.06 (0.01)*	0.09 (0.01)
<b>Cancer</b>	0.12 (0.02)	0.26 (0.01)*	0.15 (0.02)	0.21 (0.01)
<b>Stroke</b>	0.12 (0.02)	0.20 (0.01)	0.19 (0.02)*	0.18 (0.01)
<b>Heart Condition</b>	0.27 (0.02)	0.44 (0.01)	0.31 (0.02)	0.38 (0.01)
<b>Emphysema/Lung Disease</b>	0.12 (0.02)	0.21 (0.01)**	0.15 (0.02)	0.19 (0.01)
<b>Arthritis</b>	0.63 (0.02)	0.81 (0.01)**	0.81 (0.02)**	0.78 (0.01)

\*significant difference from Latinos after adjusting for other covariates with p<0.05

\*\* significant difference from Latinos after adjusting for other covariates with p<0.01

As shown in Table 8, Latinos reported significantly fewer comorbidities than non-Latinos. Table 9 provides fuller detail in to the distribution of comorbidities contained within the comorbidity scale. Latinos were significantly less likely to report arthritis than non-Latinos, and lower odds of reporting history of stroke than non-Latino blacks. When compared to non-Latino whites, Latinos had a higher risk of reporting hypertension and diabetes. However, they were less likely to report cancer and lung conditions than non-Latino whites, which may be partially driven by lower rates of smoking (Kaplan et al., 2014).

Table 10. Distribution of specific ADL disability by race/ethnicity

ADL	Latino	White	Black	Overall
<b>Transferring</b>	0.53 (0.03)	0.32 (0.01)*	0.38 (0.02)*	0.38 (0.01)
<b>Dressing</b>	0.64 (0.03)	0.57 (0.01)	0.55 (0.02)	0.58 (0.01)
<b>Bathing</b>	0.27 (0.02)	0.42 (0.01)**	0.40 (0.02)**	0.39 (0.01)
<b>Eating</b>	0.20 (0.02)	0.20 (0.01)	0.15 (0.02)	0.19 (0.01)
<b>Toileting</b>	0.22 (0.02)	0.33 (0.01)*	0.34 (0.02)*	0.31 (0.01)

\*significant difference from Latinos after adjusting for other covariates with p<0.05

\*\* significant difference from Latinos after adjusting for other covariates with p<0.01

Table 8 showed that Latinos reported a slightly higher average number of ADL disabilities than non-Latino whites. As shown in Table 10, this trend may be driven by higher reporting of difficulty with completing transferring in and out of bed. However, Latinos were less likely to report difficulty with independently bathing or toileting than non-Latinos.

*Part A: Among the ADL-disabled, are there significant differences in total number of depressive symptoms by race/ethnicity? Are there differences in odds of receiving personal care?*

Table 11. Multiple linear regression predicting CES-D score among the ADL-disabled: covariates only			
Variable	OR	SE	p-value
<b>Age</b>	-0.047	0.005	<0.001
<b>Female</b>	0.356	0.098	<0.001
<b>Educational Attainment</b>			
High School/GED	-0.214	0.128	0.096
Some College	-0.387	0.141	0.006
Bachelor+	-0.733	0.162	<0.001
<b>Comorbidity Scale</b>	0.165	0.036	<0.001
<b># ADLs</b>	0.510	0.053	<0.001
<b>Foreign Language</b>	0.089	0.179	0.620
<b>Race/Ethnicity</b>			
White	-0.478	0.179	0.008
Black	-0.557	0.188	0.003

Table 11 provides results from the covariates-only model predicting CES-D score among all respondents who reported the onset of ADL disability from a prior wave. Those who are younger actually report higher scores on the CES-D scale than those who are older, which defies prior research about age and depression. This finding may point towards the role of expectations of health and aging; younger individuals may experience more mental distress at the onset of

functional limitations. Functional disability may be particularly devastating for younger individuals who are still expecting to maintain social and/or economic activity. Women are also more likely to report higher CES-D scores, as are those with lower levels of educational attainment. Those with fewer comorbidities and fewer reported ADL disabilities have lower levels of depressive symptoms. Use of language in the home had no significant relationship with depressive symptoms. After controlling for all of those measures, Latinos on average reported 0.665 points higher on the CESD scale than non-Latino whites ( $p<0.001$ ) and 0.735 points higher than non-Latino blacks ( $p<0.001$ ).

Table 12. Multiple logistic regression predicting odds of receiving personal help among the ADL-disabled: covariates only			
Variable	OR	SE	p-value
<b>Age</b>	1.035	0.005	<0.001
<b>Female</b>	0.984	0.094	0.864
<b>Educational Attainment</b>			
High School/GED	1.114	0.138	0.384
Some College	0.949	0.131	0.707
Bachelor+	0.885	0.141	0.446
<b>Comorbidity Scale</b>	1.170	0.041	<0.001
<b># ADLs</b>	2.723	0.149	<0.001
<b>Foreign Language</b>	1.178	0.203	0.343
<b>Race/Ethnicity</b>			
White	0.671	0.116	0.022
Black	0.867	0.159	0.437

Table 12 provides the results from the covariates-only model of a multiple logistic regression predicting the odds of receiving personal help with completing a relevant ADL disability. Older respondents were more likely to report receiving help. Gender, language use in the home, and educational attainment were not significantly associated with odds of receiving

help with an ADL task. Reporting one additional comorbidity was associated with a 20% increase in odds of receiving help, and reporting difficulty with one additional ADL was associated with more than twice the odds of receiving personal help. Finally, non-Latino whites had lower odds of receiving personal help than Latinos (OR=0.671, p=0.022).

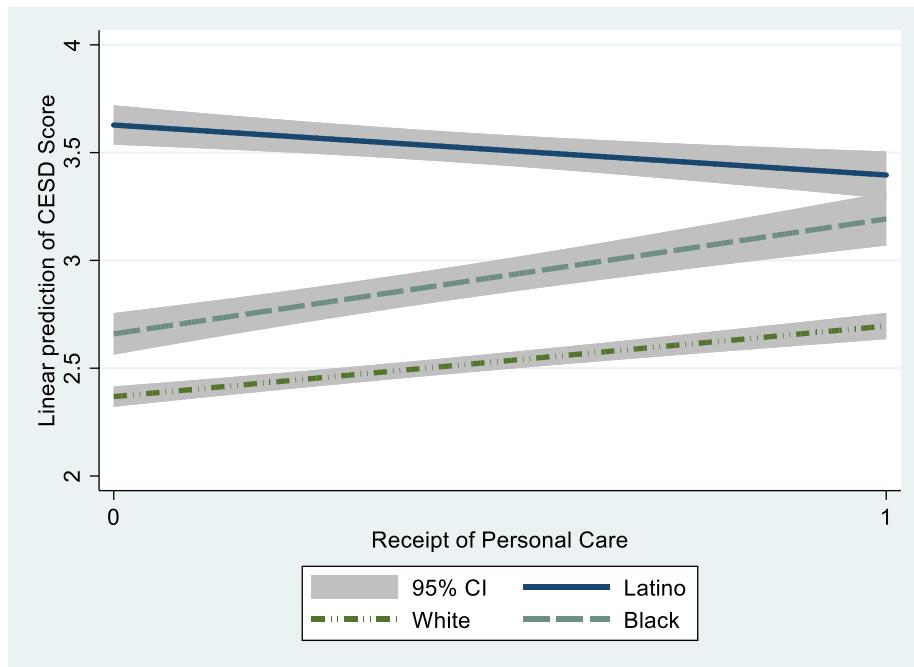
*Part B: Does the relationship between the receipt of personal care and depression vary by race/ethnicity?*

Among all of the ADL-disabled older adults in the sample, receiving personal help was strongly correlated with increased CES-D scores ( $r=0.362$ ,  $p=0.0339$ ), supporting prior research. This section asks whether or not the relationship between depressive symptoms and receiving personal help varies by race/ethnicity. To do this, a fully adjusted multiple linear regression predicting CES-D score was run with an interaction term between care receipt status and race/ethnicity. Table 13 provides the predicted mean CES-D scores by race/ethnicity and care receipt status after adjustment for the full set of covariates. Latinos who receive help demonstrate lower CES-D scores, whereas non-Latinos who receive help demonstrate higher CES-D scores. The Wald test for this interaction after full adjustment was significant ( $F=3.45$ ,  $p=0.0042$ ). This supports the prior hypothesis that Latinos may expect to receive help and care upon experiencing disability, whereas non-Latinos may have a stronger expectation to remain independent. Not receiving help would therefore defy expectations and be more stressful for Latinos, whereas receiving help might challenge notions of the independent self and cause additional stress for non-Latinos. Figure 2 visually depicts the relationship between receipt of personal care, CES-D scores, and race/ethnicity.

Table 13. Adjusted predicted mean CES-D scores among the ADL-disabled by race/ethnicity and personal help status (SE)

Care Receipt Status	Latino	White	Black	Overall
No Help	3.63 (0.04)	2.37 (0.02)	2.66 (0.04)	2.62 (0.02)
Receives Help	3.37 (0.07)	2.70 (0.03)	3.23 (0.08)	2.92 (0.03)
<b>Mean Difference (SE)</b>	0.26 (0.08)	-0.32 (0.04)	-0.57 (0.07)	-0.31 (0.04)

Figure 2. Linear prediction of CES-D scores among ADL-disabled by race/ethnicity and receipt of personal care



*Part C: Among Latinos, what role do gender and marital status play in the relationship between receipt of personal care and depression among the disabled?*

This section details results from two separate analyses examining the role of gender, marital status, and receipt of personal care among Latinos who report ADL disability. The sample of disabled Latinos was divided by gender. Then, a multiple regression model predicting CES-D score was utilized to examine the interaction effect between marital status and care receipt status for each of the two subsamples of disabled Latinos. Table 14 provides the linear

predictions of CES-D scores by gender, marital status, and receipt of personal care after full adjustment for all other covariates. The Wald test for the interaction effect was significant among women ( $F=4.76$ ,  $p=0.0032$ ) and marginally significant among men ( $F=2.59$ ,  $p=0.076$ ). Figure 2 provides a visual representation of these relationships.

Table 14. Postadjustment CES-D score predictions among ADL-disabled Latinos by gender and marital status

Care Receipt Status	Men		Women	
	Single	Married	Single	Married
No Help	3.45 (0.06)	2.94 (0.04)	4.56 (0.02)	3.03 (0.02)
Receives Help	4.34 (0.07)	2.60 (0.05)	3.56 (0.03)	3.27 (0.04)
<b>Mean Difference (SE)</b>	-0.89 (0.10)	0.34 (0.06)	1.00 (0.04)	-0.25 (0.04)

Figure 3. Predicted CES-D scores by marital status, gender, and receipt of personal care among Latinos with ADL disability

