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THE INFLUENCE OF DEMENTIA CAREGIVER MENTAL HEALTH ON QUALITY OF CARE IN ARGENTINA

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THE INFLUENCE OF DEMENTIA CAREGIVER MENTAL HEALTH ON QUALITY
OF CARE IN ARGENTINA

A thesis submitted in partial fulfillment of the requirements for the degree of Master of
Science at Virginia Commonwealth University

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Abstract

THE INFLUENCE OF DEMENTIA CAREGIVER MENTAL HEALTH ON QUALITY OF CARE IN ARGENTINA

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A Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

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This study examined the connections between cognitive functioning in individuals with dementia and caregiver burden, burden and mental health, mental health and quality of care. One hundred two dementia caregivers from San Lucas, Argentina completed questionnaires assessing these constructs. Caregiver burden, depression, anxiety, and satisfaction with life explained 18.8% of the variance in quality of care – respect and 14.7% of the variance in quality of care – provide. An SEM with generally adequate fit indices uncovered that cognitive functioning in individuals with dementia was inversely associated with caregiver burden, caregiver burden was inversely associated with mental health, and mental health was positively associated with quality of care. These findings suggest that the cascade may also be reversed with the development and use of dementia caregiver interventions that improve caregiver burden and mental health and as a result, the quality of care for individuals with dementia.

THE INFLUENCE OF DEMENTIA CAREGIVER MENTAL HEALTH ON QUALITY OF

CARE IN ARGENTINA

Dementia is a major public health issue in Latin America, yet it has not received

substantial research attention in this region (Alzheimer's Disease International [ADI], 2012). A

large increase in dementia rates will occur in developing countries, where 58% of the total world

population with dementia currently lives, and this figure is expected to increase to 71% by 2050

(Murray & Lopez, 1996). In Latin America, the prevalence of dementia (8.5%) is higher than in

any other global region, including Western Europe (6.9%), the United States (6.5%), and Eastern

Asia (4.2%; Prince et al., 2013). Multiple studies using different methodologies have suggested

that Hispanics in the US are at greater risk for developing dementia at an earlier age than White

non-Hispanics (Gurland et al., 1999; Tang et al., 2001; Clark et al., 2005; Livney et al., 2011).

Due to the myriad impairments associated with dementia, dementia patients generally

require high levels of care, most of which are provided by informal or family caregivers

(Bouldin, & Andresen, 2010). Informal caregivers are individuals who provide a broad range of

assistance without receiving any training or financial compensation; and are often family

members of the person with the chronic or disabling condition (Family Caregiver Alliance,

2014). Dementia caregivers assist in numerous tasks involving personal care, household

activities, shopping and transportation, financial management, emotion support and monitoring

care (Mace & Rabins, 2011; Atta-Konadu, Keller & Daly, 2011; Costle, 2004; Cohen, 2000;

Keating, Fast, Frederick, Cranswick & Perrier, 1999). Dementia caregivers often report increased

of depression symptoms (Covinsky, et al., 2003), burden (Papastavrou et al., 2011), anxiety

symptoms (Mahoney, Regan, Katona, & Livingston 2005), and positive and negative life

satisfaction (Savage & Bailey, 2004; Arango-Lasprilla et al., 2009). They also experience

cardiovascular problems (Roth, Howard & Safford, 2010), lower rates of wound healing and longer to recover from surgery (Kiecolt-Glaser, Marucha, Mercado, Malarkey & Glaser, 1995), and increased risk for chronic conditions, such as diabetes, arthritis, ulcers, and anemia (Kiecolt-Glaser et al., 1996; Shawn et al., 1997; Pruchno & Potashnik, 1989).

The majority of the literature looking at dementia caregivers has focused on determining the impact of providing care on caregivers' mental and physical health. Yet, there is a lack of research examining the impact of dementia caregiver's mental health on individuals' quality of care (QoC). Research has suggested that depression in caregivers of older adults is associated with the quality of care provided (Smith, Williamson, Miller & Schulz, 2011) and increased harmful behavior (e.g., screaming and yelling, threatening with nursing home placement) toward care recipients (Cooney, Howard & Lawlor, 2006; Godkin et al., 1989; Miller et al., 2006; Williamson, Shaffer & The Family Relationship in Late Life Project, 2001). Yet there is a lack of research on the impact of dementia caregiver mental health on quality of care in Latin America, as well as how cognitive functioning in individuals with dementia may influence caregiver mental health in this region. Previous studies have revealed that scores of individuals with dementia on the Mini-Mental State Examination (MMSE) are related to caregiver burden (Hirschman, Xie, Feudtner & Karlawish, 2004; Berger, Bernhardt & Weimer, 2005; Haro et al., 2014). Given the cross-cultural differences in values and approaches to caregiving, it is reasonable to expect the impact of care to be unique in dementia caregivers from Latin America. The current study begins to address these gaps in the literature. The aims of the current study are to examine (a) the connections between cognitive functioning in individuals with dementia and caregiver burden, (b) the connections between caregiver burden and mental health, (c) the connections between mental health and quality of care, (d) and the potential indirect effects of

cognitive functioning in individuals with dementia on mental health through caregiver burden, as well as burden on quality of care through mental health.

The following Introduction will first present a review the epidemiology, symptoms, impairments, and biology of dementia. Second, it will discuss caregiving characteristics and duties. Third, it will review challenges involved in dementia caregiving and psychosocial functioning of dementia caregivers. Fourth, it will discuss individual cognitive functioning and dementia caregiver well-being. Finally, it will discuss caregiver mental health and quality of care provided.

Epidemiology

Dementia is a major public health issue, and as of 2010, there were an estimated 35.6 million people living with dementia worldwide (Alzheimer's Disease International [ADI], 2012). This number is expected to double nearly every 20 years to an estimated 65.7 million in 2030, and 115.4 million in 2050 (ADI, 2012). Much of the increase will be in developing countries, where 58% of the total world population with dementia currently lives, and this figure is expected to increase to 71% by 2050 (Murray et al., 1996). In Latin America, the prevalence of dementia (8.5%) is higher than in any other global region, including Western Europe (6.9%), the United States (6.5%), and Eastern Asia (4.2%; Prince et al., 2013). This is particularly important because the number of older adults aged 60 and over in Latin America and the Caribbean will increase from 50 million individuals in 2005 to a projected 186 million by 2050 (ECLAC, 2008). In particular, Argentina, Cuba, and Uruguay have some of the longest life expectancies in Latin America, which averages over 75 years (ECLAC, 2008), and as a result, these countries may see especially high numbers of older adults with dementia.

The worldwide direct cost of dementia care was estimated at $422 billion in 2009, including $142 billion for informal care (Wimo, Winblad & Jonsson, 2010). Costs of dementia are a major economic burden on the care systems of developed countries, with an increasing burden in developing countries (Wimo et al., 2010). The direct cost of dementia care in Latin America was estimated to be almost $35 billion in 2009, including $11 billion for informal care. The direct cost per case of dementia in the same year was estimated at $8,824, and if informal care is used in the context of instrumental activities of daily living, the estimated cost was $13,917/year (Wimo et al., 2010). In Latin America, the highest costs of dementia occur in Brazil at $12 billion where over 900,000 people have dementia, followed second by Argentina where the costs of dementia soar over $7 billion and where over 300,000 people have dementia (Wimo et al., 2010).

Studies have suggested that the prevalence of dementia is lower in developing countries than in developed regions (Ferri, 2005). To explain this low prevalence, Ferri and colleagues (2005) acknowledged that differences in level of exposure to environmental risk factors (e.g. low levels of cardiovascular risk factors) or even high levels of mortality in early life could also be associated, where "constitutional and genetic factors that confer survival advantage in early years might go on to protect against neurodegeneration or delay its clinical manifestation" (Ferri et al., 2005; p. 2116). Nevertheless, more recent data have emerged not supporting the conclusion that the prevalence of dementia is lower in developing countries compared to developed countries (Lobo et al., 2000; Lopes and Bottino, 2002; Lopes et al., 2007 & Nitrini et al., 2009). Large numbers of people with dementia currently live in low-and middle-income countries (Ferri et al., 2005; Prince et al., 2009), with prevalence estimates comparable to those of the Western world (Rodriguez et al., 2008). Results of the 10/66 Dementia Research Group population-based

studies in Latin America suggested that dementia prevalence might be underestimated when the widely used DSM-IV diagnostic criteria are applied (Prince et al., 2012), particularly in rural and less developed regions. Informant reports suggested a high incidence of dementia before death, and overall incidence could be between 4% and 19% higher if these data were included (Prince et al., 2012). As previously stated, dementia rates in Latin America will grow more quickly than in any other world region in the near future (Prince et al., 2007; ECLAC, 2008).

Symptoms and Impairments

Dementia is a syndrome involving significant deterioration in cognitive ability beyond what might be expected from normal aging (Gustafson, 1996). It affects memory, orientation, thinking, comprehension, calculation, learning capacity, language, and judgment (Gustafson, 1996). Dementia is more common in the geriatric population, however, less commonly, it can occur before the age of 65, in which it is termed *early onset dementia* (Sadock, Sadock & Alcott, 2008). Presenting symptoms are different for various causes of dementia such as Alzheimer's disease (AD), vascular dementia, dementia with Lewy bodies, mixed dementia, Parkinson's disease, frontotemporal dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington's disease, and Wernicke-Korsakoff syndrome.

According to the most recent Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the term "dementia" has been replaced with the term "major neurocognitive disorder." In addition, the DSM-5 now recognizes a less severe level of cognitive impairment called "mild neurocognitive disorder," which is a new disorder that permits the diagnosis of less disabling syndromes that may nonetheless be the focus of concern and treatment (5th ed.; DSM–5; American Psychiatric Association, 2013). The term "dementia" is derived from the Latin *de* meaning "out of" and *mens* meaning "the mind," related to the word

"mad," or "insane" (Dementia, 2014). The purpose of the new term is to help reduce the stigma associated with the word "dementia" and the condition it refers to, however due to its common use it will probably remain in use. The use of "neurocognitive disorder" is likely to be used only by some health care professionals and organizations ("Major Neurocognitive Disorder: The DSM-5's New Term for Dementia, 2013), and in order to remain consistent with the published literature to date, the term "dementia" will be retained for this paper.