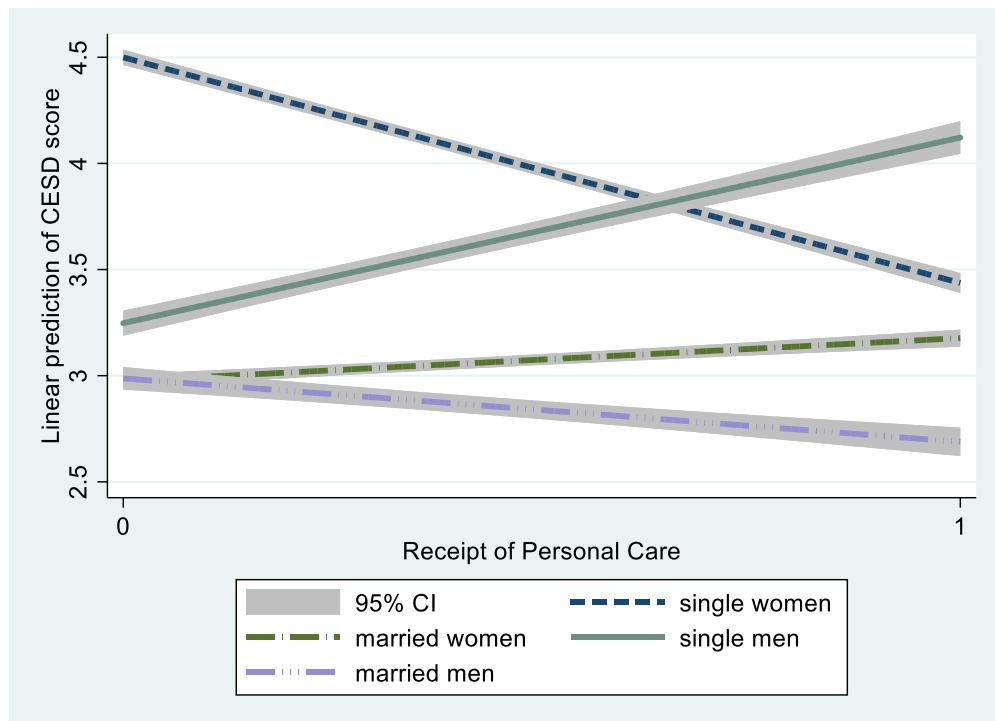
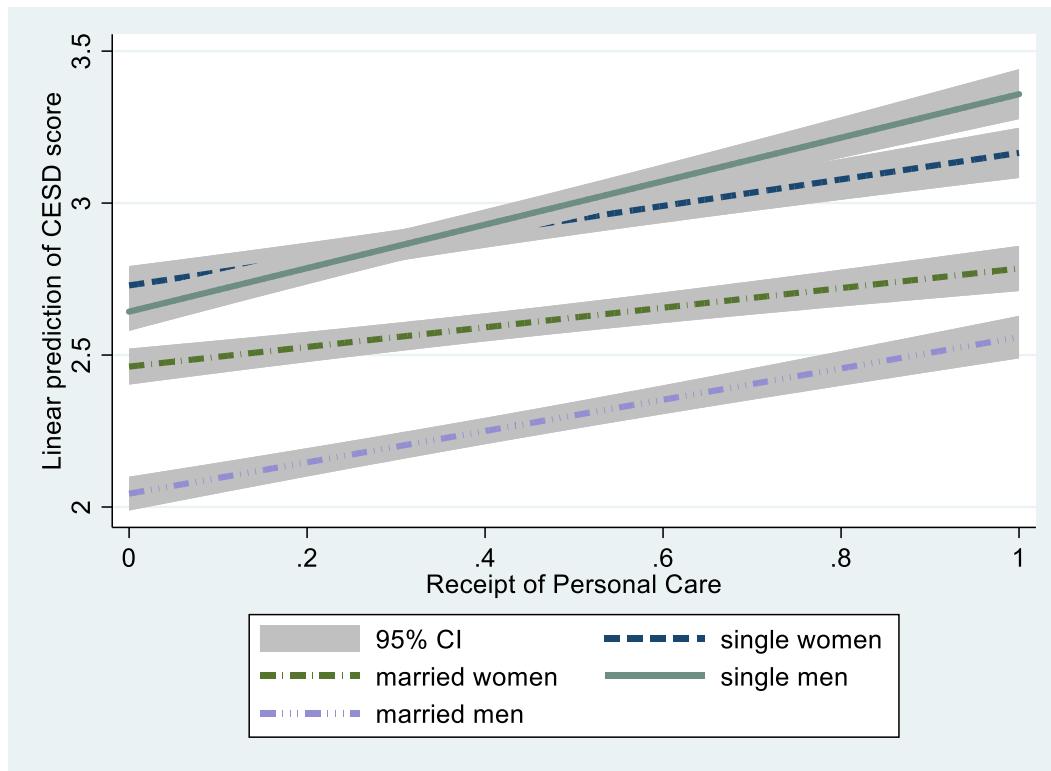


Figure 3 shows that married individuals who do not receive care report similar CES-D scores, but receiving care is associated with reporting more depressive symptoms for married women and with fewer depressive symptoms for married men. Single women who do not receive care report the highest CES-D scores, but those who receive care report fewer symptoms. For single men, the relationship operates in the opposite direction: receiving care is associated with higher scores on the CES-D scale.

For comparison's sake, Figure 4 depicts the relationship between depressive symptoms and care receipt by gender and marital status among non-Latinos. The Wald test for interaction effects between marital status and care receipt among non-Latino men was insignificant ( $F=1.59$ ,  $p=0.195$ ), but was significant for women ( $F=4.76$ ,  $p=0.0032$ ). Of note is a significant difference between single Latina women and single non-Latina women. The Latina women report more depressive symptoms on average than the non-Latina women, but single Latina women who receive care report fewer symptoms than those who do. This pattern is the opposite for single non-Latina women. This may be because Latina women expect to receive care upon experiencing disability, and most likely receive that care from younger, female family members. Receiving that personal help from family may not only comply with their expectations, but can also serve as a demonstration of care and commitment from others that buffers the stress of physical decline. For non-Latina women though, receiving care may be a significant stressor in that it forces the individual to confront their declining levels of function and independence.

Figure 4. Predicted CES-D scores by marital status, gender, and receipt of personal care among all non-Latinos with ADL disability



Note that for all subcategories of non-Latinos, receiving personal help with the completion of an ADL task is associated with the report of more depressive symptoms. Married individuals report fewer depressive symptoms than single individuals. Single men who receive personal care report the highest number of depressive symptoms.

## Discussion

### *The role of race/ethnicity in the relationship between disability and depressive symptoms*

Prior research shows that older adults with ADL disability are significantly more likely to report depressive symptoms than those without disability, and that receiving informal, personal

care further amplifies the risk for reduced psychological health. However, this chapter enriches this conversation by showing that the relationship between depressive symptoms and ADL disability varies by race and ethnicity. First, I showed that Latinos who have difficulty completing activities of daily living report significantly higher CES-D scores than their non-Latino counterparts, even when controlling for the full range of covariates. These findings suggest though that while ADL disability may predict reduced psychological health among older adults, this relationship is not homogeneous across racial/ethnic groups.

The mechanisms for this phenomenon could be varied, and provide ample opportunity for future research. For example, it could be the case that difficulty with particular ADLs—like transferring in and out of bed—are more significant predictors of depressive symptoms than others. Latinos may also not be anticipating bodily decline as a part of their aging experience, and thereby experience more disruption to their lifestyle and sense of well-being than others. They may also lack access to the necessary healthcare treatment that would mitigate their symptoms, thereby reducing psychological distress. Additionally, the pathway between disability and depression may differ by race/ethnicity, wherein Latinos who are depressed are more likely to report difficulty with basic activities than others, thereby inflating average number of reported depressive symptoms among the disabled. Each of these hypotheses could, separately or together, explain the modest increase in depressive symptoms among Latinos relative to their non-Latino counterparts. Future qualitative research could explore how Latino imagine their own aging experiences in the future, as well as how they think about the aging body and physical decline. Longitudinal research in public health could also explore the temporal relationships between depression and disability by race/ethnicity, as well as how Latinos respond to the onset of ADL disability.

### *The relationship between race/ethnicity and the odds of receipt of personal care*

Ethnicity was also a significant predictor of odds of receiving personal care, as Latinos were significantly more likely than non-Latino whites to report care receipt, even after controlling for relevant sociodemographic and health-related variables. These findings support prior research showing that minority groups are more likely to plan for and utilize informal care in old age as a coping strategy for the challenges of aging and bodily decline. It also supports the hypothesis that sociocultural groups with a strong sense of familism tend to have a higher likelihood of utilizing informal caregiving as a strategy for aging. Future research could explore whether need, enabling resources, or predisposing factors are the most significant contributors to this trend.

Additionally, though the analysis controlled for total number of ADL disabilities, it is possible that odds of care receipt vary along with the specific task that an individual reports difficulty. Prior research has found that individuals with difficulty bathing and toileting are more likely to require personal help than individuals with difficulty with the other tasks (Desai, Lentzner, & Weeks, 2001). However, Latinos were significantly less likely to report difficulty independently completing bathing and toileting, yet still reported receiving personal help at an even higher rate than non-Latino whites. As such, there may be different patterns between personal care receipt and specific ADL disability by race/ethnicity, as well as the extent to which a disability is perceived as requiring help by both the care recipient and the caregiver. Though this study did not ask about the relationship of the caregiver to the respondent, it may also be the case that family members are more likely to be the caregivers for older Latinos in need of assistance, and may be more willing and/or able to provide that care relative to individuals from other ethnic groups.

*The roles of gender, marital status, and ethnicity in the relationship between care receipt and depressive symptoms*

In Part A, I showed that disabled Latinos report slightly higher CES-D scores than others, and they are more likely to receive informal, personal care than non-Latino whites. Prior scholarship has consistently shown that receiving personal care with completing ADL tasks is associated with an increased risk for depressive symptoms. However, while Latinos simultaneously report significantly more depressive symptoms and higher odds of receiving personal care, the receipt of that care may actually *improve* their mental well-being. Latinos who reported receiving personal help from others reported slightly lower CES-D scores than Latinos who did not receive personal care. This relationship was the exact opposite for both non-Latino whites and non-Latino blacks; for non-Latinos, receiving care was associated with an increase in depressive symptoms. For non-Latinos, these findings support previous research suggesting that receiving intimate care is a disruptive force in the life of the care recipient as well as the caregiver. Receiving care may lower feelings of autonomy and self-determination, which may cause significant distress in a culture that prioritizes independence at all stages of life. For Latinos though, the relationship between personal care and well-being belies the dominant narrative of the “autonomous self”. In a population where a significant proportion are immigrants, western cultural values of autonomy may not be a significant player in health and care during old age. Instead, receiving care from family may actually *improve* well-being in that it is the fulfillment of an expectation that one may have for confronting bodily decline and aging. It may also be a demonstration of love from one’s partner or children, and thereby an indicator of an attained social status in the family, instead of an indicator of dependence. Instead of adding to

the psychological burden of physical decline, receiving care may actually provide emotional comfort and relieve some of that burden for older Latinos.

When examining the Latino population more carefully however, this pattern may be much more nuanced, and driven by single women and married men, who comprise the largest subpopulations of disabled Latinos in this analytic sample (31% and 28.49%, respectively). For those two groups, receiving help is associated with lower amounts of reported distress, whereas for married women and single men, receiving care has the opposite association with reported depressive symptoms.

Among all four of these groups, however, the relationship between gender, marital status, and expectations of the family and of the self upon experiencing health declines in old age may play a significant role in the relationship between care receipt and mental well-being. Both single women and married men report fewer depressive symptoms upon receiving care when compared to their peers who don't receive care. For single women, caregiving most likely happens from children or other family members (Spitze & Ward, 2000). In that case, receiving personal help may index care and support from family that improves a sense of well-being. For an older, single Latina woman, struggling with a disability without help may provoke feelings of loneliness or an isolated struggle done without the support of family. Meanwhile, receiving care from children or other family members may indicate that the older woman in question is still embedded within a strong, supportive social network. While ADL disability may still spark psychological distress, the presence of the family as caregiver may mitigate that response by fostering feelings of support and inclusion.

Similarly, married men who receive care nearly always receive that care from their wives (Spitze & Ward, 2000). As mentioned before, the marital relationship may provide a key source

of support that aligns with the stress-buffering hypothesis, which suggests that access to supportive relationships may ameliorate the effects of disability on psychological health (Warner & Kelley-Moore, 2012). For married Latino men, the direction of care in that particular relationship dyad may actually improve the marital relationship and/or confirm expectations wherein women are expected to care for the men in their families (Cianelli et al., 2008; Wentzell, 2013b). As wives have, in all likelihood, spent a great deal of time across the life course caring for the family, caring for a husband may be expected and note entirely unusual. In contrast, a married man who does not receive care from his wife when experiencing difficulty with a basic task may feel neglected and that his marriage is not living up to expectations.

Meanwhile, ADL-disabled Latinos who are single men or married women follow patterns between care receipt and psychological distress that are more similar to the observed patterns for non-Latinos. As shown in Figure 3, for each subgroup of non-Latinos, receiving care was associated with an increase in depressive symptoms. For Latinos though, this trend was limited to single men and married women. For those two groups, those who receive care report higher CES-D scores on average than their counterparts who do not receive care. Single men who receive care likely receive that care from their children or from non-related caregivers, such as daughters-in-law or hired help (Barrett & Lynch, 1999). This may significantly disrupt expectations for the flow of care in advanced age. Men likely expect to receive care from their wives in old age, much like they do throughout the life course. However, for men who are widowed or divorced/separated, this script about aging and care becomes an impossibility for them. Relying on children disrupts the flow of care for men, who are expected to be strong providers for their families throughout the life course, even upon experiencing aging (Wentzell, 2013). If anything, bodily decline is an indicator among older Latino men that they should be

*more* responsible for their families than before, and requiring intimate care for daily tasks may be a significant stressor to feelings of well-being (Wentzell, 2013). It's also possible that single men who require care have a more severe disability that is worsening overall health, well-being, and functioning in a way that is not captured by tallying the total number of ADL disabilities and comorbidities. Given that men may have a strong preference to prolong independent functioning, requiring personal care may indicate a more severe illness that is also related to depressive symptoms.

The story may be similar for married women, in that married women who receive care may be receiving that care from unexpected and undesired sources. Married women who receive care most likely get that care from their husbands, which may disrupt expectations for the flow of caregiving. In addition, their husbands may be less adept caregivers. Alternatively, women may receive care from their daughters or other female relationships instead of from their husbands, which may similarly lead to feeling a lack of support from their romantic partners. Taken together, these findings suggest that there may be pathways of care among Latinos that flow in a clear direction: Men receive care laterally from their spouses, whereas women receive care vertically from children. Among older Latinos, cultural tropes of machismo and marianismo may remain powerful drivers of behavior and expectations. Women are lifelong caregivers and men are lifelong providers, and care arrangements that do not align with those patterns are stressful and disrupt one's sense of self and well-being. When single men cannot receive care from a spouse and instead receive care from others, the expectation of the flow of care is disrupted. When married women receive care from their husbands or children instead of giving it, the direction of the flow of care is also disrupted. These disruptions may have a profound impact on senses of well-being and overall psychological health.

Though the role of both gender and marriage are important, it's also of note that marital status alone is a significant predictor of depressive symptoms among the disabled. Single individuals of both genders report significantly higher amounts of psychological distress, regardless of whether or not they receive help. Married individuals have lower amounts of psychological distress, regardless of gender and care receipt status. These findings support prior research that marriage provides protective psychological benefit to older adults. It also suggests that marriage and the marital relationship may be an even more central component to Latino health outcomes than familism. While a great deal of research has focused on familism among Latinos—including the importance of relationships with children and respect/care towards elders—less research has examined the marital context of Latinos and the role it may play in their health outcomes. Future research could explore whether marital status—and marital quality, for the married—interact with gender and ethnicity to produce divergent disability outcomes.

### *Conclusions*

Latinos report slightly more depressive symptoms upon the onset of ADL disability than their non-Latino counterparts. Receiving care reduces these symptoms among the general Latino population, but amplifies it among others. While a large body of research has documented highly gendered pathways of caregiving across many different communities, the salience and impacts of those pathways may vary along with other cultural forces. In cultures where independence and autonomy are highly valued at all stages of the life course, receiving or requiring intimate care from any source may be distressing. However, for individuals who have spent the life course embedded in more interdependent communities, these pathways of caregiving may be internalized in such a way that receiving care is actually desired and beneficial to overall well-

being, inasmuch as that care conforms to community ideals about quality and sources of caregiving. For that reason, receiving care is distressing among non-Latinos in the United States, who spend a lifetime embedded in a neoliberal rhetoric of independence. Among Latinos though, married men and single women are able to receive care from normalized sources: female relatives. This care may provide feelings of both instrumental and emotional support, thereby mitigating the psychological distress that can occur upon the onset of ADL disability. Married women and single men, however, may find themselves without a culturally appropriate or adept caregiver, such that receiving care further amplifies the depressive symptoms they feel upon the onset of disability. Future research should address the relationship of the caregiver to the recipient and how that impacts psychological health for both. Additionally, expectations for aging and care receipt may vary by race/ethnicity, as well as the extent to which those expectations are related to health outcomes.

## **Chapter Three. Unimagined futures: The paradox of familism and successful aging among older Latinos in the Chicagoland area**

### ***Abstract***

Scholars of gerontology have highlighted the multitude of ways in which ideas about aging vary cross-culturally. Whereas North Americans tend to describe “successful aging” as the maintenance of independence, Latin Americans have often been described as approaching aging as a more natural process of social transition. However, little research has been conducted to explore how older Latinos living in the United States conceptualize positive aging, nor how they integrate competing cultural narratives of the family. This study uses qualitative data from focus groups and interviews with 115 older adults of Latino descent in the Chicagoland area to probe how they consider successful aging, how they approach the health declines that accompany aging, and their ideal relationships with their family members. I argue that the older adults in this study adopted a North American rhetoric of “successful aging” or “aging well”, wherein a positive experience of old age includes the maintenance of independence and physical functioning. This was true even among the respondents who were immigrants, suggesting that cultural frameworks for a “good old age” may be more malleable than previously thought. However, the cultural values of *respeto* and *familismo* are not as malleable. Respondents consistently demonstrated the centrality of the family and the elevated status of elders, and their families were a frequent and ready resource to confront the challenges of aging. When taken together, a “successful old age” is one where the individual maintains physical independence with an interdependent, kin-focused, social life. This paradoxical combination produces a number of challenges and internal conflicts for Latino adults as they experience the social transition to older adulthood.

## ***Introduction***

The prior two chapters of this dissertation used national social survey data to argue that older Latinos with ADL disability experience the social world differently from their non-Latino peers, and that gender and marital context are important factors in the way that disability and care receipt are experienced. This final study uses qualitative methods to further probe these findings. Following Creswell's (2003) sequential explanatory design strategy for mixed methods, the qualitative results detailed in this chapter seek to explain and contextualize the findings from the first two quantitative studies. To contextualize the findings about aging, bodily decline, and social context probed in the first two chapters, this study asked older Latino adults to consider what "aging well" would look like for them, and how they would address any future health needs. How do they describe their ideal relationships with their family members, and what are their preferred care arrangements? To explore these research questions, I utilized data from 9 focus groups with 101 Latino older adults in the Chicagoland area, and conducted 20 additional in-depth interviews. I ultimately argue that though this is a largely immigrant population, North American ideas about "successful aging" have been largely taken up by this population, producing adverse emotional reactions to aging-related declines. While visions of a good old age are largely in line with North American ideals, the cultural values of *familismo* and *respeto* remain of critical importance. However, while the centrality of the family provides for valuable care arrangements and emotional support after the onset of illness, it can also create real tensions and internal conflicts as Latino older adults confront the social and biological changes that accompany aging.

## ***Background***

As the world's population of older adult grows at unprecedented rates, the proportion of older adults in the United States that is Latino is also growing. While there are approximately 3.6 million older adult Latinos in the United States currently (about 8% of the total older adult population), this number is expected to grow to 21.5 million by 2060, which will be 22% of the older population in the US (Administration for Community Living, 2017) . As discussed previously in this dissertation, their healthcare challenges are also significantly different from those of their non-Latino peers. While they have lower rates of some illnesses like cancer, their risk for other chronic diseases like diabetes and ADL disability is higher than it is for their peers, even when adjusting for relevant socioeconomic characteristics (Gallo et al., 2009). Adequately addressing the healthcare needs of a growing older adult population will be of increasing concern in coming decades, and this need will coincide with diversifying populations and their accompanying health concerns. Latino older adults will soon be the largest minority group of older adults and, as such, understanding how they think about aging well and how they ideally confront health challenges is crucial towards designing better healthcare policies and programs.

Aging, is, however, a primarily social experience and as such, the definition and experience of older adulthood can vary dramatically between different sociocultural groups. Which bodily changes signify old age is highly variable around the world, and frailty does not necessarily signal a decline in social status (Lamb, 2013; Lock, 1993). For example, among the Brahmins of North India, bodily changes in old age are seen as potentially difficult but desired, as they signified an important phase of transition towards death (Lamb, 2000). In contrast, Japanese law formalizes reciprocal expectations that older adults are due love and respect, and they in turn are expected to maintain physical and mental health and to participate fully in

society (Traphagan, 2000). Similarly, many North American and European contexts associate bodily decline and frailty with dependence, which creates deep threats to personhood for both older adults and those who care for them (Buch, 2013). In Botswana, the rising prevalence of chronic illness means that many older adults exhibit the physical signs of aging long before they are seen socially as elders, thus limiting their ability to claim and receive care from younger relatives. At the same time, changes in the national pension system have imposed numerical definitions of old age, therein adding yet another layer to the meaning of old age in the Botswanan context (Livingston, 2003, 2005).

This large body of research in the anthropology of aging repeatedly demonstrates that aging and bodily decline are socially defined experiences, wherein individuals' responses to bodily change in old age are shaped by the sociopolitical environment. As an extension, conceptualizations of successful aging are culturally determined as well, and merit attention if we are to adequately address the healthcare needs and desires of an ever-growing, ever-diversifying population. Research in Latin America has found that conceptualizations of successful aging more closely follow the Indian model, where aging and bodily changes are not necessarily seen as a mark of dependence and shame. In Mexico for example, aging is a particularly gendered experience where bodily aging—including the loss of erectile function—is viewed as part of a wider array of changes in which older men begin focusing more on the home and family, rather than on infidelity and other demonstrations of their sexual virility (Wentzell, 2013b, 2013a). A multinational study examining ideas about “successful aging” found that Latin Americans from seven different countries were more likely to focus on maintaining a positive outlook, living in the present, enjoying a sense of community, and relying on family as critical components of aging well when compared to their Anglo or Japanese counterparts (Hilton et al.,

2012). Another study found that older Mexican Americans viewed aging positively as long as cultural expectations for the family were fulfilled (Beyene, Becker, & Mayen, 2002). Taken together, these findings suggest a more holistic view towards aging among Latin Americans that extend into the Latin American immigrant community in the United States. For Latinos, aging may be seen as a natural component of the life cycle that can be a positive experience with the right family and community environment.

In the previous chapters of this dissertation, I found that among the disabled, mortality and social context are differentially associated according to race/ethnicity, and that gender, marital status, and ethnicity play a significant role in how care receipt is associated with depressive symptoms. However, both of these studies were associative in nature, and though they accurately depict national-scale trends in health among the ADL-disabled, the quantitative methods deployed are unable to adequately contextualize how health challenges are experienced by Latinos. Therefore, in order to adequately provide meaning to the findings from my quantitative research, in this study I complete the second step of a sequential explanatory design for mixed methods research. This design, first proposed by Creswell (2003), is a two phase design where the quantitative data is collected first, followed by qualitative data collection. The purpose is to use the qualitative results to further explain and interpret the findings from the quantitative phase. In this study I use data from both focus groups and interviews with older adult Latinos in the Chicagoland area. Participants were asked to describe what “aging well” would look like for them, what their ideal relationships with their families would look like, and what their preferred care arrangements would be. By asking these questions, I aim to contextualize the findings from my prior research and contribute to the literature by challenging

current lines of thought about minority aging, immigrant populations, and what it means to age well.

## ***Data and Methods***

### *Study Design*

This study utilized data from focus groups and interviews of elderly Latinos in the Chicagoland area with a total of 115 different participants. The focus groups and interviews emphasized slightly different aspects of the research question, though their combined data were used to explore how stressful physical decline may be for elderly Latinos, what their optimal solutions for overcoming any difficulties are, and the role they imagine for their families in this process. In this way, this qualitative study seeks to provide meaning to the findings from the prior two quantitative studies.

Focus groups foster the creation of a group dynamic that leads to brainstorming, generating ideas, and a deeper discussion of the ideas at hand. As the research questions of this project concern the ways in which sociocultural context shape expectations and ultimate mental health outcomes, observing individuals from the same sociocultural background debate and interact on the topic allowed for richer insight to the dynamics and tensions at play. In this study, all focus groups were conducted in either Spanish or English with older Latinos in the Chicagoland area. Cook County has the fourth largest Latino population by county in the country. Additionally, the Latino population of Chicago has a high number of Mexicans, Puerto Ricans, and Central Americans, allowing for a more cohesive picture of Latinos in the United States. The focus groups were a component of a larger research project that was funded by

Mather LifeWays to explore local understandings of "positive aging" among Latinos in the Chicagoland area.

A total of 9 focus groups were completed, with a total of 101 participants. All of the focus groups were conducted in various social service organizations across the city. Some of these organizations included an adult day center, a residential facility, a café oriented towards older adults, and a public healthcare clinic. Participants in the focus groups were recruited through their connections to the respective organization that sponsored their focus group. Three focus groups were done in English, and six in Spanish. Ages ranged from 50 to 97, with a median age of 70 years old. 72% of the focus group participants were women, and 80% were immigrants. In the focus groups, participants were prompted to discuss what "aging well" or "aging positively" meant to them.

Initial findings from the focus groups guided the construction of an interview guide that was used with 20 older (aged 60+) Latinos—8 men and 12 women. Six of the interview participants also participated in the focus groups. Eight additional participants were recruited from local churches and community centers that differed from the focus group recruitment centers. Six participants were recruited via snowball sampling in order to reach individuals that were not connected to any of the aforementioned social institutions. Among the interview participants, 12 were interviewed individually and 8 were interviewed with a partner. These partners included one pair of sisters that lived together, and three married couples. Table 15 provides basic demographic descriptors for all study participants.

Table 15. Study participant demographic features

Variable	Focus Groups (N=101)	Interviews (N=20)
<b>Mean Age</b>	71.26	73.95
<b>Percent Female</b>	72.00%	60.00%
<b>Educational Attainment</b>		
< Primary (8th grade)	21.11%	15.00%
Primary (8th-11th grade)	32.22%	40.00%
Secondary or Equivalent	24.44%	30.00%
Some College+ <sup>1</sup>	22.22%	15.00%
<b>Place of Birth</b>		
US	19.49%	15.00%
Mexico	57.14%	45.00%
Other <sup>2</sup>	23.47%	40.00%
<b>Preferred Language</b>		
English	13.27%	15.00%
Spanish	70.41%	70.00%
Both equally	15.31%	15.00%

1. This category includes completion of some college credits, trade/technical school, an associate's degree, or higher

2. Includes 9 additional Caribbean and Central/South American countries, including Puerto Rico.

#### *Data Collection and Analysis*

Focus groups lasted approximately 60 minutes, and the interviews lasted between 45 and 60 minutes each. The focus groups all asked the participants to describe what “successful aging” or “positive aging” meant to them, with limited guidance or prompting from the researcher. The interview guide featured three main topics with appropriate follow-up questions. The first topic asked the participants to broadly consider how they think about “aging well”, and whether or not they themselves are aging well or anticipate aging well. Then, participants were asked how declines in health or functioning might impact how they feel about themselves, and what their

preferred care arrangements would be. Finally, participants were asked to consider their relationships with family, friends, and spouses, and how they wanted those relationships to look in the future. After each focus group and interview, participants were asked to fill out a short demographic questionnaire. All participants were compensated with \$10 in cash for their time.