As the condition progresses, nearly all brain functions come to be globally affected (Khachaturian, 1985). The progression of dementia varies among individuals, but there are characteristic features at different stages. In the early stages, individuals with dementia become forgetful (O'Brien et al., 1992), show orientation difficulties (confusion about places and people) (Spector, Orell, Davies & Woods, 2000), and have difficulties in making decisions (including managing personal finances) (Price et al., 2010) and in carrying out household tasks (Phinney, 2007). In addition, mood and behavior can be affected, with a loss of motivation and interest, depression (Landes, Sperry & Strauss, 2005), and increased anger (Lyketsos et al., 1999). In the middle stage, all these symptoms worsen, and difficulties in communication increase. Behavior changes (e.g., wandering, repeated questioning, and calling out, clinging, agitation, and aggression) can occur, sometimes driven by psychological features such as delusions, hallucinations, and disturbed sleep patterns (McKeith & Cummings, 2005). In the final stages of dementia, individuals can be unaware of time and place, unable to recognize relatives, friends (Josephs et al., 2008) or familiar objects (Lee, Rahman, Hodges, Sahakian & Graham, 2003), unable to eat without help (Volicer et al.,1989), severely restricted in mobility, and sometimes bed-bound (Jirovec & Wells, 1990).

Dementia is a very well-documented syndrome; however there is a comparitively little research on dementia in countries with low levels of education (Prince et al., 2012). Older adults in developing countries often have little formal education, and therefore occupational status and literacy levels tend to be low in this group. Education and occupational status have been suggested to confer advantages in brain structure or function that then buffer the effects of neurodegenerative brain damage in late-life (Jones et al., 2011). If cognitive reserve (mind's resistance to damage of the brain) is less stimulated in countries with low and middle incomes, then a higher incidence of dementia might be expected in these developing countries than in developed countries. However, because responsibilities for older adults and normative roles are different across cultures, so might be the metacognitive skills needed to slow neurodegeneration. Education and occupational status based on hierarchies from developed countries might be less relevant, and hence less clearly associated with dementia risk, when they might be important factors for dementia incidence in developing countries. A national cohort study done in Mexico suggested that education was inversely associated with dementia incidence (Mejia-Arango & Gutierrez, 2011). In another study, Prince and colleagues (2012) showed that in countries with diverse cultures and lifestyles, and much greater variance in levels of education and literacy than in countries with high incomes, these variables are related to better performance on verbal fluency and motor sequencing tasks, and confer protection against the onset of dementia.

Biology of dementia

The most common cause of dementia is Alzheimer's disease (AD), accounting for an estimated 60-80% of cases (Thies & Bleiler, 2013). AD has been identified clinically as a disease that causes dementia with a deceptive onset and slowly progressing course (Ashford, Schmitt & Kumar, 1998). It is estimated that, by 2050, the number of people aged 80 years or older will

approach 370 million worldwide and that 50% of those aged 85 years or older will be afflicted with AD (Suh, Cacabelos, Fernandez-Novoa & Corzo, 2004). It has been estimated that the brain has approximately 100 billion nerve cells. Each of these nerve cells communicates with many others to form networks that involve thinking, learning and remembering. Like all types of dementia, Alzheimer's is caused by brain cell death (Dementia: Hope through research, 2013; Butterfield & Lauderback, 2002; Yang, Geldmacher & Herrup, 2001). It is a neurodegenerative disease, meaning there is a progressive brain cell death that develops over time and thus, fewer nerve cells and connections are found in the brain tissue.

Neurodegeneration in AD is estimated to start 20 to 30 years before the first clinical symptoms become apparent (Goedert & Spillantini, 2006); and so early diagnosis with reliable biological markers are essential to distinguish and detect AD. Biomarkers are biological indicators that can be used to measure the onset or progression of a disease and to see how a disease is reacting to treatment (Sprott, 2010; Henley, 2005). They are reliable predictors therefore they are important tools to prove significant diagnosis in AD. Three biomarkers have been well-established and validated internationally to diagnose AD in cerebrospinal fluids (CSF): β-amyloid (1-42; Zetterberg, Blennow & Hanse, 2010; Sunderland, Hampel, Takeda, Putman & Cohen, 2006), total tau (Blennow, 2004) and phosphorylated tau (Hampel et al., 2010). Previous research suggests that the combination of these three CSF biomarkers significantly increases the diagnostic validity for sporadic AD, which yields a combined sensitivity of >95% and a specificity of >85% (Blennow, Hampel, Weiner & Zetterberg, 2010; Marksteiner, Hinterhiber & Humpel, 2007).

However, the regular use of CSF biomarkers has several disadvantages like the collection process of performing lumbar puncture diagnosis, collection of CSF is an invasive treatment with

potential side effects, and it can be time-consuming, or expensive (Zetterberg et al., 2010). Therefore, there is a need to search biomarkers in other body fluids to diagnose AD (Blennow et al., 2010). Thus blood-based biomarkers may be a more attractive option (Thambisetty & Lovestone, 2010). A recent study published online by Mapstone and colleagues (2014), identified ten-metabolite profile in the blood that can determine with 90% certainty whether a cognitively normal elderly person will go on to develop dementia symptoms in the next 2-3 years. The findings could help with patient selection for clinical trials aimed at preventing dementia. This is the first time that blood-based lipidomics has been used to describe an at-risk population with very high accuracy for detecting preclinical AD. A major advantage of blood samples is that the analysis of blood cells (e.g. peripheral blood mononuclear cells, lymphocytes, monocytes or platelets) might be more restricted to specific AD-related pathologies (Henriksen et al., 2014).

Pathological hallmarks for AD are extracellular plaques of amyloid-β (Aβ) peptides (Glenner & Wong, 1984; Masters et al., 1985) and intraneuronal tangles of hyperphosphorylated tau protein (Ballatore, Lee & Trojanowski, 2007). Formation of these plaques and tangles in the brain destroy nerve cells as most people age (Ohm et. al., 1995; Bancher et. al., 1989), however those with Alzheimer's have a tendency to develop far more Aβ in the spaces between the nerve cells and tau proteins inside the cells (Khan, 2012). These plaques and tangles form in areas important to learning and memory (Sydow et. al., 2011; Wippold, Cairns, Vo, Holtzman & Morris, 2008), blocking communication among nerve cells and destroying nerve cells that cause memory loss (Guillozet, Weintraub, Mash & Mesulam, 2003), personality changes (Gauthier & Neto, 2012; Terracciano et. al., 2013), and other symptoms of Alzheimer's.

Recent data suggest that the ε4 allele of the apolipoprotein E gene (APOE) could also increase the risk of AD (Holztman, Herz & Bu, 2012; Liu, Kanekiyo, Xu & Bu, 2013). The ε4 allele frequency is estimated to be about 15% in the general population but is present in approximately 40% of AD patients (Farrer et al., 1997). In addition to increasing the prevalence of AD, the presence of the APOE ε4 allele is also associated with a lower age of onset for AD in a gene dose-dependent manner (Farrer et al., 1997; Corder et al., 1993). Among ε4 homozygotes, the frequency of AD and mean age at clinical onset are 91% and 68 years of age, respectively, compared to 47% and 76 years of age in ε4 heterozygotes and 20% and 84 years in ε4 non-carriers (Corder et al., 1993).

Multiple studies (Gurland et al., 1999; Tang et al., 2001; Clark et al., 2005; Livney et al., 2011) using different methodologies have suggested that Hispanics from both eastern and western US regions may be at greater risk for developing dementia at an earlier age than White non-Hispanics. For White non-Hispanics and African Americans, the APOE ε4 genotype is a significant risk factor for the development of AD and may be responsible for an earlier age of disease onset (Reitz et al., 2013). For older Hispanics in the US, the nature of the association between AD, APOE genotype, and race/ethnicity is perhaps more complex, as Hispanics in the US are a heterogeneous group with different ancestries largely influenced by a mixture of various proportions of Native American, European, and West African populations (Fitten et al., 2014). Tang and colleagues (1998), found that Caribbean Hispanics have an increased frequency of AD compared with White non-Hispanics, regardless of APOE genotype. Furthermore, the risk for early onset of AD associated with APOE ε4 genotype is significantly lower in older Mexicans and Caribbean Hispanics compared with White non-Hispanics (Kwon, Khaleeq, Chan, Pavlik & Doody, 2011; Villalpando-Berumen et al., 2008; Olarte et al., 2006). Fitten and colleagues

(2014), found that White non-Hispanic groups were consistently older and modestly more likely to have one or more copies of the APOE ε4 allele compared with the Hispanic group; suggesting that other genetic or biopsychosocial risk factors possibly related to diet, lifestyle, or immigrant status may contribute to an earlier onset of dementia diagnosis in Hispanics.

Caregiver characteristics and culture

Due to the myriad impairments associated with dementia, individuals with dementia generally require high levels of care, much of which is provided by informal or family caregivers (Bouldin, & Andresen, 2010). An informal caregiver is any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition (Family Caregiver Alliance, 2014). Schumacher and Colleagues (2006), extend the definition of informal caregiving to the overwhelming burden caregivers experience on a daily basis as a result of providing care that goes beyond what is considered "normal" care or help within families. Dementia caregiving is the most frequently studied type of caregiving represented in the literature (Schulz, 2010). Dementia is a neurodegenerative condition, and it often requires a considerable amount of time spent caregiving. More than 15 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia, spending an average of 21.9 hours of care per week (Thies & Bleiler, 2013). Caregivers in developing countries spent a median of 3 to 6 hours a day with the person with dementia, and 3 to 9 hours assisting with activities of daily living (Prince, 2004). In another study, dementia caregivers from South America reported provided care for an average of 40.2 months and 128 hours per week (Arango-Lasprilla, Moreno, Rogers & Francis, 2009). In another study, dementia caregivers reported caring for an average of 47 months and 138.1 hours per week (Arango-Lasprilla et al., 2010). The majority of individuals with dementia

receive assistance from their spouses as opposed to other family members or friends (Qureshi, 2013; Hennings, Froggatt & Payne, 2013, Arango-Lasprilla et al., 2010, 2009).