Upon completion of all data collection, all of the recordings were transcribed in their original language. These transcriptions were entered in to QDA Miner Lite 2.0 for data analysis. Transcriptions were coded thematically and organized into various domains, such as health behaviors, health beliefs, and relationships, for example. These codes were then analyzed for key trends in the data. All data was kept in its original language for analysis.

### ***Results and Discussion***

With a surging population of older adults across the world, there has been renewed and continued interest in how to age well, or “successfully”. As that body of research has grown, so too has interest in experiences of aging among minority populations. As I led a focus group exploring ideas about “aging well” at a large day center for older Latino adults on the west side of Chicago, a woman named Clara shared that she had recently had a fall in her apartment. She commented, “Four months ago I fell. It took me six hours to get up, but I got up!”. As others in the room chuckled, she went on, “Well, my sister had to help me up. She came home and said ‘What are you doing down there?’, and I said ‘Well, I fainted!’. ‘How long ago?’ ‘Well, there isn’t a clock down here!’”

Clara’s humorous recounting of what would otherwise be a concerning tale disguised what would become a pivotal moment in her life. Clara later explained to me that her daughter had been asking her to move in with her for years. Clara’s daughter was concerned for her

mother's health, and had been offering her mother a room in her home for many years. Clara had refused because she valued her independence, and enjoyed living in the same building as her sister. After the fall though, Clara agreed to move in with her daughter on the condition that her sister come as well. Soon, Clara's daughter was caring for her two sons—who now shared a room—and her mother and aunt. Despite the more cramped living quarters, Clara acquiesced that the situation was, in some ways, better. She claimed, "Well at first, [my sister and I] didn't want to, but we're little old ladies now. It's good to help my daughter, and to also know that if I fall again, someone else is at home."

Clara's story highlights multiple themes I found throughout my conversations with the older adults in this study. She strongly valued her physical independence, even as her daughter encouraged her to let her care for mother. Clara instead preferred the mutual support with her sister instead of imposing on her daughter, until the decline in her physical strength became undeniable. Even as she acknowledged her growing health needs and moved in with her daughter, the care relationships were dynamic and multidirectional. This struggle to accept the realities of aging, the conflicting emotions about the role of the family, and intergenerational care relationships were common themes among the older adults I spoke with. The current cohort of Latino older adults is a majority immigrant population whose own aging experiences are a continuation of the lifelong journey of migration, assimilation, and adjustment into a host culture with competing values and interests. Their struggles to 'age well' are shaped by the dominant cultural values of both their host country and sending communities, which can combine in paradoxical and challenging ways. While other scholars have argued that Latinos approach aging as a natural, inevitable process, I instead find that the older adults in my sample viewed aging as an altogether undesirable, stressful process of physical decline and dependence. However, even

as their ideas about aging were more aligned with neoliberal North American narratives, the cultural ideals of *familismo* and *respeto* remained of key importance. The result is a paradoxical landscape of aging, where, in order to age well, one must maintain both independent physical functioning and highly interdependent family relationships—both of which can come at a cost.

*“I wouldn’t like to be in my 90s”: Aging well by not aging*

As the global population is aging, there has been an uptick in research exploring global aging and how “aging well” is perceived cross-culturally. In Latin America, this research has documented the importance of interdependent kin ties in the aging process, as well as a more holistic and spiritual view of the body as an aging vessel (Fernández-Ballesteros et al., 2010). For example, Emily Wentzell (2013b) has documented that among aging Mexican men, experiencing erectile dysfunction and bodily decline can be a trigger that encourages them to refocus on the family, instead of on demonstrating sexual virility. A study by McCarthy and colleagues (2004) argued that older Latina women view the decline of health in old age as natural and anticipated. They embody a more collectivist perspective in that health and illness are connected to an interdependence with family; elderly expect care from family as they become frailer. These qualitative findings are mirrored in quantitative social survey analysis; Latinos over the age of 65 are less than half as likely to live alone as non-Latino whites, and they are more likely to report more kin-centered social networks (Cornwell & Waite, 2009) and residence in multigenerational households (Cohen & Casper, 2002).

Despite a large body of research suggesting that aging may be viewed as a positive social process among Latin Americans, the older adults in this study were often puzzled when asked to consider what ‘aging well’ would look like for them. In an interview, a 74-year old immigrant

woman named Delia commented, “I feel like you can never say ‘I’m getting old’. You can’t. It doesn’t fit in my, in my dictionary.” Another woman, Ana, who was born in Chicago, remarked in a focus group, “Is there a positive in aging? All I see is old, crabby people. I don’t want to be like that.” Both of these comments reflected a highly negative view of the word “aging” (*envejecimiento*), and rejected the idea that it was possible to age well at all. Despite their differing backgrounds, both women verbalized the idea that aging is a negative life experience that should be avoided at all costs. Their negative views of aging and explicit desires to not age at all were common among the respondents, and suggest that “aging” was more of a social change to be avoided than an inevitable biological reality. Ana associated aging with being “crabby”, and Delia associated “oldness” with a pessimistic attitude at as well.

This view is reminiscent of the “successful aging” movement that has dominated much of the biomedical discourse about how to properly support a burgeoning population of older adults. Rowe and Kahn (1997) first suggested that successful aging may be defined as avoiding the onset of disease and disability and the maintenance of a high degree of physical and cognitive functioning. Though their framework has been challenged and redefined many times, most operational definitions of “successful aging” maintain that the preservation of physical functioning and freedom from disability is an integral component of aging well (Bowling & Dieppe, 2005; Kim, 2009; Stowe & Cooney, 2015). This clearly presents a problem for older adults with ADL disability, as, by definition, they would be barred from what it means to age successfully. As documented by Ormel et al. (2002) and by the second chapter of this dissertation, ADL disability and depression can often go hand-in-hand, potentially because of conflicts with Western ideals for independence and maintenance of high functioning at all stages of the life course.

The older adults in this study highlighted these tensions by often describing “old age” as a period of dependence and decline which was altogether undesirable. As such, they expressed great trepidation at the possibility of physical decline in late life. Still, those who had already experienced adverse health situations found ways to alleviate the emotional burdens of their health problems. For example, in a focus group one older woman named Alicia, who regularly participated in folkloric dance classes, replied that her way of thinking about positive aging was that, “well, I think...we’re all going to get that age, but for me personally, I’m saying, I wouldn’t like to be in my 90s. I wouldn’t like to be that age. It means depending on other people, that they do everything for me. If it’s the will of God though, you just have to accept it.” For her, the possibility of facing dependence in old age provoked a strong negative reaction. Similar to Delia and Ana, she associated “aging” with decline, and preferred to never have to depend on someone else. Still though—she found comfort in religion, suggesting that even in an undesired situation, God could be a source of comfort.

Meanwhile another woman named Patricia, who was born in Chicago, had already faced a major health setback. After being diagnosed with kidney disease, she was informed that she would need a transplant, and that until then she would need to be on dialysis. She said,

“...it was like someone hit me on the head. It was actually like, a part of my fault too. Not taking care of myself earlier on, but then they said it was inherited, but still in all—I’ve always had issues with my weight. I remember my drive home I just cried all the way....but I said, if you want to live you’ve gotta go with it. The other part with dialysis, just so people understand, anybody with dialysis, it’s not easy. You really have to wrap your head around that. Sometimes I’d sit in the chair and I’d have a little meltdown and think, you know, this really sucks. I have to sit here in order to survive, and there’s these poor little seniors they bring in. They come in on the ambulance and they’re amputees and you know what? I have to get it together. You can do this! Look at the will that person has to live! To come here at that age! And I’m here like, girlfriend, come on. You can do this!”

At this point, another man in the focus group interjected, “Yah! You have to realize that there are people out there that are worse off than you. They can’t do this, they can’t do that...”. Patricia’s initial diagnosis sparked an immediate emotional reaction for her. She was concerned for her own life and health, and distressed at the disruption to her current lifestyle. Her initial instinct to blame herself for her health condition because of her lifelong struggle with her weight is reminiscent of the “successful aging” movement that argues that every person is responsible for his or her own health and independence, even in old age. Even the knowledge that this may have been an unavoidable health condition for her did not alleviate her instinct for self-blame. Still, she found comfort in the dialysis center itself; though she was struggling emotionally, she saw others who were in even worse condition than herself. This downward comparison gave her the motivation to continue her dialysis treatments with a more positive outlook. As her male companion affirmed, there are always those are worse off.

Interestingly, both of them seemed to distance the plight of Patricia from the plight of true “seniors”. Patricia was in her 60s and therefore younger than many, but was struggling with the same health conditions. Still, she did not believe herself to be old. This too echoes what Delia and Ana proposed; that ‘aging well’ means to not age at all. For Patricia, seeing older people with more severe health conditions allowed her to distance herself from them; they were the true older adults—not her. Taken together, these comments suggest that “old age” is not an objective number, but is instead marked by an undesirable social change sparked by health declines and dependence that is unrelated to one’s actual age. These social changes were often brought on by severe illness or disability, as is the case of the older adults receiving dialysis in Patricia’s story. As such, those with disability or any degree of dependence are immediately seen as “old”, which

was seen as an altogether undesirable state, and not an inevitable result of bodily decline over time.

The beliefs of these respondents—even of those who had already experienced health declines and dependence—echo what biomedical researchers have maintained about “successful aging”. Researchers of public health and biomedicine have emphasized maintained physical functioning as integral to successful aging. However, the optimization-selection theory proposed by Baltes and Baltes (1993) argues that elders can maintain a subjective feeling of satisfaction by making adaptations to optimize functional domains that are important to them. In support of this theory, a study of diverse, disabled elders by Romo et al. (2013) found that despite late life disability, most of their subjects felt that they had aged successfully, primarily by using adaptation and coping strategies to align their perceptions of themselves with their perceptions of a positive old age. Similarly, Patricia was able to readjust her perceptions of dialysis and its health challenges by comparing herself to others, and rationalizing that she wasn’t as “old”, or as sick, as others. Alicia too suggested that should she find herself in a situation of severe dependence, she would be able to rely on God and her spirituality to find meaning in the situation.

Still though, for nearly all of the participants I spoke with, aging was associated with decline and dependence, and was therefore not a desirable life outcome. The phrase “successful aging” or “aging well” often struck confusion, and responses generally concerned the continuation of their current life circumstances, a trend that Sarah Lamb terms “permanent personhood” (2014). As she spoke with aging North American adults and compared them to her experience with aging Indian adults, she noticed that in the North American context, there was a vision of ‘permanent personhood’ wherein the ideal person does not really age at all in late life,

but rather maintains the self of one's earlier years. She notes that this particular cultural model of healthy and successful aging is highly prevalent and desirable to many North Americans, but may overemphasize independence and declining to decline at the expense of coming to meaningful terms with late-life changes, situations of impending interdependence, and the possibilities for frailty. Prior research in aging and health among Latin Americans has posited that, as a more interdependent culture, Latinos may have less negative reactions to health declines and need for care than non-Latinos (Beyene et al., 2002; McCarthy et al., 2004), yet the respondents in my sample all suggested the opposite. Regardless of their gender or nativity, they all suggested that aging and health declines were intricately linked, and that to "age well" meant to not age at all.

Because these individuals saw aging as such a negative experience, they all hoped to entirely avoid the health challenges that frequently accompany an aging body. As such, very few seemed to have any sort of care plan in place in case of adverse health setbacks. In each interview, I asked the respondents what they would do if they faced a health challenge and required care. Many admitted to having not considered that before, such as Armando and Teresa, a married couple in their late 60s from Puerto Rico. Armando and Teresa arrived at the interview with their arms linked, and Armando helped Teresa take off her coat before pulling her chair out for her. They shared many mutual jokes between them, and each went out of their way to acknowledge how the other partner contributed to their shared life together. During the interview, Teresa told me that her own aging parents had lived with them for several years before they passed away. Teresa had been their primary caregiver, as each of them suffered from dementia and severe disability. When I asked the couple what they would do if they needed care themselves, they replied:

*Armando:* Well, for me, I suppose Tere would take care of me, as my wife. I don't want her to though. It was so hard for her, and for us, to take care of her parents...

*Teresa:* Of course I would take care of my husband. I bathed my parents and my children and I'll bathe him too!

We all chuckled, and Teresa continued,

*Teresa:* But yes, it would be difficult...It's that... we rely on each other for so much, you know? When I was taking care of my parents, my husband was a great support for me, emotionally. If I had to take care of my husband, well, I don't know who would support me like that. I don't know what I would do.

*Interviewer:* And if your health was bad, who would take care of you?

*Teresa:* I don't know. Armando, maybe...

*Armando, nodding:* I would.

*Teresa:* But with our daughter too, I think, especially with the, with the more intimate things. I don't know though. She has her own children too, but she lives close and would be worried.

For Armando and Teresa, they had not considered their own care arrangements, even though they had spent several years living with and caring for Teresa's parents. Armando, who had seen the toll that caregiving took on his wife, accepted that his wife would likely be his caregiver, though he expressed pain at the potential for burdening his wife. Teresa struggled more with her answer. Though she and her husband had a supportive relationship, she expressed reservation at the thought of Armando being her only caregiver. He readily accepted that he would care for his wife, but Teresa suggested that their daughter would also provide support. Notably, she didn't mention either of their two sons, even though they all seemed to have a close relationship.

Armando and Teresa's narrative was a common one. As Teresa's own parents aged and required care, they moved in with their daughter. For Armando, the most obvious caregiver

would be his wife, and for Teresa, her own daughter seemed to be an appropriate caregiver, particularly with the more “intimate” care needs of an aging parent. As is common both in Latino culture and elsewhere, caregiving burdens are disproportionately allotted to women (Buch, 2015; Cruz-Saco & López-Anuarbe, 2016). When asked about their own future plans regarding caregiving arrangements, the most natural response was for the wife to care for her husband, and for the daughter to care for her mother.

Not all older adults have such an easy care arrangement, however. For sisters Rosa (76) and Delia (71), neither was married, and there were no female children between them. Delia and Rosa were immigrants who had been living together on their own for more than a decade. Delia had initially immigrated to Chicago on her own, leaving her two young sons behind in Guatemala with her sister Rosa, who raised them for ten years. Delia was eventually able to bring those sons to Chicago, who finished high school in the city and had since married and moved out of state. Rosa had no children of her own, and eventually joined her sister in Chicago. When I asked the sisters what they would do if their health declined, they responded:

*Rosa:* Yes, you have to think about that...

*Delia:* In that yes, in reality, we don’t know. Who would take care of us? For me, the last thing I want is to go to some sort of old people’s home. That’s why I exercise, because if someday I become a little old lady, I want to walk....I think, if one of us needs it, we’ll take care of each other. My son says, no Mom—my other son too—he says, my wife and I, we’ll take care of you...but they have children too.

*Rosa:* Yes, we’ll always take care of each other first. But the boys always call me their second mom.

These unmarried sisters had not considered what might happen should one of them face a major health setback. Though generally quite healthy, they were each small of stature, and walked slowly—albeit with great confidence. They put great attention and pride in to their physical appearance and were proud of the facility with which they continued to live

independently. Still, it seemed as though each would face some physical difficulty in providing any sort of serious care to the other. Their immediate reaction was to lean on each other, as they had done for decades already, but expressed reluctance to rely on the younger generation below them, even though both sons had repeatedly expressed their willingness to bring the women into their own household (albeit with the support of their wives). Though their families were willing to help, Delia and Rosa were unwilling to give up their independence and uproot their lives in a cross-country move. They did not want to move in with Delia's sons, but also did not want to live in a care facility. As such, they were uncertain about what would happen should one of them require care. Notably, neither woman mentioned the possibility of paid in-home care. Latinos have the lowest rate of paid home care utilization by race/ethnicity, for reasons that many hypothesize to be both structural and cultural (Cruz-Saco & López-Anuarbe, 2016).

An older man named Victor had had a similar experience. Victor was in his late 70s and had lived in the United States for more than 50 years. His wife had passed away several years earlier after a long illness, and he had decided to continue living at home on his own. Initially, many of his friends, neighbors, and family members checked in regularly and would bring him prepared food while he was in mourning. Those visits slowed down over time though, and he found himself struggling to maintain the house. He described,

*Victor:* It's just that I don't know how to cook or clean. So, well, I would visit my daughter because I didn't want her to see the house, you know? She always cooked me something to take home, and...and well, one day she says to me, 'Dad why don't I come to your house to cook?' and the reality is that it embarrassed me. I didn't want her to come, but, well...  
*(pausing)*

*Interviewer:* What did she say?

*Victor:* She was sad, because she didn't know that I couldn't maintain the house. I was embarrassed to see her cleaning.

*Interviewer:* Does she visit you now?

*Victor:* Yes, well, she comes a few times a week now, to cook and clean.

*Interviewer:* How do you feel about that?

*Victor, pausing:* It's better, I think. I can live in my house and she cares for me.

Victor struggled to ask for help after the death of his wife. He wanted to continue living independently because he was still in good health and could care for himself, but he had not realized the difficulty of both cooking and caring for the house as well. The condition of his home embarrassed him, but so did his inability to completely care for himself and his home. They challenged his previously-held notions of autonomy and independence. However, once his daughter recognized and addressed the problem, Victor admitted he was more comfortable in his home and felt cared for. Even though his wife had been ill for some time before her death, Victor had not imagined that he would also need care and assistance upon her passing, and for the embarrassment of admitting his struggles to live independently, did not want to ask for help.

These respondents provide support for my findings in the prior chapter wherein care receipt among married men and single women may reduce depressive symptoms, but care receipt for married women and single men may do the opposite. Armando, who was married, readily accepted that his wife would provide care for him if needed, whereas Teresa expressed more uncertainty and trepidation about receiving adequate care. The unmarried sisters easily turned towards one another for support, and appreciated the outreach and support from Delia's two sons. The sons' verbal affirmations that they would care for their aging mother and aunt were signs of *respeto*, or a confirmation of their love, support, and willingness to sacrifice for the women that had raised them. Meanwhile Victor, a single man, struggled to accept support from his daughter after a lifetime of being the strong male figure of the family. Combining these quantitative and qualitative findings suggests clear pathways of care in Latino families. Receiving care from expected and capable sources relieves emotional burdens, but receiving that care in unexpected or uncertain ways can amplify the stressor of the initial health decline.

While many of the respondents were able to provide responses for who their caregivers might be, they also frequently expressed uncertainty and a lack of planning in those proposed care arrangements. Of the twenty interviewees in this study, 15 verbally acknowledged that they had not considered what they would do in the case of health declines. One woman responded, “Well, I haven’t thought about it much. It makes me sad to think about that.” Several mentioned an extreme aversion to any sort of senior care facility, such as one man who man answered, “I hope I never need help because I live alone. I don’t know who would take care of me, and I’m not going to one of those old people homes.” For those that did list their potential caregivers, their options were unsurprising. All of the married men in the study mentioned their wives, whereas the women provided more varied responses (albeit nearly always female relatives). As is the case of Patricia and Alicia, questions about aging in this study overwhelmingly provoked responses that aging was a negative, undesirable life experience. The respondents all articulated a preference for the “permanent personhood” model described by Sarah Lamb. As one woman mentioned in a focus group, “I am also arriving at the age in which I’ll have to depend on others. The day I need my children—I have three—I would like them to let me be me. And if I live with them, and if I want to do something and they won’t let me, I’ll leave.” This woman, though still healthy, had a preoccupation with being allowed to continue being herself, even in the face of requiring daily assistance.

Aging and the potential for physical dependence on others repeatedly provoked feelings of anxiety and fear among the respondents. Perhaps in this lens, to consider how and when one might receive care in the future is to admit that one may not “age well”. The result is an underprepared population, both materially and psychologically. One woman named Julia recounted that she had recently experienced a surgery with unexpected complications that left

her bedbound for several months, during which time her husband and children cared for her. She said, “My husband and my daughter had to help bathe me and dress me, and I felt a profound sadness, and I don’t like that. My daughter took time off work, and her boss was really bad about it. It made me feel despair<sup>4</sup>.” She explained that she was only supposed to spend a single night in the hospital and then come home to recuperate, but because of the surgery complications, her recovery was much more difficult. When I asked her if she had realized that she was going to need so much support, she said no, and that they were unprepared. While experiencing the dependence would likely have been stressful for Julia anyway, the unexpectedness of the situation amplified the stressor. She exclaimed, “But I was healthy! How was I going to know that everything would go so bad?”.

In sum, even though this population is a majority immigrant group, their beliefs about aging subscribe largely to North American trends, and not the trends documented by scholars of Latin American aging. To “age well” is to not age at all, and experiencing health setbacks requiring major care and attention is not viewed as a natural part of life, but instead as a personal failure. Being “old” is synonymous with decline and dependence, and marks an undesirable social change---not an inevitable transition in life. The older adults in this study imagined “aging well” as the continuation of independence and their prior social roles. As such, any lived or potential changes to that brought about by health declines were a threat to their personhood. Because these health declines provoked such anxiety about those changing social roles, the respondents in this study preferred to imagine their futures as a continuation of their current selves, and made very few concrete plans for any future health setbacks. When asked to consider the question, they readily reported that their families would provide them with the needed

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<sup>4</sup> *Me desesperaba.*

support, though as the following section documents, this centrality of the family was not without its own challenges.

### *Tensions of Familism*

As seen in the prior section, many respondents immediately referenced their closest family members when considering future care arrangements, and expressly rejected the idea of a nursing facility or paid care. These findings seem to confirm what prior literature suggests about aging among Latinos in the United States. The concept of familism (*familismo*) describes an idiosyncratic form of family orientation wherein individuals place the good of the family ahead of their own good, and as such are expected to be dedicated, committed, and loyal to their families, including to extended kin. Integral to familism is the concept of *respeto*, which refers to an important age hierarchy and respect for elders. Many scholars of health and aging assume that the cultural values of *familism* and *respeto* are beneficial for aging Latinos in that they increase the degree of social cohesion and integration in their communities. Prior research in public health and sociology have shown that a high degree of social support and integration can be protective against adverse health outcomes (Berkman et al., 2000). Scholars have therefore hypothesized that these cultural trends among Latino families may contribute to the Latino Mortality Paradox; Latino older adults are more likely to live in supportive environments with their families and to receive valuable, life-extending care (Acevedo-Garcia & Bates, 2008).

These hypotheses are bolstered by research suggesting that Latinos may have a more collectivist or interdependent view of positive aging. For example, one research team conducted focus groups with both older non-Latina white women and older Latinas in order to compare their interpretations of good functional health in old age (McCarthy et al., 2004). The research

team argued that the older Latina women placed more value on interpersonal relationships and spirituality as "essential to the promotion, maintenance, [and] restoration of health and day-to-day functioning", whereas the Anglo women "seemed to depend on themselves and relied upon their own ability to implement personally devised interventions" (pg. 963), The research team concluded that older non-Latina women generally aligned themselves with individualist attitudes, whereas the Latina women articulated more collectivist priorities. The more interdependent, family-oriented cultural values of Latinos may provide valuable, life-extending care in old age.

This strong sense of familism among Latinos was evident in every focus group and interview. Respondents continually referenced the centrality of their siblings, children, and spouses in their social lives, living situations, and preferred care arrangements. While the intense focus on the family provided for immediate emotional, financial, and instrumental support in the case of health crises, it did not also mean that anxieties about aging were relieved, nor that physical health declines were somehow less serious or stressful. Instead, the intense focus on sacrifice for the family actually provoked conflicting emotions and anxiety among older adults in three particular ways. First, for many older adults, they often expressed desire for the care and support of their children, while simultaneously expressing anxiety about burdening them. Second, those living with their children and grandchildren felt satisfaction at their continuing roles in the family, while also expressing frustration at their reduced ability to leave the home and socialize with their peers. Third, the intense cultural focus on the family provoked intense feelings of despair and abandonment among those who did not have access to the kinds of family relationships and support that were normalized and expected by their peers.

### *1. Fears of Burden*

As shown in the prior section, many respondents commented on their anxieties about potential or lived dependence, though this fear of dependence was also concerned with a fear of burdening family members. When asked in a focus group about potentially requiring care from others, Jorge, a widower, and Vanessa had the following exchange:

*Jorge:* That's my greatest fear. Getting to a certain age in which my children or my family members have to help, apart from their own lives, to help me.  
*Vanessa:* On one hand, it makes you happy because then you know the love and company of your children or family members that still love you. That's their way of showing it—helping us, no? But at the same time, it interrupts their own life process, by helping us.

Similarly, when I asked Wilma what the phrase “positive aging” meant to her, she responded,

“I think [positive aging] is about the attitude you have in life. It also has a lot to do with the families, how united families are, how we all help each other. We don’t let the sickest or the oldest fall, I mean, we’re like a solid base there to help each other and make each other strong, no? But still, I have four children and to think that tomorrow...I could depend on them to the point of, I don’t know, even changing me, it’s the fear of any person, to get to that point. It’s not just the fear of depending on your children, but also of interrupting their lives just so you can live.”