Although there is a large body of literature examining the influence of dementia symptoms on caregivers, most of the studies have focused heavily on Anglo Saxon or White caregivers (Connell & Gibson, 1997). There is a need for research on caregiver experiences from other cultures, as given the cultural differences in values and approaches to caregiving, it is reasonable to expect unique aspects of caregiver experiences in Latin America. It is well-documented in the literature that Latinos' value of *familismo*—a strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity, and solidarity among members of the same family (Scharlach et al., 2006; Sabogal, Marin, Otero-Sabogal, Marin & Perez-Stable, 1987)—leads to greater involvement of extended family in the care of ill family members and reduced perception of caregiving burden, since providing care is expected and valued (John, Resendiz & De Vargas, 1997). Previous research has documented that in Latino culture *familism* influences the fulfillment of family needs over one's own. Hence children and older adults alike are often reminded that during good or bad times, *la familia* comes first (Cuellar, 1990). For example, the idea of placing a family member in a nursing home is often seen as an unacceptable way of caring for older adults in many Latin American countries (Wallace, Levy-Storms & Fergunson, 1995). This is particularly important because several studies comparing the functional status of older Latinos and Whites have found that Latinos experience a higher level of disability (Jette, Crawford, & Tennstedt, 1996; Tennstedt et al., 1998).

Caregiver duties

Individuals with dementia tend to have a significant number of needs, often greater than those of many other patient populations. As a result, caregivers spent a great deal of time every day assisting patients with complex tasks or activities of daily living that may be unpleasant, uncomfortable, stressful, and physically exhausting. Caregiving tasks for individuals with dementia can be broken down into six categories: 1) *personal care*, which most often involves assistance in tasks such as getting in and out of bed or a chair, taking medication, grooming, eating, walking, bathing, dressing, cutting toenails, and toileting (Mace & Rabins, 2011; Smith & Buckwalter, 2005; Lawton & Brody, 1970); 2) *household activities,* which include assistance in making beds, doing laundry, cleaning, vacuuming, preparing meals, yard work, minor repairs, and washing windows (Atta-Konadu, Keller & Daly, 2011; Costle, 2004); 3) *shopping and transportation,* which includes assistance in shopping and errands (Costle, 2004); 4) *financial management,* such as assistance in paying bills, filing tax forms, and balancing checkbooks (Costle, 2004); 5) *emotional support,* which involves assistance in maintaining social interactions, validating attitudes or perceptions, cheering up, and self-affirmation (Cohen, 2000; Schulz, 2000; Dhooper, 1992); and 6) *monitoring care,* which includes ensuring that the dementia patient's needs are met and quality services are provided (Keating, Fast, Frederick, Cranswick & Perrier,1999). Yet, these concepts do not fully capture the complexity and stress of caregiving (Reinhard, 2004). For example, assistance with bathing does not capture bathing a person who is resisting a bath (Sloane et al., 1995; Joanne-Rader et al., 2010), or helping with medications does not capture the hassles of medication administration, especially when administering multiple medications several times a day (Travis, Bethea & Winn, 2000).

Effects of dementia caregiving on caregivers

Caregiving for an individual with dementia can have profound effects on many aspects of the caregiver's life such as, work, social life, self-care, finances, and mental and physical health. Previous research has found that dementia caregivers often take less demanding jobs, retire early, turn down promotions, lose job benefits, or have to give up work entirely (Schulz & Martire 2004; Ory et al., 1999; Neal, Chapman, Ingersoll-Dayton & Emlen, 1993; Anastas, Gibeau & Larson, 1990). In addition to missed days, interruptions at work and leaves of absence can result in reduced productivity because of caregiving obligations (Brodaty, Green & Low, 2005). The economic drawback associated with caregiving in developing countries is associated with substantial economic disadvantage, as a high proportion of caregivers in those countries have to cut back on their paid work in order to provide care (Prince, 2004).

People with dementia in developing countries tend to use a lot of health services, which is associated with high direct costs. Low income and limited financial resources result in increased risk for negative caregiver outcomes, especially if there are significant out-of-pocket costs for care recipient needs (Stephens, Townsend, Martire & Druley, 2001). Caregivers spent a large proportion of their income on health care for the person with dementia (Prince, 2014). Caregivers often lack social contact and support and experience feelings of social isolation, tending to sacrifice their hobbies, leisure activities, and time with friends and family in order to provide care to the individual with dementia (Leong, Madjar & Fiveash, 2001; Brodaty & Hadzi-Pavlovic, 1990; George & Gwyther, 1986).

Providing care poses a threat to the overall health of caregivers, which can compromise their ability to continue their caregiver role. High levels of caregiving activities can affect the caregiver not receiving adequate sleep or having time to exercise (Burton Newson, Schulz, Hirsch & German, 1997). Poor nutrition is also a frequent problem among dementia caregivers,

and previous research has found that caregivers reporting higher depressive symptoms are more likely to be at risk for malnutrition (Rullier et al., 2014; Torres et al., 2010).

Psychosocial functioning of dementia caregivers

In addition to these challenges associated with caregiving, one of the most substantial is reductions in caregiver mental health. Caring for a person with dementia often places a major burden on the informal caregiver, reducing their mental health (Zarit, Todd, & Zarit, 1986; Donaldson, Tarrier & Burns, 1998; Bell, Araki & Neumann, 2001). Given the psychological and physical consequences of their roles, dementia caregivers have been referred in the literature as "hidden patients" or "forgotten clients" (Pratt, Schmall, & Wright, 1987; Zarit, 1985; Fengler & Goodrich, 1979). Chronic fatigue, anger, depression, and anxiety symptoms are among the problems associated with caregiving (Chenoweth & Spencer, 1986; George et al., 1986; Rabins, Mace, & Lucas, 1982), depression being the most commonly documented negative consequence (Covinsky, et al., 2003; Cohen, 2000).

Previous research had identified very high rates of depression in dementia caregivers (Schulz, O'Brien, Bookwala & Fleissner, 1995; Yesavage et al., 1983). Several studies have found that Latino caregivers report more depressive symptoms than caregivers from other racial/ethnic groups (Coon et al., 2004; Covinsky, et al., 2003; Adams, Aranda, Kemp & Takagi, 2002; Harwood et al., 1998). Depression is also known to be predicted by caregiving irritability, poor health, and a poorer quality of the relationship with the person with dementia (Mahoney, et al., 2005). Previous studies have found that when severely depressed caregivers begin to feel hopeless, they sometimes think of taking their own life and even the life of the person for whom they are caring. The increasing numbers of homicide-suicides involving older couples highlight the deadly effects of overwhelming depression and hopelessness (Cohen, Llorente & Eisdorfer,

1998). Furthermore, some studies suggest that many caregivers are at risk of experiencing clinical depression (Williamson & Schulz, 1993; Cattanach & Tebes, 1991) that often lasts beyond institutionalization or death of the individual with dementia (Gallagher-Thompson et al., 2003; Wright, Hickey, Buckwalter, Hendrix & Kelechi, 1999).

One specific psychosocial response to caregiving is burden. It results from the physical, psychological, emotional, social, and financial problems experienced by family caregivers (George & Gwyther, 1986). Dementia caregivers who report being highly burdened by their caregiver duties exhibit more depressive symptoms (Papastavrou et al., 2011) and higher anxiety symptoms (Mahoney, Regan, Katona, & Livingston 2005; Cooper, Katona, Orrell & Livingston, 2008). Mahoney and colleagues (2005) found anxiety symptoms to be predicted by caregiving activities, living with the patient, being a female caregiver, and reporting poor quality of the relationship with the person with dementia. In a recent study conducted in South America, Arango-Lasprilla and colleagues (2009) found that approximately 70% of dementia caregivers reported some type of burden related to their caregiving role, which is similar to the literature looking at White caregivers.

Caring for a person with dementia has also been associated with positive and negative aspects of life satisfaction (Nolan, Grant & Keady, 1996; Savage & Bailey, 2004). Previous research in Latin America reported almost 90% of caregivers being satisfied or extremely satisfied with their life on and around their caregiver duties (Arango-Lasprilla et al., 2009; Andrén & Elmståhl, 2005). These high levels of satisfaction might be in part due to cultural factors. Latin American cultures emphasize high respect for elders and people with disabilities and also encourage a sense of obligation for their care (Hurtado, 1995). As previously stated, valuing family over individual needs is strongly held among Latin American caregivers (Cuellar,

1990), perhaps resulting high levels of life satisfaction (Arango-Lasprilla et al., 2009). Previous research has found that caregivers with larger numbers of friends and close relationships and greater subjective satisfaction with their social networks reported higher levels of overall life satisfaction (Haley, Levine, Brown & Bartolucci, 1987). In addition, higher levels of social activities with friends and church attendance were also significantly correlated with greater life satisfaction (Haley et al., 1987). Moreover, high levels of satisfaction with life are more likely to occur when the dependent individual is valued as a person, treated with dignity, and not viewed as a problem (Hirschfeld, 1983; Nolan & Grant, 1992). Thus, those who experience low satisfaction in life might provide valuable insights into the kind of relationship caregivers have with the patient that could potentially be abusive (Nolan & Lundh, 1999).

In addition to mental health problems, a growing body of research reports dementia caregivers to be at an increased risk for negative physical health outcomes (Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991; Patterson & Grant, 2003; Vitaliano, Zhang, & Scalan, 2003; Mittelman, Roth, Clay & Haley, 2007). Many studies have shown an increase in cardiovascular problems among dementia caregivers in comparison to non-caregiving controls, especially in the context of depression and stress (von Känel, et al., 2008; Haley, Roth, Howard & Safford, 2010). Moreover, caregivers with symptoms of stress, experience lower rates of wound healing, longer time to recover from surgery (Kiecolt-Glaser, Marucha, Mercado, Malarkey & Glaser, 1995), and increased vulnerability to infectious disease (Vedhara et al., 1999). Some caregivers are also at risk for chronic conditions, such as diabetes, arthritis, ulcers, and anemia (Kiecolt-Glaser et al., 1996; Shawn et al., 1997; Pruchno & Potashnik, 1989).