Jorge, Vanessa, and Wilma were all still managing very independent lives, and did not require any sort of daily assistance from their loved ones. Jorge and Wilma both expressed an explicit fear of someday requiring the help of their children. While they were concerned about the implied dependence of such a care arrangement, they also expressed anxiety about disrupting the lives of their children. Vanessa expressed anxiety at interrupting the lives of her children, but also recognized that such care would provide her with active demonstrations of love and support from her family. Similarly, Wilma described that the entire point of having a family was to be a “solid base” for every member to rely on. In this way, receiving care from a family member—

particularly a child—may be both a blessing and a curse. While it provides the older adult with needed support, care, and love in a moment of physical health decline, it also provokes anxiety at the thought of burdening that loved one. Whereas the North American discourse of positive aging emphasizes that dependence is to be avoided, the older adults in this study also explicitly stated an aversion to being a burden on their loved ones—particularly their children. While experiencing dependence and a lack of autonomy was still a concern, the explicit anxiety about burdening one’s children, who may be in the midst of their careers and childcare responsibilities themselves, was mentioned frequently. Thus, the concern wasn’t merely an idiocentric concern about the loss of independence, but also an allocentric fear about the accompanying burden to one’s family.

Researchers who explore health outcomes among Latinos often romanticize the notion of familism, arguing that it is associated with a strong social support network that protects against adverse outcomes in the face of health challenges. As one research team summarized, the argument is that “Latino cultural values contribute to a tighter social fabric which confers resilience through pathways that promote social support and capital across varied contexts, such as family and community…Latino values such as *simpatia*, *familismo*, and *respeto* contribute to greater social integration and cohesion…” (Ruiz, Campos, & Garcia, 2016: 64). While this may very well be true, there remains a paucity of objective evidence to support that such cultural values are tied to the paradoxical health outcomes of Latinos. Furthermore, the sociocultural hypothesis does not acknowledge the negative mental health consequences that can arise from a lifetime of sacrificing for the family. The respondents in this study show that familism can be more of a double-edged sword. While the strong family bonds among the respondents made the selection of a potential or actual caregiver an easy exercise, it also provoked anxiety at both

disrupting the life of the caregiver and at the reversal of the flow of care that had been experienced previously. While sacrificing for one's own parents, siblings, or children may have been a routine endeavor, accepting that same help from family members in return was not an easy adjustment.

## *2. Challenges of Intergenerational Caregiving*

The importance of valuing the family ahead of oneself not only provoked tensions of desire among older adults who receive care, it also caused anxieties among older adults engaged in providing intergenerational care for their families. Many respondents in the focus groups and interviews were grandmothers who were highly involved and engaged with their grandchildren. While these relationships provided them with a strong sense of personal fulfillment within their families, the accompanying responsibilities also limited their ability to build meaningful, extrafamilial relationships as well. One of the focus groups occurred in a day center for older adults. During a debate about the value of living with family versus living independently, one woman commented that,

“The perfect life isn’t the same for everyone. I feel very happy and very content with my daughter. I cook. Well, I make breakfast for my granddaughter and bring her to school. For that I feel very, very happy, very content. But I was a little depressed before coming here. That’s why they pushed me. I didn’t want to come, but they talked to me and talked to me....and now I come here and I’m even happier than before. I have friends here, and we go out together sometimes. I didn’t do that before.”

In a different focus group at an immigrant service center, one man commented,

“In my experience, there are also people that are in their house because they’re taking care of grandchildren and they’re keeping the house for their children. I think those children should help support their parents to participate in places like this one, because those people end the day tired and in their chair and all day all they did was work for the family. They’re getting old in that house without ever getting to live.”

The second man was perhaps ruminating on someone specific in his life, but he described a similar experience to that of the first woman. While the first woman found great pleasure and satisfaction in providing care for her granddaughter, she also felt depressed, even if she was uncertain of why. It wasn't until her family pushed her to attend the social events of the adult day center did she feel more fulfilled socially. Similarly, the second man commented on the difficulty of providing care to grandchildren in old age, and how it can leave an older adult feeling isolated and locked inside. Much like the older adults in this study understood that their own children would likely be their future caregivers, they also viewed themselves as potential caregivers for their grandchildren if they were able. Neither of these care arrangements were without consequence though, however normalized or routine they may be. In the case of receiving care, there was anxiety and fear about burdening one's children, whereas in the case of providing care for grandchildren, the responsibility of the task prohibited the development of meaningful activities and relationships outside of the home.

In both scenarios described above, it was not apparent that either person recognized the ways in which their involvement with their grandchildren was impacting their own sense of well-being. The first woman expressed a great deal of reluctance to attend the day center at first, even though she felt depressed. It was only at the encouragement of her family that she left the home and made more social connections with peers, which alleviated her depressive symptoms. She was still able to live with her granddaughter and provide care, while simultaneously developing her own interests and peer relationships at a social center outside of the home. Though the second man was describing someone else's situations, he too theorized that the children of the older adult should push their parent to leave the home. He expressed concern that his peers may be "getting old in that home" without the opportunity to ever "live". For him, he was concerned

that one day the older adult in question may someday need care themselves and be unable to participate socially in the world, without ever having had a break from caregiving and home maintenance. Additionally, his belief that the children are responsible for ensuring their parent is fulfilled echoes the first woman's story. The older adults engaged the in the daily demands of caring for children may not be aware of the ways in which such care demands limit their own possibilities for meaningful engagement and relationships elsewhere. As familism as a cultural value centers on the belief that sacrificing for the family is of supreme importance, continued sacrifice and support in to old age is not unusual, and its negative consequences may not be immediately apparent to those choosing to focus on its benefits. These multigenerational households may foster the very social integration and cohesion theorized to be beneficial for physical health outcomes, but these findings suggest that there may also be a cost to be paid for that social harmony.

### *3. Increased Feelings of Abandonment*

Finally, the intense focus on the family among Latinos can have significant consequence for those without the strong, intimate family relationships they had previously imagined for themselves. As shown in the first chapter of this dissertation, Latinos with a higher percentage of kin in their social networks have lower risk of mortality relative to those with a lower concentration of kin. While kin can provide critical instrumental and physical support, the emotional support too is significant. The impact of frayed family relationships was undeniable and highly distressing for several study participants. For example, at the beginning of a focus group, I asked the participants what the perfect life might look like for an older adult. One woman answered, without hesitation, "that your children attend to you<sup>5</sup>", which caused another

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<sup>5</sup> "Que los hijos estén pendiente de uno."

woman—Veronica—to become highly emotional. While Veronica left the room to collect herself, her friend explained that she had recently become estranged from one of her daughters and grandchildren after an argument about the son-in-law. The daughter had not called Veronica to repair the relationship, causing the emotional upset. In another focus group held in an independent living facility, a widowed woman named Yolanda commented,

“Some of us live here because we don’t have family nearby, and that’s really sad. The people that have family close are better...when they don’t come to visit us, it makes us sad because we don’t have anything to keep us busy and with love...the loneliness is really difficult and I cry sometimes.”

When I later asked her for more details about her family, she responded that one of her daughters called her several times a week, and the other came to visit twice a month. Still, this level of involvement had not met with her expectations for what that those filial relationships would look like in old age. Both Yolanda and Veronica expected their children to take responsibility for their relationships with their parents. While Veronica was still waiting on her daughter to call her, Yolanda was upset that her children were not more involved in her life. Given that her children visited often, it’s possible that she had expected to live with them like many of her peers. More than 75% of older adult Latinos live with a spouse and/or in an intergenerational household (Administration for Community Living, 2017). According to the 2017 American Community Survey, around 23% of older Latina women live alone, compared to 40% of older non-Latina women. Only 13% of older Latino men live alone, though unmarried men are less likely to move in with children than unmarried women (ibid). While Yolanda never stated what her actual expectations were, it was also clear that whatever expectations she had had for her relationships with her children were not being met, which caused her to feel sad, lonely, and uncared for.

Women were not the only ones who felt distress at distance from their children, however.

In a separate focus group, one woman related the story of a man who also lived in her building.

She said,

“There are a lot of people who are very negative because they have children that don’t visit them. There’s a guy that lives here and I always invite him to church with us or to walk with us and he never comes because he’s depressed that his children don’t visit. But one has to think too that your children already live in their world apart from us. A lot of people don’t accept that and get depressed because their children don’t share with them...”

This woman noticed that many of her peers felt like their children weren’t involved in their lives anymore, which caused feelings of depression. For her personally, she felt that children were just focusing on their own families and lives, but for someone with a more intergenerational and interdependent view of family like her neighbor, this could feel like a rejection. Her neighbor had expressed distress at the lack of care from his children, and as a result chose to isolate himself even from his peers. This man’s response to that distance from his children was similar to other men’s responses; while women who perceived a lack of filial commitment openly expressed their dismay and negative emotions, men faced those situations with more stoicism. When I interviewed Fernando, a divorced father of three, he seemed reluctant to describe what he expected of his family as he aged. He had remarried a younger woman and said that she would care for him as he aged, but that he didn’t expect much of children. He explained,

*Fernando:* I don’t have much of a relationship with my children. They’re more attentive to their mother.

*Interviewer:* What is that like for you?

*Fernando:* It’s normal. When we divorced, well, they blamed me. It’s ok. I raised my children and I love them, but they still don’t visit me...

After a moment of silence, he continued:

*Fernando:* I would like for them to visit me....that would be good. It's that, well, the situation bothers my wife, but I can't change it now.

Fernando was reluctant to share the details of his divorce, or why he wasn't close to his three children even though they all lived in the same Chicago neighborhood. When Fernando initially arrived at the interview location, he was enthusiastic and in a good mood. However, as we discussed his children and his desires for his family, he looked at the ground or off to the side, and worked his hand repeatedly over the top of his cane. Fernando was distressed at the decay of his relationships with his children, even if he showed less emotion about the situation than some of his female peers. Still, he articulated that receiving visits from his children would be a "good" thing, and would be an affirmation of his work as a father raising them. In this way, familism and *respeto* create cyclical expectations across the life course. Parents view themselves as sacrificing for the well-being of their children; in turn, they develop certain normative expectations for what their children will provide for them in return during their old age. When those expectations are not met, it provokes a profound crisis of self for the older adult in question.

In summary, there were multiple ways in which the family could be a simultaneous source of both comfort and distress. When the older adults in this study were asked about aging well and/or about their future or present care arrangements, they consistently and frequently mentioned the importance of family—particularly children. They themselves had provided care for their own parents and their own children, and expected that cycle to continue. While the integral and central nature of the family for these individuals often provided them with emotional, instrumental, physical, and financial support, it did not come without a cost. While

the older adults I spoke with strongly desired the support and care of their children, actually receiving that support felt burdensome and threatening to their emotional well-being. However, not receiving that support had an even more significant impact on self-esteem and happiness. Similarly, ongoing involvement with caretaking for grandchildren brought great satisfaction to many, yet limited their opportunities for engagement and meaningful interactions outside of the home. In this way, familism both alleviates and produces anxieties about aging. It alleviates worries for receiving high-quality care in old age, while producing worries of burden. It provides opportunities for continuing feelings of utility in older adulthood, while also limiting the ability to enjoy the retirement age without family responsibilities. Finally, the intense cultural focus on the family can produce extreme reactions for those who find themselves without the highly interdependent family relationships they had imagined for themselves in old age. In these ways, familism is a double-edged sword that can provide for support and care in old age, while also contributing to feels of stress and depression.

### *Families in Transition*

These tensions about familism may in part arise due to rapid cultural, geographic, and demographic changes that occur within a transnational, immigrant population. Out of the 120 older adults in this study, 80% were foreign-born and only three of the rest had parents who were also born in the United States, suggesting that these respondents were all embedded within transnational families. Migration is not, though, a single event. Rather, it is a process that occurs over time and affects all aspects of the migrant's life, and requires constant reimagining of the life course. As previously shown, this population has largely taken up the Western ideology of "successful aging" as the maintenance of bodily health and independence, without abandoning

their own cultural values of interdependence and familism. Some of the older adults in this study were able to embrace the changes brought on by their own migration and by demographic and technological changes by leaning more heavily into the “independent” model of successful aging and imagining for themselves novel care arrangements in their old age. Others though resisted these transitions towards a novel cultural model, and expressed more anxiety about these perceived changes to family values, and struggle to adapt their expectations.

The process of migration often brings cultural values into conflict, as migration begins with the displacement from the culture of origin and continues with the prolonged and often difficult, lifelong practice of inserting oneself into a foreign culture that often has divergent values (Evans, 1987; Markides & Gerst, 2011). While modern technology has allowed for immigrants to maintain closer ties with loved ones in their sending countries, the stresses of adjusting to a new climate remain. Part of that stress includes the negotiation of competing cultural interests; whereas North American culture is often characterized as a highly independent one, Latin American migrants generally come from more interdependent cultures where the family is the center of social life.

The challenges presented by old age and bodily decline can bring these competing discourses into sharp focus. In Latin America, the overwhelming majority of older adults live with their spouse and/or their children; living alone is quite rare. In Mexico for example, only 10% of older adult men and 14% of older adult women live alone (Oca et al., 2014). Meanwhile in North America, only 3.25% of non-Latino whites live with grandchildren, compared to 13.06% of Latinos (Chen et al., 2015). In the United States, older adult Latinos and their children are generally exposed to both models, which can create intergenerational conflict about visions of care in old age.