These health effects may be due in part to the fact that reduced preventive health behaviors in caregivers are associated with poorer immune response after vaccination

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(Segerstron, Schipper & Greenberg, 2008; Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991; Kiecolt-Glaser, Glaser, Gravenstein, Malarkey & Sheridan, 1996) and increased use of tobacco, alcohol, and prescription medications (Connell, 1994; Given & Given, 1998; McKibbin, Walsh, Rinki, Koin & Gallagher-Thompson, 1999). Previous studies have found that caregivers with mental health problems and greater stress are more likely to have poor physical health and to be at a higher risk for mortality (Brodaty et al., 1990; Schulz & Beach, 1999; Lee, Colditz, Berkman & Kawachi, 2003). Maintenance of physical health is essential for caregivers to begin and continue providing informal care (McCann, Hebert, Bienias, Morris & Evans, 2004).

Caregiver psychosocial functioning and patient cognitive functioning

Cognitive decline, functional impairment, and behavioral/psychological problems are some of the main symptoms of dementia. Their impact on caregivers' mental and physical health has been documented in the literature, and this effect becomes more severe as the disease progresses (Zarit, 1985). Scores of individuals with dementia on the Mini-Mental State Examination (MMSE) are related to caregiver burden, and specifically when dementia severity surpassed a threshold of MMSE <20, caregiver burden increases substantially (Hirschman, Xie, Feudtner & Karlawish, 2004; Berger, Bernhardt & Weimer, 2005; Haro et al., 2014).

On the other hand, some studies have not found significant relationships between cognitive deficits and caregiver depression (Haley et al., 1987), or for dementia disease severity to be related to caregiver burden (Reed et al., 2004). One reason for these inconsistent findings may be due in part to strong correlations between predictors when controlling for each other. For example, Reed and colleagues (2014) reported an association between patient activities of daily living, MMSE, and time spent caregiving; yet, activities of daily living eclipsed the predictive effects of these other variables on caregiver burden. Previous research looking at Malaysian

dementia caregivers has found that cognitive impairments were not associated with caregiver burden, despite generally low MMSE scores (Rosdinom, Zarina, Zanariah, Masrhani & Suzaily, 2013). Rosdinom and colleagues (2013) interpreted this finding to suggest that Malaysian caregivers see cognitive impairment in older adults as part of normal aging, accounting for the low levels of caregiver burden in their sample.

Despite a recent increase in the literature looking at Latino dementia caregivers' mental and physical health issues, relatively little is known about the connections between these variables and patient cognitive functioning in Latin America. A study that approximates this idea in the United States found that levels of cognitive dysfunction significantly increased the risk for caregiver depression among Hispanic dementia caregivers, but not among White caregivers (Harwood et al., 1998). This authors found that Hispanic caregivers caring for an individual with severe levels of cognitive impairment (MMSE < 17) specifically showed higher symptoms of depression compared to those caring for a patient with a mild-to-moderate cognitive impairment (MMSE > 17).

Caregiver psychosocial functioning and quality of care provided

The majority of the literature on dementia caregivers has focused on determining the impact of providing care on caregivers' mental and physical health. Yet, there is a budding area of the literature expanding this examination to the predictors of quality of informal care for individuals with dementia. Research has found that caregiver depression is associated with potentially harmful behavior toward the person with dementia (Smith, Williamson, Miller & Schulz, 2011; Cooper et al., 2010), including behaviors like screaming, yelling, and threatening with nursing home placement (Cooney, Howard & Lawlor, 2006; Godkin et al., 1989; Miller et al., 2006; Williamson, Shaffer & The Family Relationship in Late Life Project, 2001). Cooper

and colleagues (2010) also found dementia caregivers who had higher levels of anxiety and depression symptoms were more likely to report having acted abusively toward the individuals with dementia. In this study, anxious caregivers who reported higher tended to attribute their distress to caregiving, rather than to unrelated life events or stressor (Cooper et al., 2010). Another study found that caregiver anxiety symptoms did not predict potentially harmful behavior toward individuals with dementia in the absence of caregiver anger, suggesting that caregiver anxiety symptoms may not be directly related to harmful behavior but due in part to anger produced by anxiety symptoms (MacNeil et al., 2010). As anger increased, both depression and resentment became more highly associated with potentially harmful behavior (MacNeil et al., 2010).

The research on the connections between dementia caregiver mental health and other aspects of care quality has been mixed. For example, one study failed to find that caregiver depression was related to the provision of respectful care (e.g., considering care recipient feelings, wishes, opinions, and values), but when respectful care declined, harmful behavior increased (Smith et al., 2011). Another study found that quality of informal care for individuals with dementia was inversely associated with caregiver depression and burden (Harris, Durkin, Allen, DeCoster & Burgio, 2011), suggesting that caregiver mental health may be directly associated with informal care.

Objectives

From this literature review, it is clear that research has begun to document the connections between cognitive functioning in individuals with dementia and caregiver burden, between caregiver burden and mental health, and in a cursory way between mental health and quality of informal care. Yet, to the author's knowledge, no study to date has examined the

potential indirect (mediational) effects in this series of events in order to link them in a theoretical causal chain, nor have these associations been examined in dementia caregivers from Latin America, despite the rapidly expanding representation of older adults in this global region's population. This is particularly unfortunate given that previous research has documented unique facets of the mental health of Latino individuals, for example that they are more likely to endorse positive affect items (happy, cheerful, joyful, lively, proud) on measures of depression than other racial/ethnic groups (Kim, Chiriboga & Jang, 2009). Similarly, caregiving itself in Latino families has been shown to be different in comparison to that in other racial/ethnic groups in terms of greater involvement of extended family in care as well as reduced perceptions of caregiving burden due to the fulfillment of traditional family values (John, Resendiz & De Vargas, 1997).

The published research cited in this review poses the question as to whether culturally unique features exist in the connections among cognitive functioning in individuals with dementia, caregiver burden and mental health, and the quality of informal care provided to individuals with dementia (Harris et al., 2011). This study begins to address these gaps in the literature by attempting to fulfill the following aims using a sample of dementia caregivers from Argentina: to examine (a) the connections between cognitive functioning in individuals with dementia and caregiver burden, (b) the connections between caregiver burden and mental health, (c) the connections between mental health and quality of care, (d) and the potential indirect effect of cognitive functioning in individuals with dementia on quality of care provided through caregiver burden and mental health.

Hypotheses

Hypothesis 1. Low levels of cognitive functioning in individuals with dementia will be associated with higher caregiver burden. This is based in part on a study by Harwood and colleagues (1998) that found Latino caregivers who cared for an individual with severe levels of cognitive impairment had higher depression than caregivers caring for a patient with a mild-to-moderate cognitive impairment.

Hypothesis 2. Higher caregiver burden will be associated with decreased caregiver mental health. Dementia caregivers that report being highly burdened by their caregiving duties have been shown to exhibit more depressive symptoms (Papastavrou et al., 2011) and higher anxiety symptoms (Mahoney, Regan, Katona, & Livingston 2005; Cooper, Katona, Orrell & Livingston, 2008).

Hypothesis 3. Reduced caregiver mental health (depression, anxiety, and satisfaction with life) will be associated with a lower quality of informal care for the person with dementia (provide and respect). This is based on a study by Cooper and colleagues (2010), which found that dementia caregivers who reported higher levels of anxiety and depression symptoms were more likely to report acting abusively towards individuals with dementia.

Hypothesis 4. Indirect (mediational) effects will emerge for cognitive functioning in individuals with dementia on caregiver mental health through burden, as well as burden on quality of care through caregiver mental health. Although no research to date has examined these potential mediational effects, they stand to reason. Reduced cognitive functioning in individuals with dementia should lead to a higher level of caregiver burden, which will then reduce caregivers' mental health. Similarly, higher burden will reduce caregivers' mental health, which will limit their ability to provide high quality care. See Figure 1 for a theoretical path model linking all of these constructs through both direct and indirect effects.

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Figure 1. Theoretical Path Model
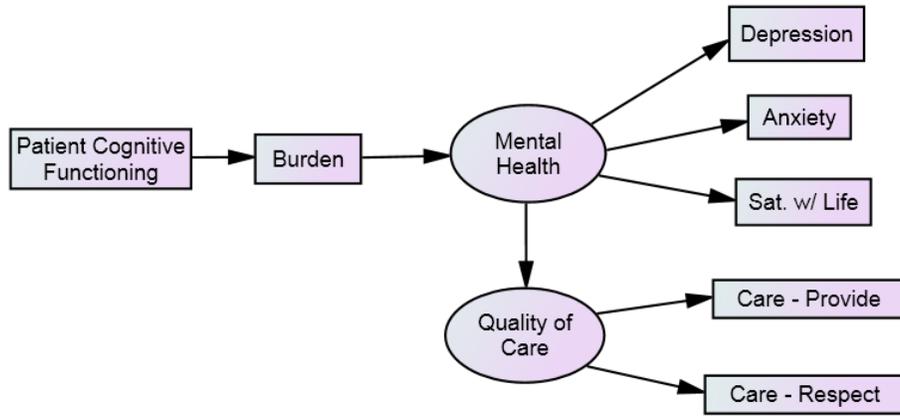
Method

Participants

Caregivers were defined as family members actively providing day-to-day care for a person with dementia and who were familiar with the patient's medical and social status. One hundred and two caregivers were recruited from the Institute of Neuroscience in San Lucas, Argentina. The inclusion and exclusion criteria were that the participant must 1) be the primary caregiver of a patient with a diagnosis of dementia; 2) have provided care to the patient for a minimum of 3 months; 3) have no personal history of neurological and serious psychiatric disorders; 4) have no history of learning disabilities; and 5) be at least 18 years of age. All caregivers provided care to a patient who had had a diagnosis of dementia, which was confirmed by a medical records review.

The sample consisted of 26 men (25.50%) and 76 women (74.50%), with a total average age of 57.81 years (*SD* 13.49) and an average educational level of 14.17 years (*SD* 4.87). Most of the caregivers were spouses of the patients (52.00%), followed by sons or daughters (47.10 %), and parents (1.00 %) of the individual with dementia. The majority reported being currently married/ partnered (80.40 %). With regard to income, the majority reported earning two to three

times minimum wage (45.10 %). Caregivers reported having provided care to their patients for

an average of 48.88 months (*SD* 23.04) and spending 63.75 hours per week (*SD* 18.58) providing

care (See Table 1 for more in detail dementia caregiver characteristics).

Table 1. Characteristics of Dementia Caregivers (*N* = 102)

Demographic Variable	Value
Age, years, mean (SD)	57.81 (13.49)
Sex, %	
Female	74.50
Male	25.50
Years of education, mean (SD)	14.17 (4.87)
Marital status, %	
Married or partnered	80.40
Single or separated	14.7
Relationship to individual with Dementia, %	
Spouse	52.00
Child	47.10
Parent	1.00
Duration of caregiving	
Number of months, mean (SD)	48.88 (23.04)
Hours per week of care, mean (SD)	63.75 (18.58)
Current occupation, %	
Part-time employment	41.20
Homemaker	29.40
Retired	16.60
Full-time employment	9.80
Student	2.00
Unemployed	1.00
Monthly household income, %	
1-2 times minimum wage	10.80
2-3 times minimum wage	45.10
4-5 times minimum wage	28.40
More than 5 times minimum	15.70

Measures

Caregivers completed a series of questionnaires assessing caregiver personal strengths,

mental health, and quality of care. Spanish versions of the Patient Health Questionnaire (PHQ-9),

the Satisfaction with Life Scale (SWLS), the Zarit Burden Interview (ZBI), and the Generalized

Anxiety Disorder Assessment (GAD-7) and, the Mini Mental State Examination (MMSE) were

available. The Exemplary Care Scale (ECS) did not have Spanish versions and was translated for the purpose of this study.

Patient Health Questionnaire (PHQ-9). The PHQ-9 is a nine-item self-report measure of depression (Kroenke, Spitzer, & William, 2001). Participants indicate how often they have been bothered by each symptom of depression over the past two weeks using a scale ranging from 0 (not at all) to 3 (nearly every day). Total scores ranges from 0 to 27 with higher scores reflecting higher levels of depression (0 to 4 = no depression, 5 to 9 = mild depression, 10 to 14 = moderate depression, 15 to 19 = moderately severe depression, and 20 to 27 = severe depression). The PHQ-9 is often used in clinical primary care settings and epidemiological studies and can be given in English or Spanish. The Spanish version of the PHQ-9 used in the current study has a well-established reliability and validity (Diez-Quevedo et al., 2001). The PHQ-9 was found to be reliable in the current sample (α = .81).

Satisfaction with Life Scale (SWLS). The SWLS is self-reported measure of general life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985). Participants rate each of its five items on a scale from 1 (strongly disagree) to 7 (strongly agree). Total scores range from 5 to 35, with higher scores indicating higher life satisfaction. A score of 20 represents the neutral point on the scale, and as such, scores from 5-9 indicate being extremely dissatisfied with life, 10-14 dissatisfied, 15-19 slightly dissatisfied, 21-25 slightly satisfied, 26-30 satisfied, and 31-35 extremely satisfied. The Spanish version of the SWLS has shown adequate reliability (Martinez et. al., 2004). The SWLS was found to be reliable in the current sample (α = .93).

Zarit Burden Interview (ZBI). The ZBI (Zarit, Reever, & Bach-Peterson, 1980) is a commonly used self-administered measure of caregiver burden consisting of 22 items with response options ranging from 0 (never) to 4 (nearly always). Caregivers evaluate specific

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domains of life that can be affected by the provision of care, such as stress level, emotional health, financial strain, relationships, embarrassment, and overall burden. Total scores range from 0 to 88 with higher scores indicating higher levels of burden (Karlikaya, Yukse, Varlibas, & Tireli, 2005). Scores between 0 to 20 indicate little or no burden, 21 to 40 mild-to-moderate burden, and 41 to 60 moderate-to-severe burden. The current study used the Spanish version, which has shown adequate internal consistency and test-retest reliability (Martin et al., 1996). The ZBI was found to be reliable in the current sample in the current sample ($\alpha = .92$).

Generalized Anxiety Disorder Assessment (GAD-7). The GAD-7 is a 7-item self-report scale designed to assess the presence of the symptoms of Generalized Anxiety Disorder as listed in the DSM-IV (Spitzer, Kroenke, Williams & Lowe, 2006). Items in the GAD-7 ask participants how often during the last 2 weeks they were bothered by each symptom. The total score is calculated by adding the scores from the 7 items, which have response options ranging from 0 (not at all) to 3 (nearly every day). Total scores range from 0 to 21 with higher scores indicating higher anxiety. The total scores are categorized into four severity groups: Minimal (0-4), mild (5-9), moderate (10-14), and severe (15 and above). The current study used a Spanish version of the GAD-7 which has shown adequate reliability (García-Campayo, Zamorano, Ruiz et al., 2010). The GAD-7 was found to be reliable in the current sample ($\alpha = .82$).

Exemplary Care Scale (ECS). The ECS is an 11-item assessment of the provision of exceptional care for an individual with a health condition (Dooley, Shaffer, Lance and Williamson, 2007). Participants rate each item on a scale from 1 (never) to 4 (always). The ECS contains two subscales reflecting the provision of exceptional care: Provide and Respect. The Provide subscale has four items reflecting caregivers' attempts to provide special attention or niceties that go beyond routine assistance of daily living. The Respect subscale has 7 items

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assessing caregivers' respect for care recipient wishes, viewpoints, self-esteem, and desire for autonomy. Total scores range from 0 to 33, with higher scores representing more exemplary care. Scores on Provide range from 4 to 16, and scores on Respect range from 7 to 28. Coefficient alphas for the two subscales during the scale's initial construction were acceptable (Dooley et al., 2007). The ECS - Provide was found to be reliable in the current sample (α = .91), as was the ECS – Respect (α = .94).

The Mini Mental State Examination (MMSE). The MMSE is a 30-item questionnaire that measures the severity of cognitive impairment (Folstein, Folstein & McHugh, 1975), commonly used to screen for dementia. The MMSE test includes simple questions and problems in a number of areas like arithmetic, memory, orientation, language use and comprehension, and to basic motor skills. For example, participants are given questions like "What year is this?", "Spell the word WORLD. Now spell it backwards", and "SHOW pencil. ASK: what is this called?" Each category has different points assigned, for a total of 30 points possible. Total scores ranges from 0 to 30 with lower scores indicating poor cognition. Any score greater than or equal to 27 points (out of 30) indicate normal cognition. Below this, scores can indicate mild (19-24), moderate (10-18) and severe (≤9 points) cognitive impairment. The MMSE is often used in clinical primary care settings and epidemiological studies and can be given in English or Spanish. The Spanish version of the MMSE used in the current study has a well-established reliability and validity (Black et al., 1999; Ortiz, LaRue, Romero, Sassaman, & Lindeman, 1997).

Procedure

Caregiver participants were recruited from the Instituto de Neurociencias de San Lucas in Rosario, Argentina at neurologist appointments for the family member with dementia. The

caregiver was interviewed by while the patient was seeing his or her physician. A psychologist met with each caregiver for approximately one hour to collect socio-demographic information and complete the questionnaires that assessed caregiver mental health (depression, anxiety, satisfaction with life), burden, and quality of care (respect and respect). All participants provided informed consent and could withdraw from the study at any time. Procedures were approved through the ethics committees at the University of Deusto in Bilbao, Spain.

Data Analysis

Tests for skewness and kurtosis were run in order to determine whether the variables indexing cognitive functioning in individuals with dementia, as well as caregiver burden, mental health, and quality of care were normally distributed. Any non-normal variables were transformed using square-root transformations.

A correlation matrix was then generated showing bivariate relationships between caregiver demographic variables and the two types of informal care. The purpose of this analysis was to determine potential demographic covariates that could account for relationships among burden and mental health variables with quality of care. A second correlation matrix was generated showing bivariate relationships between burden, mental health variables, and the two types of informal care. Then, two hierarchical multiple regressions investigated the extent to which burden and mental health variables (burden, depression, anxiety, and satisfaction with life) were associated with each of the two types of quality care (provide and respect) after controlling for demographics and caregiving characteristics. In each of the two regressions, demographic variables shown to be associated with quality of care were entered as variables in the first step, and the three mental health variables were entered as independent variables in the second step.

A structural equation model (SEM) was created mirroring the visual presentation of the study's theoretical model in Figure 1. The manifest variables in the model included cognitive functioning in individuals with dementia (MMSE), and caregiver burden (ZBI). The latent variables included caregiver mental health (comprised of the PHQ-9, GAD-7, and SWLS) and quality of care (comprised of the two subscales of the ECS). Direct effects were examined between variables (directional arrows in the SEM) to test Hypotheses 1-3, as well as indirect (mediational) effects of caregiver burden and mental health to test Hypothesis 4. Traditional fit indices were examined in order to determine whether the theoretical model fit well with the data, such as the Tucker-Lewis Fit Index, Comparative Fit Index, Goodness of Fit Index, Root Mean Square Error of Approximation, and the ratio of the chi-square statistic to degrees of freedom.

Results

Distributions of the Scores

Based on the cutoffs established by the authors of the Patient Health Questionnaire-9 (Kroenke et al., 2001), 90.2% of dementia caregivers reported mild depression symptoms, with 7.8% reporting moderate depression symptoms, 1% reporting moderate to severe depression symptoms, and 1% experiencing severe levels of depression symptoms. Based on the classification scheme for the Satisfaction with Life Scale (Diener et al., 1985), 35.3% of dementia caregivers were classified as being satisfied with life, 26.4% being slightly satisfied, 21.7% being slightly dissatisfied, 8.8% being highly satisfied, and 7.8% being dissatisfied. When using the categories set by the authors of the Zarit Burden Interview (Zarit et al 1980), 44.4 % of caregivers experienced mild-to-moderate burden, 36.5% moderate-to-severe burden, 17.6% little to no burden, and 3% severe burden. Based on the cutoffs for the Generalized Anxiety Disorder Assessment (Spitzer et al., 2006), 92.2% of dementia caregivers experienced mild anxiety

symptoms, 5% moderate anxiety symptoms, and 3% severe anxiety symptoms. Based on the

scheme for the Mini Mental State Examination (Folstein et al., 1975), 51.1% of individuals with

dementia experienced moderate cognitive impairment, 48% mild cognitive impairment, and 1%

severe cognitive impairment.