Like Patricia in the previous segment, Geraldina felt embittered by a perceived separation from her children. Geraldina was a widow in her 70s who had immigrated to Chicago from Mexico in her late 30s. When she moved to Chicago, she brought all five of her young children with her, where they joined her husband who had already settled in the area. Geraldina did not speak English, and had worked sporadically as a housekeeper. When her husband passed away, she went to live in an independent living facility, where she received weekly visits from two of her children and monthly visits from a third. Two other children had moved out of state, but called her regularly. Despite their regular social contact, Geraldina was unhappy about her current living arrangement. She described,

“It makes me sad...it’s not right, and it hurts me that my children have abandoned me as if I were a bad mom. They say I need real doctors and nurses, but that’s what your family is supposed to do.”

Geraldina, who had several chronic conditions, explained that her children argued that she needed more medical care than they could provide. She also said that her two daughters worked full time and couldn’t afford to quit. Her children recognized her significant medical challenges, and did not feel prepared to care for her physical needs. Instead, they pooled financial resources to provide for her at a facility that offered regular medical checkups. While such an arrangement was common among her peers at the facility, the situation caused great distress to Geraldina, who found that it broke with her understanding of love and care for one’s parents. In fact, she associated her living situation with that of a bad parent, not of one who had been a good mother to her children.

While Geraldina struggled with her living situation, others were able to more easily reconcile the cultural changes. Another woman, Gladys, found pleasure in living independently. Gladys was a Mexican immigrant in her 60s who had arrived in the United States in her early

20s. She was bilingual, but preferred speaking in Spanish. At the beginning of our interview, she discussed how she had cared for her mother twenty years earlier. She explained, “When my mother got sick, I told her to move in with us and I took care of her. My husband worked and I was a homemaker, so it wasn’t a big thing. She needed a lot of help with everything but it made me happy to do it.”

We continued discussing the kinds of care her mother required and how it had been a benefit for her two children to have a closer relationship with their grandmother, and to see how family supports each other. Still, when I asked her about her wishes for the future should she herself require care, she responded, “My daughter works in an office—it’s a good job. I couldn’t have taken care of my mom and worked, and it makes me proud that [my daughter] works, and provides for her family that way. I hope we find another way.” Even though Gladys’s daughter expressed desire for her mother to live her, much like her grandmother had, Gladys didn’t want the same situation for herself. Gladys said that she was able to care for her mother because she already worked in the home, but her daughter had a good job outside of the home. As family dynamics and workforce participation have changed, so too have available care arrangements. While Geraldina was distressed that her children could not adequately care for her, Gladys instead wanted to find an alternative care arrangement for herself that would not require her daughter to quit her job. Aging and bodily decline are significant stressors that can be mediated not just by the social context, but by one’s expectation of the social context. Geraldina was distressed because she expected to be living with one of her children, whereas Gladys had an entirely different set of expectations that were more aligned with North American visions of aging. Their expectations may have been shaped by the degree to which they had adjusted to North American customs. Gladys had arrived in the United States at a younger age than

Geraldina, spoke English, and had had all of her children in the United States. Geraldina however arrived later in life, spoke only Spanish, and had immigrated with her children in tow. Their divergent tales of immigration may have played a role in their preferred care arrangements and in their expectations for their families.

This cohort of older adults find themselves in the midst of rapidly changing worlds. As the global lifespan lengthens, so too does the intensity and duration of care that many people require as a result of extended periods of disability and frailty. Immigrants find themselves with even more significant changes, as they are exposed to models of aging and care in both their sending and receiving countries. As individuals grapple with the challenges of aging, cultural and political forces play a significant role in who performs care-work, when that work is performed, and how it is received and perceived by the care recipients (Cruz-Saco & López-Anuarbe, 2016; Lamb, 2013). Caregiving demands substantial social, emotional, and financial resources, and just as experiences of aging vary by cultural and political context, so too does the availability and preference for informal, intimate caregiving. The decisions surrounding caregiving within a family therefore require careful negotiation. Some older adults have the availability to receive personal care from family but prefer not to, whereas others would prefer to receive that care from their family members who are unable to. When these desires come in to conflict, there can be significant impact on both physical and mental health, particularly in communities where there are rigid social norms surrounding intergenerational interaction between family members.

While the current cohort of older Latinos is predominantly an immigrant population, the share of older Latinos who are U.S.-born will grow in future generations. Intergenerational conflict can be sparked by differing value systems in migrant families, and also by the demands

placed on families confronting the challenges of aging. The intersection of migration and aging is therefore ripe territory for conflict, and can pose a significant mental health challenge in communities where *familismo* and *respeto* are key cultural values. The most significant predictor for psychological distress among any of the study participants was the degree to which their relationships with family members met their expectations, and those expectations were shaped by a multitude of factors including their gender, migration history, and marital status.

### *Conclusions*

The older adults in this study were asked to consider what aging well meant to them and what their preferred care arrangements would be in the case of a significant health challenge. In considering what aging well would like, this mostly immigrant population largely adopted the “successful aging” mantra that is prominent in North America. In considering what it means to age well, most of the responses suggested that aging well would be to not at age at all. Instead, a “successful” older adult would maintain both physical independence and the same social roles they had held in middle adulthood. The potential for physical decline and dependence in old age provoked anxiety in every respondent. Whereas other scholars have argued that the health declines that frequently accompany aging are viewed as a natural part of life for older adults in non-Western cultures like India and Mexico (Lamb, 2000; Lewis, 2011; Wentzell, 2013b), that was not the case with this particular population of older adults—despite their strong cultural ties to Latin America.

This immigrant population instead adopted a North American, neoliberal ideal of the “successful” elder as a responsible, independent citizen who maintains their physical health and important social roles. This ideal differs from what scholars have documented in other Latin

American countries, including Mexico. In those contexts, religiosity coupled with the cultural trope of *respeto* make the transition to social elderhood a less stressful one (Montes-de-Oca et al., 2015). However, the immigrant population in this study rarely talked about old age as a natural transition to a new social position. As few respondents in the sample were recent immigrants, the decades of exposure to a culture highly valuing independence throughout the life course may have also shifted what “aging well” meant to them. In adopting this new vision of aging, they also adopted its consequences. Any real or potential disability and dependence in old age sparked great anxiety, and physical decline was seen as a personal failure. Men and women alike did not believe that health declines were an expected result of old age, nor that their dependence provided opportunities for closeness with their children. Instead, these health setbacks were seen as a challenge to both their bodily integrity and their personhood.

Even as this population largely adopted North American, neoliberal ideals of the ‘successful’ older adult, they held on tightly to the cultural ideals of *familismo* and *respeto*, though this also was not without consequences. Because the loss of independence was seen as a failure to age well, many felt anxiety about the potential for health declines and went to great lengths to protect their independence. Those who had already required some degree of care experienced the onset of that need with a great deal of stress and depression, and were often reluctant to ask for that help when they needed it. This internal struggle with allowing one’s children to provide care contradicts what many scholars of aging and health have hypothesized about familism. These hypotheses argue that the centrality of the family in Latino communities allows for more readily available instrumental and emotional support in old age, which translates to better health outcomes. However, while the family was certainly the default center of the social world for this population, this did not mean that these older adults had an easier time

accepting help and support from their children. In fact, their anxieties about the potential loss of independence in old age were also accompanied with fears of burdening one's children; there was just as much anxiety about being burden as there was about losing one's independence. While the centrality of the family may have provided for more immediate, high-quality care that protects physical health and extends life, it may have come at the cost of mental health and sense of the self. In the previous chapter, I found that Latinos with ADL disability reported significantly more depressive symptoms than their non-Latino peers, and that receiving care from unexpected sources exacerbated those symptoms. This qualitative study demonstrates that even if the family is better positioned to protect the physical health of their loved one, the particularities of the individual's social context and their expectations of their family members play a significant role in how that disability is emotionally experienced.

In this way, familism can be a double-edged sword. For those individuals that had not considered their potential care arrangements, children were the default potential caregivers. However, the transition for these older adults from caregiver to care recipient was fraught and the feeling of burdening their loved ones was particularly difficult, given their own lifelong sacrifice for their families. The intense devotion to the family also created feelings of isolation for grandmothers who devoted a great deal of time towards grandchild care. While their labor was rewarding, it also limited the possibility of interactions with peers or with finding fulfillment outside of the home and its responsibilities. Finally, the cultural focus on the family also caused tremendous distress for individuals whose expectations for family involvement were not met. For those individuals, the stress caused by the perceived or actual distance from their children was amplified because of their expectations for what aging and the family should look like.

Close family relationships are expected, highly desired, and so normative that every focus group and every interview stressed the importance of the family for “aging successfully”. However, this particular cultural centrality of the family has combined with North American ideals of permanent personhood to produce a unique vision of the ‘successful elder’ wherein the older adult in question maintains their social and familial relationships without change, even as the body ages and declines. This conflicting desire for independent living within an interdependent familial context can create intergenerational tensions and conflict that challenge older adults and their families. As the Latino population in the United States continues to both grow and diversify, addressing these cultural and intergenerational shifts will be an important challenge to healthcare providers and policy makers.

As the older adult population grows, so too do cries for policies that support the ability of older adults to ‘age in place’ in their homes and communities, even as increased life expectancy has brought with it an increased risk for multiple years of ADL disability and dependence towards the end of life. Understanding what ‘aging in place’ looks like for older Latino adults will be of critical importance towards addressing their healthcare needs, including the need for extended years of care. The research presented here shows that the cultural values of *familismo* and *respeto* are lifelong values among Latino immigrants, even as other cultural attitudes—like understandings of aging—shift over time. Finding a way to reframe a positive old age away from the “successful, independent” model and towards one that allows dignity and meaning-making among the realities of aging can contribute to better mental health outcomes among older adults of all racial or ethnic backgrounds. Still though, this research demonstrates the ways in which migration is lifelong process with intergenerational impact and significant implications for both physical and mental health outcomes among aging Latinos. Meeting the health needs of our

diverse aging population will require careful attention to cultural context, personal history, and the social environment in which these older adults are embedded.

## Conclusions

This dissertation endeavored to explore how sociocultural context contributes to health outcomes of disability in old age by specifically examining the largest ethnic minority group of older adults in the United States. This research question was motivated by the need to understand the mechanisms through which culture has an impact on health behaviors and outcomes, rather than simply attributing differences in risk or outcomes to poorly defined or understood elements of culture. To that end, I began by exploring to what extent the social context of disabled Latinos differs from their non-Latino counterparts, and how the social context is differentially associated with mortality risk by race and ethnicity. Then, I explored the role of ethnicity in odds of receiving personal care upon the onset of disability and in the psychological responses to receiving (or not receiving) care. Finally, I sought to contextualize these findings by conducting interviews and focus groups with Latino seniors in the Chicagoland area to explore their own ideas about what it means to age well, and how to best to confront health setbacks that can accompany aging. All of these studies highlighted the importance of considering how the cultural environment can shape expectations about health, the body, and the family as one transitions into older adulthood.

Each of the three studies highlighted the importance of considering the macrolevel cultural context when exploring the pathways between meso-level social context and health outcomes. In Chapter One, I found that some aspects of the social world were associated with mortality risk among the disabled, though those relationships depended on the ethnicity of the individual in question. Specifically, I found that an increase in social strain predicted increased mortality risk for Latinos, but reduced risk for others. I also found that having a larger social

network size was protective against mortality for non-Latinos, but that having a higher percentage of kin in the network—regardless of its size—was protective for Latinos. These findings contribute to prior research that documents a connection between social health and physical health, but also suggest that the cultural environment of the individual shapes which aspects of the social world matter, and in which ways.

In Chapter Two, I found that Latinos who are experiencing the onset of ADL disability report more depressive symptoms than their non-Latino counterparts. While receiving personal assistance with the completion of ADL tasks was associated with an increase in the number of reported depressive symptoms for non-Latinos (regardless of gender and marital status), care receipt was associated with fewer depressive symptoms for Latinos who were single women or married men. Prior research has established that ADL disability is associated with increased risk for depression, and that receiving personal care further elevates that risk. However, this study argues that the cultural environment can shape expectations for both the body and the family, thereby producing divergent patterns of depression and disability. For married men and single women, receiving care upon the onset of disability may be seen as a sign of solidarity, support, and intimacy from loved ones that confirms expectations about the role of the family. For single men and married women however, care receipt may come from unexpected and undesirable sources that further elevate the stress of bodily decline.

Finally, in Chapter Three I show the ways in which cultural values like *familismo* and *respeto* can shape expectations for what a “good old age” looks like. While this groups had largely adopted North American beliefs and values about independence at all stages of the life course, they maintained a strong sense of family and obligation such that there were often clear expectations that wives and children would provide care and support as the individual aged.