Tests for Skewness and Kurtosis

Satisfaction with life, burden, exemplary care – respect, and exemplary care – provide all

had skewness and kurtosis values below the cutoff of 2.0. However, anxiety and depression were

both slightly skewed (2.39 and 2.49, respectively) and very kurtotic (9.18 and 11.12,

respectively), and as a result were transformed using a square-root transformation. The MMSE

was only slightly kurtotic (2.14) but not skewed (-.95), so no transformation was undertaken for

that variable.

Correlation Matrix

A correlation matrix was created to examine the relationships among participant

demographic variables (years of school, gender, hours per week of caregiving, duration of

caregiving, and income), and the two primary outcome variables (respect and provide; Table 2).

Quality of care – respect was not correlated with any of the demographics. Quality of care –

provide was inversely correlated with years of school, months spent caregiving, but positively

correlated with hours per week spent caregiving.

Table 2. Correlations between caregiver demographics and quality of care subscales

Variables	1	2	3	4	5	6	7	8
1. Gender								
2. Years of school	-.20*							
3. Months caregiving	-.17	.02						
4. Hours per week caregiving	.04	-.50**	.10					

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5. Income	-.13	.37**	.11	-.10			
6. Marital status	.01	.25*	.00	.34**	.14		
7. Exemplary care: Respect	.06	-.12	-.12	.17	-.01	.03	
8. Exemplary care: Provide	.14	-.23*	-.28**	.20*	.02	.06	.79**

Note. *$p < .05$. **$p < .01$. Marital status coded as partnered vs. not partnered.

A second correlation matrix was created to examine the bivariate relationships among

burden and the mental health variables (depression, anxiety, and satisfaction with life; Table 3).

These correlations were all statistically significant and ranged in magnitude from .23 to .49,

suggesting a lack of multicollinearity among these variables.

Table 3. Correlations among caregiver burden and mental health variables

Variables	1	2	3	4
1. Burden				
2. Anxiety	.49**			
3. Depression	.44**	.39**		
4. Satisfaction with Life	-.40**	-.23*	-.44**	

Note. *$p < .05$. **$p < .01$.

Hierarchical Multiple Regressions

Two separate multiple regressions examined whether the three mental health variables

and burden were associated with quality of care – respect and provide. In the first multiple

regression with quality of care – respect as the dependent variable, the three mental health

variables (depression, anxiety, and satisfaction with life) and burden were entered

simultaneously as independent variables. Because no demographic variables had been

significantly correlated with quality of care – respect in the correlation matrix, none were

controlled for in this analysis. The model accounted for 18.8% of the variance in quality of care

– respect, $F(4, 97) = 5.63$, $p < .001$, $R^2 = .19$. Satisfaction with life was uniquely related to respect, ($\beta = .36$, $p = .001$), but depression ($\beta = .07$, $p = .539$), anxiety ($\beta = -.07$, $p = .510$), and burden ($\beta = -.14$, $p = .213$) were not.

A second hierarchical multiple regression with quality of care – provide as the dependent variable was conducted. The independent variables in the first step were the demographics shown to be correlated in the correlation matrix with quality of care – provide (years of school, hours per week of caregiving, and duration of caregiving). Together, these variables accounted for 14.7% of the variance in quality of care – provide, $F(3, 98) = 5.61$, $p = .001$, $R^2 = .15$. Months caregiving was uniquely related to quality of care – provide, ($\beta = -.29$, $p = .002$), but hours per week ($\beta = .15$, $p = .180$), and years of school, ($\beta = -.15$, $p = .157$) were not. In the second step, the three mental health variables and burden were entered as independent variables, and this resulted in a significant improvement in the model $F(4, 94) = 4.93$, $p = .001$. The second step accounted for 29.5% of the variance in quality of care – provide, $F(7, 94) = 5.61$, $p < .001$, $R^2 = .30$. Satisfaction with life was uniquely related to provide, ($\beta = .38$, $p < .001$), but depression ($\beta = -.07$, $p = .536$), anxiety ($\beta = .03$, $p = .797$), and burden ($\beta = .04$, $p = .691$) were not.

Structural Equation Model

A structural equation model (SEM) was developed using AMOS 21.0 (Arbuckle, 2007) to validate a hypothesized pattern of relations among manifest and latent variables leading from cognitive functioning in individuals with dementia through caregiver burden and caregiver mental health and finally to quality of care. For this analysis, it was hypothesized that cognitive functioning in individuals with dementia would a have direct and inverse effect on caregiver burden. Caregiver burden was hypothesized have a direct and inverse effect on caregiver mental

health, which would have a direct and positive effect on quality of care provided. Further, it was hypothesized that there would be an indirect effect of cognitive functioning in individuals with dementia on caregiver mental health through burden, as well as burden on quality of care through mental health.

Cognitive functioning in individuals with dementia and caregiver burden were used as manifest variables (represented by boxes in Figure 1). The latent variable of caregiver mental health was comprised of the depression, anxiety, and satisfaction with life. The latent variable of quality of care was comprised of the two subscales of the ECS – Respect and Provide. Both latent variables are represented by ovals in Figure 1.

The following criteria were used to assess goodness of fit for the models: ratio of chi-square to degrees of less than 2.0; traditional fit indices, including the comparative fit index (CFI) goodness of fit index (GFI), adjusted goodness of fit index (AGFI), normed fit index (NFI), incremental fit index (IFI), and Tucker-Lewis index (TLI), higher than .90 which would indicate adequate fit (Byrne, 1994; Hu & Bentler, 1999); and a root mean square error of approximation (RMSEA) of .08 or less (Tabachnick & Fidell, 2001). Two separate SEMs were conducted, one including burden as a manifest variable (as seen in Figure 1) and a second SEM with burden incorporated into the latent variable of mental health.

The first SEM with factor loadings (standard regression weights) appears in Figure 2. The overall fit for the first model was generally adequate or good, $\chi^2/df = 1.87$, CFI = .95, GFI = .94, NFI = .90, IFI = .95, TLI = .92, although two fit indices were slightly below adequate, AGFI = .86 and RMSEA = .09. All observed variables were found to be good indicators of their latent factors (factor loadings ranged in magnitude from .58 to 1.08, all $ps < .001$). As hypothesized, cognitive functioning in individuals with dementia was inversely associated with caregiver

burden, caregiver burden was inversely associated with mental health, and mental health was positively associated with quality of care. Additionally, patient cognitive functioning yielded a significant indirect effect on caregiver mental health through burden ($\beta = 0.32$, $p < .001$), as well as a significant indirect effect of caregiver burden on quality of care through mental health ($\beta = -.28$, $p < .001$).

Figure 2. Theoretical Path Model with factor loadings
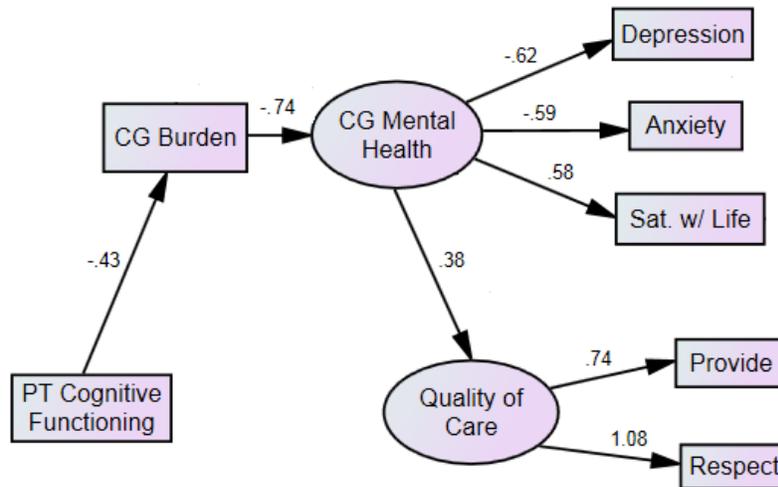
In the second SEM, three of the indices were adequate, CFI = .91, GFI = .92, IFI = .91, although five were below adequate, χ^2/df = 2.51, AGFI = .83, NFI = .86, TLI = .85, RMSEA = .12. All observed variables were good indicators of their latent factors (weights ranged in magnitude from .53 to 1.07, all $ps < .001$). Cognitive functioning in individuals with dementia was positively associated with caregiver mental health ($\beta = .41$, $p < .001$), and mental health was positively associated with quality of care ($\beta = .36$, $p = .002$). Additionally, patient cognitive functioning yielded a significant indirect effect on quality of care through caregiver mental health ($\beta = .15$, $p < .001$). When comparing the fit indices of Models 1 and 2, those from the first model were generally superior, suggesting a better fit with the data and the retention of Model 1 over Model 2, keeping burden as a separate construct.

Exploratory Analyses

A one-way analysis of variance (ANOVA) was conducted to compare the effect of relationship to the person with dementia (spouse vs. children only) on burden and mental health variables. There was a significant effect of relationship to patient on depression, F (1, 99) = 9.312, p = .003, with spouses experiencing greater depression symptoms (M = 1.67, SD = .85) than children (M = 1.13, SD = .91). There were no effects for burden, anxiety, or satisfaction with life (all ps $\geq$ .060.)

Discussion

The purpose of this study was to examine the connections between cognitive functioning in individuals with dementia and caregiver burden, burden and mental health, mental health and quality of care, and the potential indirect effects of cognitive functioning in individuals with dementia on caregiver mental health through burden, as well as burden on quality of care through caregiver mental health. Several notable caregiver demographic characteristics were associated with higher quality of care provided to individuals with dementia, including fewer months providing care, lower education level, and greater hours per week providing care. Two multiple regressions suggested that caregiver burden, depression, anxiety, and satisfaction with life explained 18.8% of the variance in quality of care – respect and 14.7% of the variance in quality of care – provide. In both regressions, only satisfaction with life was uniquely related to quality of care, (β = .36, p = .001, β = .38, p < .001, respectively). An SEM with generally adequate fit indices uncovered that cognitive functioning in individuals with dementia was inversely associated with caregiver burden, caregiver burden was inversely associated with mental health, and mental health was positively associated with quality of care. Patient cognitive functioning yielded a significant indirect effect on caregiver mental health through burden (β = 0.32, p <

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.001), and caregiver burden had a significant indirect effect on quality of care through mental health (β = -.28, p < .001).