When those expectations were violated—either by receiving care from an unexpected source or not receiving it at all—there were often intense emotional responses. While the cultural value of familism often did provide the older adults in question with needed emotional and instrumental support upon experiencing setbacks however, this did not come out without cost. An anxiety about being a burden, the risk of social isolation for those involved in intergenerational caregiving, and intense feelings of abandonment for those without close interdependent family ties were all potential side effects of familism as well. I ultimately argue that the intense focus on the family among the Latino respondents played a significant role in both forming their expectations for life as an aging adult and in the mental health consequences of physical health declines. Taken together, all three of these studies point towards the particularities of the Latino context, and how understanding the nuances of the cultural environment can enrich our understandings of how the social environment is related to health outcomes.

The findings from Chapter Three in particular further contextualized what I found in the first two studies. In the first study, I found that social strain may be beneficial for non-Latinos, but detrimental to Latinos. The qualitative research demonstrated the importance of *respeto*, or the elevated status of the elder. The older adults in the study reported feeling love and respect from their loved ones when they had experienced care receipt, and those who felt more distanced from their family struggled with feelings of abandonment. This suggests that receiving criticisms or demands from their children or spouses would be particularly harmful and not at all supportive of positive health outcomes, while those same experiences may be felt quite differently for an individual from a different cultural background. Similarly, Chapter One showed that disabled Latinos with a higher concentration of kin in their social network had reduced odds of mortality, whereas the size of the social network only mattered for non-Latinos.

The older adults in the focus groups and interviews repeatedly mentioned their family members, including siblings, spouses, and children, as key determinants of their aging experiences. Though they would on occasion mention the importance of socializing with peers, they nearly always turned towards their families as sources of support. In this way, non-kin contacts can be important for general socializing and enjoyment of the retirement years, but kin are consistently turned to as key sources of support—and not friends. For Latinos then, having a kin-centered social network can be a key predictor in reduced odds for mortality because kin are the most readily seen sources of instrumental and physical support.

In the second study, I found that Latinos who experienced the onset of ADL disability also reported a higher average number of depressive symptoms than non-Latinos, which contradicts prior research and hypotheses. Though other scholars have found that Latinos tend to have a more holistic and family-centered approach to aging than North Americans, I instead found the “successful aging” mantra that prioritizes independent function at all stages of life was a consistent theme among the older adults in my study. Though the older Latinos in the focus groups and interviews may have had origins in Latin American countries with differing views of aging, they seemed to adopt neoliberal ideals of permanent productivity and independence. In addition, the high concentration of immigrants in the sample may be a self-selected group that naturally values independence. For these reasons, experiencing health declines and setbacks that challenge one’s ability to care for themselves adequately may actually be more stressful to Latinos—not less stressful. Chapter Two did show, however, that Latinos who are single women or married men report fewer depressive symptoms when receiving care. My qualitative research showed that married men readily accepted that their wives may some day provide care to them, and single women all turned toward their children as potential caregivers. Single men, however,

struggled to consider their children as caregivers—potentially due to a lifetime of fulfilling traditionally masculine roles as a provider. Married women similarly struggled; even when their husbands expressed a willingness to provide care, the married women still suggested their children may also be involved. This balance of caregiving responsibilities may further aggravate the stressors of health declines, resulting in heightened reporting of depressive symptoms.

All of these studies further highlight the role of culture in shaping expectations for the aging experience, and that failing to meet those expectations can result in negative physical and psychological health outcomes. Cultural values of *familismo* and *respeto*, combined with prior experiences with parents and grandparents, contributed to the older adults' desires for their own aging experiences. At the same time, this largely-immigrant population was also exposed to North American models of aging. While their own cultural background shaped their expectations of family, their exposure to North American models of continued independence shaped their expectations of their own health outcomes and ability. Experiencing ADL disability defied what they had hoped or imagined for themselves in their old age and was a significant stressor, just as not receiving adequate and/or appropriate family support upon health setbacks was a negative experience as well. These expectations—and the various pathways in which they were produced—played a significant role in health outcomes among this population. Meeting expectations was associated with positive health outcomes, whereas the violation of those expectations was frequently associated with negative physical and mental health outcomes. Future research should consider the ways in which the macrolevel cultural context shapes our expectations for both ourselves and our social ties, and how those expectations and realities can interact to produce divergent health experiences.

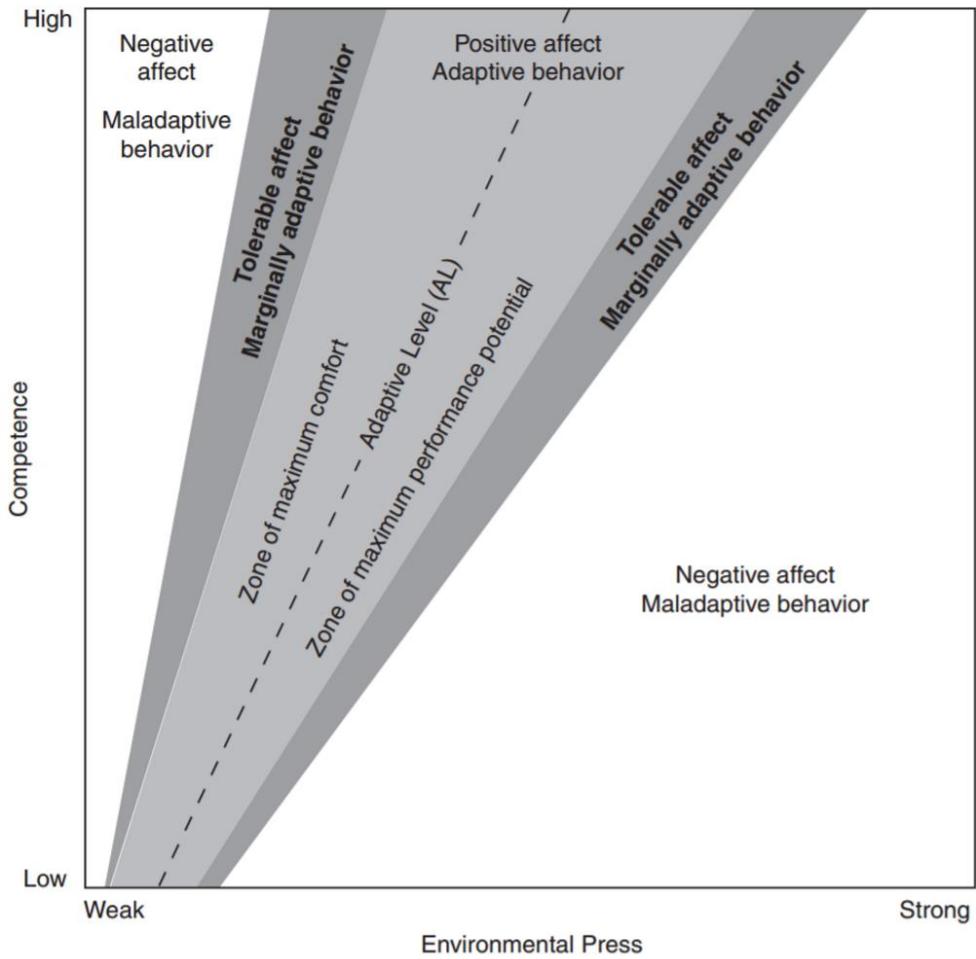
This dissertation also makes significant contributions to the ways we think about ADL disability and bodily decline in old age, as well as the sorts of environmental supports that are protective against further adverse health outcomes. In the Lawton-Nemahov Press-Competence Model, both the environmental press and the individual competence are assumed to be equal forces across groups, though my findings show not only significant variation in what external environments individuals are embedded within, but also significant variations in how those environments are experienced and valued. Similarly, the Verbrugge-Jette model of disability disaggregates intra-individual and extra-individual factors, without considering how each mutually constitutes the other. For Latinos, the cultural forces at work that push them towards intense interdependence on family also shape their views of themselves and how they respond to health setbacks. This dissertation therefore argues that considering multiple levels of analysis is of critical importance in exploring how the environment and the abilities of the individual interact to produce experiences of disability, and what long-term outcomes of that disability may be.

Finally, we should consider the ways in the which the cultural environment of an older adult can be an asset towards effective healthcare intervention, and not a barrier. Familism, respeto and simpatia, curanderismo, and the use of the Spanish language have been described as aspects of Latino-American culture that are barriers towards adequate and effective healthcare delivery (DuBard & Gizlice, 2008; Krakauer, Crenner, & Fox, 2002; Molina & Alcántara, 2013). More responsive approaches could treat these cultural attributes as strengths, not barriers, and consider them as part of the larger experience of this population. Recent research has shown strategies that draw on the cultural characteristic of familism in particular as a useful tool in reaching underserved Mexican Americans and their families. For example, a study by McEwen and

colleagues (2017) found that emphasis on enduring relationships with kin across generations can be used to encourage Mexican Americans to make behavior changes that benefit their health. As familism has shown to be an enduring cultural value, even in native-born Latinos, utilizing the family as an important resource for medical intervention—while recognizing its limitations and potential stressors—could serve as an important tool for the social workers and healthcare providers who are tasked with aiding a growing and diversifying aging population. Cultural beliefs can be both a benefit and a stressor to improved healthcare outcomes, but by carefully considering how culture can operate to produce health outcomes, we can strive to produce better policies and programs to more effectively improve the quality of life for today's aging seniors.

## Appendix 1

Figure 5. The Press-Competence Model, as first proposed by Lawton (1986).



**FIGURE 2–3** Lawton and Nahemow's Press-Competence Model

## Appendix 2

Figure 6. The disablement process, as first proposed by Verbrugge and Jette (1994)

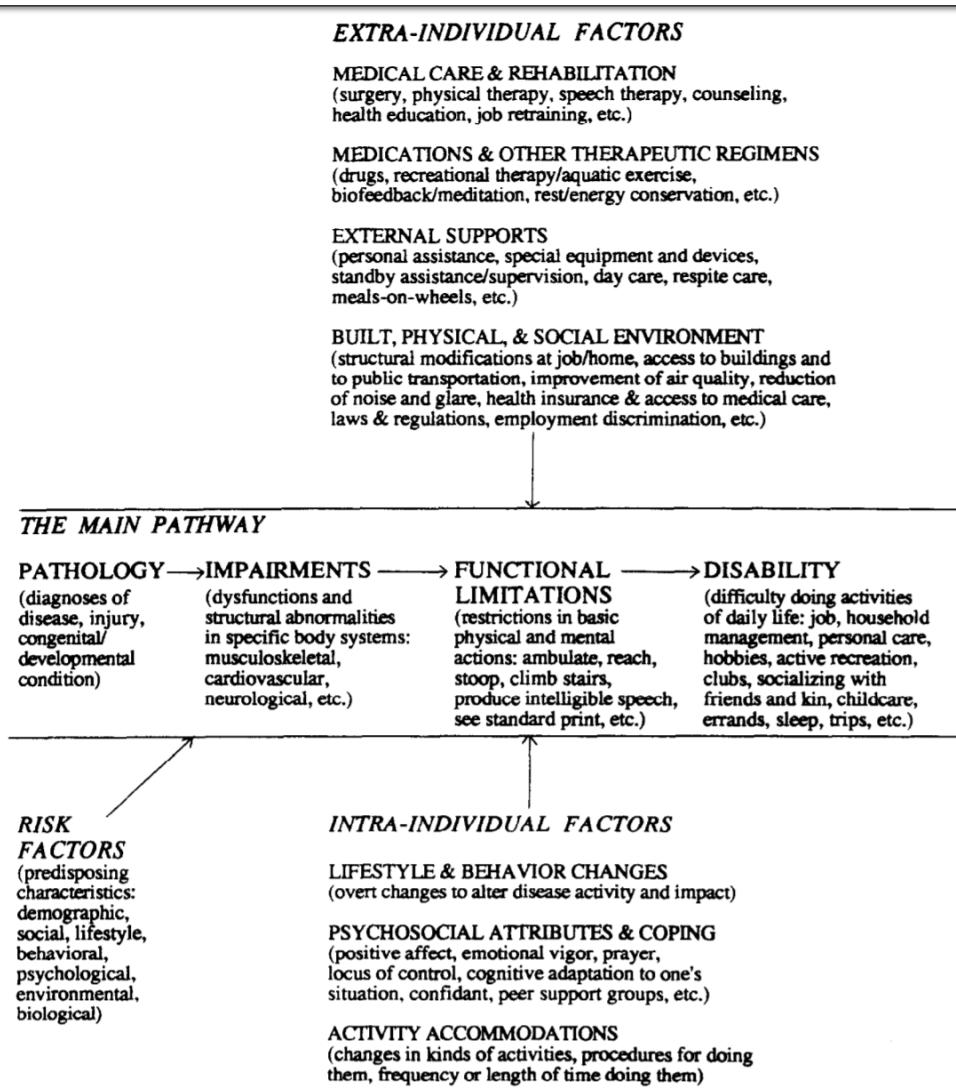


Fig. 2. A model of The Disablement Process.

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