Bivariate Correlations with Demographics

In the correlation matrix, an inverse relationship emerged between years of school and quality of care – provide, which differed from previous research on dementia caregivers that has not found education and quality of care to be related (Christie et al., 2009). Other previous research has, however, shown that higher education was associated with a greater likelihood of helping with transport/mobility outside of the home and medical care, but not with personal care or household activities (Hosseinpoor, Bergen, & Chatterji, 2013). In the current sample, years of school was also negatively associated with hours per week providing care, which in turn was inversely associated with quality of care – provide. This combination of findings perhaps suggests that caregivers with a higher education did not provide as many hours of care per week for the individual with dementia, which could be confounded as a construct with the quality of care provided. Indeed, many of the items in the ECS (e.g., "I take the time to sit and talk with [care recipient].") index both quality of care and also *quantity* of care. The caregivers in this sample had an average educational level of 14.17 years, which is fairly high by Argentinian standards, and those with higher education did not tend to take on the greatest care responsibilities within the family, or provide the highest quality of care. This combination of results suggests that caregivers with a higher education may not be providing the most care, and as a result less quality care. Differential patterns of care may exist in Argentina based on socio-demographic determinants like education level, highlighting a need for further research on caregiver interventions that take into account a caregiver's education level and amount of care provided. This type of research may uncover ways to engage caregivers of higher and lower

education levels by providing them with referral to services, and more information and support at diagnosis that is sensitive to their actual caregiving duties.

Additionally in the correlation matrix, a significant inverse relationship emerged between months spent caregiving and quality of care – provide. Previous research has similarly found that a greater length of time in the caregiving role was related to lower exemplary care (Christie et al., 2009). Some caregivers in the current sample had spent many years being a caregiver, as the average number of months in the caregiving role for this sample was 48.88. Providing care for extended periods of time could have resulted in higher burden and reduced mental health, which would likely reduce the quality of care provided to the individual with dementia. Previous research has also found high levels of burden in caregivers who have provided care for extended periods of time to older adults with physical limitations (Horowitz, 1985). The current findings in light of this previous research suggest that interventions are particularly needed for dementia caregivers who have been providing care for several years or more in order to decrease their burden, improve mental health, and perhaps as a result, improve the quality of care they provide.

Multiple Regressions

The two multiple regressions explaining 18.8% of the variance in quality of care – respect and 14.7% of the variance in quality of care – provide both yielded similar findings, with unique effects only for satisfaction with life. Research has shown that caregivers' satisfaction with life is one of the strongest buffers against negative stress (Lundh, 1999). Although many caregivers provide care for extensive periods of time which can increase caregiver burden (Horowitz, 1985), a great number of caregivers still find personal satisfaction in the act of providing care (Kristensson, 2004), which could potentially increase the quality of care they provide. The provision of high quality care has indeed been identified as a source of caregiver

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satisfaction (Andrén & Elmståhl, 2005), so the opposite causal direction could also be operating in the current findings. Researchers have emphasized that the fulfillment of care responsibilities for family members can garner gratification, meaning, and life satisfaction among caregivers (Grant et al., 1993; Nolan et al., 1992). The unique relationship between caregiver satisfaction with life and quality of care in the current study could also exist in part because of the extreme importance placed on providing care in Latino families (Hurtado, 1995). Dementia caregivers in the current study and in Latin America more generally may derive particular meaning and pleasure from performing the role of caregiver, contributing to increased life satisfaction.

The lack of significant unique effects of depression, anxiety, and burden on either type of care is likely due to the fact that satisfaction with life fully eclipsed any possible effects of the other mental health variables. This combination of variables did significantly explain 18.8% of the variance in quality of care – respect and 14.7% of the variance in quality of care – provide, so holistically they were a good set of predictors, but perhaps not much better than satisfaction with life alone. Generally speaking, these findings do suggest that good mental health could facilitate a higher of quality of care among dementia caregivers. Past research has shown that providing exemplary care to individuals with dementia is associated with lower caregiver depression symptoms (Harris et al., 2011), but the researchers did not assess satisfaction with life in that study. Results of the current study in light of the previous research suggest that interventions aimed at helping caregivers examine the relationship between providing care and their own life satisfaction may be of particular benefit in Argentina.

Structural Equation Models

A comparison of the fit indices between the two SEMs suggests that caregiver burden is better treated as a separate construct from mental health and that the likely pattern of connections

among variables examined in this study involves a series of direct effects from cognitive functioning in individuals with dementia to caregiver burden, to mental health, to quality of care provided. The first part of the retained model with higher cognitive functioning in individuals with dementia being inversely associated with caregiver burden is consistent with previous research that has shown Mini-Mental State Examination (MMSE) scores of individuals with dementia to be inversely related to caregiver burden, especially when dementia severity exceeds a threshold of MMSE <20 (Berger et al., 2005; Haro et al., 2014). This relationship found in the current study and in previous research may be due to the fact that increased cognitive impairment in individuals with dementia often entails greater care responsibilities, which can increase caregiver burden and psychiatric morbidity (Garand, Amanda Dew, Eazor, DeKosky, & Reynolds, 2005). The current findings in light of this previous research suggests that when individuals with dementia have lower scores on the MMSE (especially below 20), clinicians should assess caregivers for high levels of burden, which if found to be present, should trigger an appropriate referral for caregiver services. Caregivers with high burden may be ideal targets for elective preventive interventions to reduce burden, which if not treated, can initiate a cascade of other problems, as found in the SEM in the current study.

The second aspect of this cascade uncovered was that caregiver burden was inversely associated with mental health. A fairly extensive body of research has shown that dementia caregivers who are highly burdened by their caregiving duties exhibit more depressive symptoms (Papastavrou et al., 2011) and higher anxiety symptoms (Mahoney et al., 2005; Cooper et al., 2008). The current findings and those from the previous research suggest there is a need for interventions targeting those specific caregivers with higher levels of burden, which could be a pathway for reducing mental health problems and improving satisfaction with life. Garand and

colleagues (2005) advocate for interventions for caregivers specifically with high levels of burden in order to prevent the worsening of psychiatric symptoms. In particular, when considering the extent to which Latino caregivers tend to take on extensive care duties, placing themselves at high risk for burden (Hurtado, 1995), caregiver interventions in Latin America could benefit from teaching caregivers to seek out and accept care provision by other family members in order to decrease burden and mental health problems in the primary caregiver.

The third major association identified in the SEM was that caregiver mental health was positively associated with quality of care. Research has shown an increase in caregiver depression symptoms to be associated with potentially harmful behavior toward the person with dementia (Smith et al., 2011; Cooper et al., 2010), including screaming, yelling, and threatening the care recipient with nursing home placement (Cooney et al., 2006; Godkin et al., 1989; Miller et al., 2006; Williamson et al., 2001). Similarly, a longitudinal study found that increased caregiver depressive symptoms predicted potentially harmful behavior over time (Smith et al., 2011), and high rates of depression symptoms in Latino caregivers (Gallagher-Thompson et al., 2000) may suggest depression symptoms to be associated with resentful feelings and aggressive coping strategies, which are risk factors for harmful care behavior (Shaffer et al., 2007). The current findings, as well as the previous research, suggest that treating mental health problem in dementia caregivers from Argentina may improve the quality of care they provide to the individual with dementia.

Lastly, patient cognitive functioning yielded a significant indirect effect on caregiver mental health through burden, and burden yielded a significant indirect effect on quality of care through mental health. To the author's knowledge this is the first study to date that has examined indirect effects in this series of events in order to link them in a theoretical causal chain, and

moreover, this has not been done among caregivers in Latin America. The first indirect effect is important because much research has linked reduced cognitive functioning in individuals with dementia with caregiver mental health problems (Hall et al., 2014). This is the first set of findings to suggest that this connection may be linked causally by the level of burden that reduced cognitive functioning in individuals with dementia puts on caregivers. The second indirect effect is similarly important because the findings suggest that increased burden may be linked causally to the quality of care provided through burden's effect on caregiver mental health. This pattern of psychological events supported in the current study presents a number of foci for caregiver interventions.

Clinical Implications

Because all hypotheses in the current study were supported, the findings in conjunction have important implications for the development of dementia caregiver interventions in Latin America, especially in light of the previous research. When cognitive impairments are high in individuals with dementia, clinicians can alert caregivers about the burden they are likely to experience, if not already experiencing. Routinely administering a validated measure of caregiver burden when patients have low cognitive functioning, such as the Zarit Burden Inventory used in the current study, can help clinicians identify at-risk caregivers. In these situations, clinicians can assist caregivers in finding appropriate support groups (Mittelman et al., 2004) and, if necessary and available, respite care (Salin, Kaunonen, & Astedt-Kurki, 2009). It is indeed critical to identify caregivers who are at risk for the initiation of this cascade of psychosocial problems and care difficulties, given that as cognitive impairment increases in patients, burden may increase as well, which if not treated, can reduce caregiver mental health, and ultimately but unfortunately, the quality of care they are able to provide for the individual with dementia.

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Interventions tailored to the specific needs of the caregiver that may be creating high subjective burden may be particularly important, especially if they involve the caregiver and care recipient as active participants and occur continuously over the course of caregiving (Brodaty et al., 2003; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). Several dementia caregiver interventions have shown particular promise in reducing caregiver burden, such as the Family Intervention: Telephone Tracking-Dementia (FITT-D), which is telephone-based and involves providing emotional support, referring caregivers to appropriate resources, encouraging caregivers to attend to their own physical, emotional, and social needs, and teaching caregivers strategies to cope with ongoing problems (Tremont, Davis, Bishop, & Forinsky, 2008). Given the challenges many caregivers in Latin America may have with regular transportation to a medical clinic, this type of approach may better serve caregivers who are socioeconomically disadvantaged or more remote areas.

In addition to the reduction of caregiver burden, the current findings suggest that clinicians can also directly target caregiver mental health problems, which likely decrease the quality of care provided. Social support is a well-documented resource that is particularly important in Latin America and has been shown to reduce caregiver depressive symptoms (Jacobson, Martell, & Dimidjian, 2001; Mausbach et al., 2011). Interventions that help increase caregivers' participation in daily social activities and establish or strengthen a support network are very likely to improve caregiver mental health. A group cognitive-behavioral intervention for dementia caregivers in Latin America was found to decrease caregiver depression symptoms and increase satisfaction with life, with the authors asserting that a group intervention format is particularly important in increasing social support (Arango-Lasprilla et al., 2014). Additionally, research has found that the use of solution-focused, emotional, and acceptance-based coping

strategies are helpful in reducing caregiver anxiety symptoms (Li, Cooper, & Livingston, 2014), so interventions employing these techniques may also have promise. Perhaps the most researched dementia caregiver intervention is Resources for Enhancing Alzheimer's Caregiver Health (REACH) which comprehensively involves information provision, didactic instruction, role-playing, problem solving, skills training, stress management techniques, and telephone support and has been shown to improve caregiver quality of life and reduce depression symptoms (Belle et al., 2006). In the context of the findings from the current study, these interventions that target caregiver mental health problems may have the potentiation to increase the quality of care provided, although this assertion awaits support from future research.

Limitations and Future Directions

The current study has several limitations that should be taken into account which also present directions for future research. First, one of the main limitations was the convenience sampling method used which likely affected the representativeness of the sample and the generalizability of the findings. Data were collected from the Institute of Neuroscience in San Lucas, Argentina, where caregivers had an uncharacteristically high level of education. Higher education also leads to higher socioeconomic status and greater resources, limiting the representativeness of the sample to the larger region. The sample demographics reflect only a segment of the population of caregivers in Latin America, so it is important to replicate this study using a less educated sample from other communities throughout the region.

Second, the scale used to measure quality of care was the Exemplary Care Scale, which conceptualizes quality of care as the two constructs "provide" and "respect." As a result, the current findings would not necessarily apply to other potentially important aspects of quality of care, such as the absence of caregiver abusive behavior, which has been focused on heavily in

the previous literature. Similarly, as mentioned above, the Exemplary Care Scale unfortunately confounds quality of care and time spent in caregiving duties, which can be two very different constructs. This scale was chosen because it is the only validated measures of care quality available in the literature, and this limitation presents a dire need for future research to develop a more comprehensive measure of quality of care to provide more nuance to the construct.

A third limitation to the current study is the inference of a causal chain of psychosocial events in the SEM from cross-sectional and correlational data. Although two models were tested and the better fitting model retained, the cascade may be due to additional variables not measured or controlled for in the current study. One of the main purposes of an SEM is to make causal inference, but with cross-sectional data, an inference can only find support, not proof. Future research can more directly test the cascade supported in the current study by using a cross-lagged panel, longitudinal design to more strongly infer causation. Better still would be an experimental design with an intervention shown to decrease burden or caregiver mental health problems, and to examine the potential of the intervention to improve the quality of care provided. However, no known studies to date have examined an intervention's effect on quality of care in the context of dementia caregiving.

Conclusion

Despite these limitations, the current study was the first to link cognitive functioning in individuals with dementia, caregiver burden and mental health, and quality of care in a theoretical causal chain, as well as to find support for it through a series of direct and indirect effects. This study also contributes to the extremely limited research literature on dementia caregiving in diverse global regions such as Latin America. Future clinical work and research in

line with the trajectory of the current findings may help identify dementia caregivers with high

burden providing care for individuals with low cognitive functioning. These individuals are

particularly at risk for negative mental health outcomes and a reduction in care quality. However,

most importantly, this study suggests that the cascade may also be reversed with the

development and use of dementia caregiver interventions that improve caregiver burden and

mental health and as a result, the quality of care for individuals with dementia.

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Appendix A

Zarit Burden Inventory (ZBI)

Please circle the number for the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spent with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4

13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Appendix B

Patient Health Questionnaire-9 (PHQ-9)

1. Over the last 2 weeks, how often have you been bothered by any of the following problems? Read each item carefully, and circle your response.

	Not at all	Several days	More than half the days	Nearly every day
	0	1	2	3
a. Little interest or pleasure in doing things	0	1	2	3
b. Feeling down, depressed, or hopeless	0	1	2	3
c. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
d. Feeling tired or having little energy	0	1	2	3
e. Poor appetite or overeating	0	1	2	3
f. Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down	0	1	2	3
g. Trouble concentrating on things such as reading the newspaper or watching television	0	1	2	3
h. Moving or speaking so slowly that other people could have noticed. Or being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
i. Thinking that you would be better off dead or that you want to hurt yourself in some way	0	1	2	3

2. If you checked off any problem on this questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not Difficult At All	Somewhat Difficult	Very Difficult	Extremely Difficult
0	1	2	3

Appendix C

Satisfaction With Life Scale (SWLS)

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

1 = Strongly Disagree

2 = Disagree

3 = Slightly Disagree

4 = Neither Agree or Disagree

5 = Slightly Agree

6 = Agree

7 = Strongly Agree

_____1. In most ways my life is close to my ideal.

_____2. The conditions of my life are excellent.

_____3. I am satisfied with life.

_____4. So far I have gotten the important things I want in life.

_____5. If I could live my life over, I would change almost nothing

Appendix D

Mini-Mental Status Examination (MMSE)

The Mini-Mental Status Examination offers a quick and simple way to quantify cognitive function and screen for cognitive loss. It tests the individual's orientation, attention, calculation, recall, language and motor skills.

Each section of the test involves a related series of questions or commands. The individual receives one point for each correct answer.

To give the examination, seat the individual in a quiet, well – lit room. Ask him/her to listen carefully and to answer each question as accurately as he/she can.

Don't time the test but score it right away. To score, add the number of correct responses. The individual can received a maximum score of 30 points.

A score below 20 usually indicates cognitive impairment.

Name _____ DOB _____
Years of School _____ Date of Exam _____

Orientation to Time	Correct	Incorrect
What is today's date?		
What is the month?		
What is the day of the week today?		
What is the year?		
What season is?		
Total:		

Orientation to Place	Correct	Incorrect
Whose home is this?		
What room is this?		
What city are we in?		
What country are we in?		
What state are we in?		
Total:		

Ask if you may test his/her memory. Then say "ball", "flag", "tree" clearly and slowly, about 1 second for each. After you have said all 3 words, ask him/her to repeat them – the first repetition determines the score (0-3):

Immediate Recall	Correct	Incorrect
Ball		
Flag		
Tree		

Total:		

A. Ask the individual to begin with 100 and count backwards by 7. Stop after 5 subtractions. Score the correct subtractions.

Attention	Correct	Incorrect
93		
86		
79		
72		
65		
Total:		

B. Ask the individual to spell the "WORLD" backwards. The score is the number of letters in the correct position.

Attention	Correct	Incorrect
D		
L		
R		
O		
W		
Total:		

Ask the individual to recall the 3 words you previously asked him/her to remember.

Delayed Verbal Recall	Correct	Incorrect
Ball		
Flag		
Tree		
Total:		

Show the individual a wristwatch and ask him/her what it is. Repeat for pencil.

Naming	Correct	Incorrect
Watch		
Pencil		
Total:		

Ask the individual to repeat the following:

Repetition	Correct	Incorrect
"No if, ands, or buts"		

Give the individual a plain piece of paper and say, "Take the paper in your hand, fold it in half, and put it on the floor."

3 Stages Command	Correct	Incorrect
Takes		
Folds		
Puts		
Total:		

Hold up the card reading: "Close your eyes" so the individual can see it clearly.
Ask him/her to read it and do what it says. Score correctly only if the individual actually closes his/her eyes.

Reading	Correct	Incorrect
Closes his/her eyes		

Give the individual a piece of paper and ask him/her to write a sentence. It is to be written spontaneously. It must contain a subject and verb and be sensible.

Writing	Correct	Incorrect
Write a sentence containing a subject and verb and is sensible		

Give the individual a piece of paper and ask him/her to copy a design of two intersecting shapes. One point is awarded for correctly copying the shapes. All angles on both figures must be present, and the figures must have one overlapping angle.

Copying	Correct	Incorrect
Copy a design of two intersecting shapes		
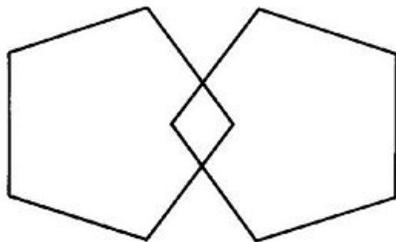
Total Score: _____

Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at All sure	Several days	Over half The days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen.	0	1	2	3
Add the scores for each column				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

Source: Spitzer RL, Kroenke K, Williams JBW, Lowe B. A brief measure for assessing generalized anxiety
disorder. Arch Inern Med. 2006;166:1092-1097.

Appendix F

The Exemplary Care Scale (ECS)

1. I make sure (care recipient) is included in special gatherings such as family and friends getting together or holidays when at all possible.
   1= never   2= sometimes   3=often,   4=always

2. To make (care recipient) feel refreshed and good about him/herself, I do things like being sure that he/she is dressed nicely or that his/her hair is clean and styled.
   1= never   2= sometimes   3=often,   4=always

3. I make sure that where (care recipient) lives is bright and cheery.
   1= never   2= sometimes   3=often,   4=always

4. I make sure the food (care recipient) likes is available for meals and snacks.
   1= never   2= sometimes   3=often,   4=always

5. I actively avoid treating (care recipient) like a child.
   1= never   2= sometimes   3=often,   4=always

6. I take the time to sit and talk with (care recipient).
   1= never   2= sometimes   3=often,   4=always

7. I do everything I can to avoid making (care recipient) feel that he/she is a burden to me.
   1= never   2= sometimes   3=often,   4=always

8. I really try to avoid interrupting (care recipient) when he/she is talking
   1= never   2= sometimes   3=often,   4=always

9. When at all possible, I make sure that (care recipient) gets to do some of the things that he/she enjoys (e.g., visiting friends, listening to music).
   1= never   2= sometimes   3=often,   4=always

10. I try to maintain a relaxed, unhurried atmosphere.
    1= never   2= sometimes   3=often,   4=always

11. I avoid being overcritical of (care recipient).
    1= never   2= sometimes   3=often,   4=always

Vita

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