Burden of Care Impacting Family Caregivers of Dependent Community-Dwelling Older Adults in Rural and Urban Settings of Southern Turkey:
A Mosaic of Caregiver Issues and Recommendations

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Abstract

BURDEN OF CARE IMPACTING FAMILY CAREGIVERS OF DEPENDENT COMMUNITY-DWELLING OLDER ADULTS IN RURAL AND URBAN SETTINGS OF SOUTHERN TURKEY:
A MOSAIC OF CAREGIVER ISSUES AND RECOMMENDATIONS

Population ageing is taking place at an unprecedented rate in Turkey and expected to continue through 2050. This study represents an important first initiative aimed at understanding dimensions of informal family caregiver burden in Turkey. The future implications for primary family caregivers of community-dwelling dependent older adults will be significant as fertility rates and the ratio of potential caregivers to care dependent older adults will decrease, leading to a reduction in the availability of informal carers of community-dwelling dependent older adults in Turkey’s foreseeable future.

The study sample comprised 332 informal caregiver/care-recipient dyads that involved direct access to an informal family caregiver and a community-dwelling dependent older adult. Data was drawn from the Antalya Home Care Survey (AHCS) conducted over the period April 2009 through to March 2010. The age range for informal family caregivers was 20 to 89 years of age with the average age being 50.1 years. In the case of the community-dwelling dependent older adults, the age range was 44 to 100, with the average age being 78.5 years. The informal family caregivers were predominantly female representing 87.8% of the informal caregiver group. Females again were overrepresented in the dependent community-dwelling older adult sample with 62.0% being female compared to 38.0% older males.

The aim of the study was primarily concerned with determining the nature and extent of informal caregiver burden in urban, quasi-rural and rural environments in the Province of Antalya, Turkey. Independent variables related to caregiver characteristics, a comparison of past and present dyadic relationships, and a framework of caregiver components of care were tested for statistical correlation to three factor-analysis-derived-components of care-related burden, namely, psycho-spiritual, social, and physical burden. The three components combined explained 53.8% of the variance in caregiver burden. Results suggest that the psycho-spiritual component, explaining 31.2% of variance, represented the most significant consequence of caregiver burden. Hypotheses tests revealed only living arrangements to be significantly related to all three burden components while support for Activities of Daily Living support, self-rated health, present and past-present comparison of quality of relationship, and physical environment were found to be significantly related to two of the three burden components. Additionally, six of eleven variables namely, economic burden, caregiver income, kin relationship, anxiety of future, self-rated health, and past-present comparison of dyadic quality of relationships were found to be significantly related to the selected environmental contexts comprising urban, quasi-rural, and rural.

Supportive interventions at the provincial and central government levels need to be informed by further research that further investigates the growing elder care needs of families, particularly those related to the health and well-being of informal primary caregivers. An array of emerging issues that warrant future attention included a) concerns relating to caregiver fatigue, b) absence of regular respite with potential consequences for unintended neglect and/or abuse of community-dwelling older adults in receipt of caregiving, and c) the need to address the differential support needs of urban as well as rural-based informal family caregivers of dependent older adults. A range of recommendations placed in four sub-categories provides useful insights and challenges for further research and policy formulation.

Dedication

This dissertation is dedicated to the memory of my uncle, Robert “Bobby” Holdsworth. Soon after my grandfather was diagnosed with Alzheimer’s disease, my grandmother suffered a major stroke. During the prime years of his adult life, Bobby left the life he’d established to move back to the ‘country’ to co-reside with and care for his parents. Bobby spent the next seven years caring for my grandfather and an additional seventeen years looking after my grandmother, affording them both the dignity of remaining in and dying in their own home. Shortly after my grandmother’s passing, Bobby was diagnosed with lung cancer. When he was no longer able to look after himself, my parents, John and Gerry, took Bobby into their home and cared for him in the way Bobby had cared for his parents, affording him the same dignity in his last days on this earth prior to passing to his eternal home in glory.

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Definition of Terms

Ageing in place "Living in the same location, usually a home or apartment, until late old age or death" (Novak, 2009, p. 473), as opposed to living in a care facility such as a nursing home.

Caregiver see "Primary Caregiver".

Caregiving "whether informal or formal, denotes supportive, non-medical, mostly low-tech services, such as help with bathing or eating, and some medical services, such as administering medications and attending to wounds" (Schmieding, 2006; as cited in Hooyman & Kiyak, 2008, p. 386).

Caregiver burden "the personal energy, time restrictions, financial strains, and/or psychological frustrations associated with assisting persons with long-term care needs" (Hooyman & Kiyak, 2002, p. 279).

Care-recipient an individual 60 years of age and older, care-dependent [e.g. requiring assistance in Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living (IADL)], and having cognitive health sufficient to reliably respond to questionnaire inquiries.

Clientelism "a social order that depends upon relations of patronage; in particular, a political approach that emphasizes or exploits such relations" (Oxford Online Dictionary, n.d.)

Community-dwelling living in the mainstream community rather than in a formal institutional type setting.

Co-morbidity "the concurrent presence of two or more medically diagnosed diseases in the same individual, with the diagnosis of each contributing disease based on established, widely recognized criteria."(Fried et al., 2004, p. 258).

Decommodification [Based on it's conceptualization in Esping-Anderson's *The Three World's of Welfare Capitalism* (1990)] a concept which places the provision of welfare entitlements as a right, independent of market participation.

Defamilialization [As conceived by Esping-Anderson (1999)] an outcome of policies that reduced dependency on familial support by maximizing the "individuals' command of economic resources independently of family or conjugal reciprocities" (as cited in Leira, 2002, p. 41).

Disability "difficulty or dependency in carrying out activities essential to independent living, including essential roles, tasks needed for self-care and living independently in a home, and desired activities important to one's quality of life" (Fried et al., 2004, p. 255).

Frailty (1) "a state of high vulnerability for adverse health outcomes, including disability, dependency, falls, need for long-term care, and mortality"; (2) "clinicians identify 'frailty' in the presence of a critical mass of consequences of disease and aging-related changes, including: a) generalized weakness, b) poor endurance, c) weight loss and/or undernourished, d) low activity (even homebound), and e) fear of falling and/or unsteady gait" (Fried et al., 2004, p. 257).

Helping others distinctly informal in definition, it refers to help based on relationship between family member, friend, or neighbor and the care-recipient and is typically based on historical patterns of reciprocity and sense of obligation(Rozanova et al., 2008).

Informal caregiving "unpaid assistance provided by family, friends, and neighbors for persons requiring help with ADL [Activities of Daily Living] and IADL's [Instrumental Activities of Daily Living]" (Hooyman & Kiyak, 2008, p.419).

Maltreatment (of elder) (1) “a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm and distress to an older person” (WHO, 2011a, p. 1). (2) “Physical, sexual, mental and/or financial abuse and/or neglect of people aged 60 years and older“(WHO, 2011b, p. viii).

Objective burden (1) reference to “time, efforts, tasks services, and financial supports” (Koerin & Harrigan, 2003, p. 66); (2) “time infringements”, meaning, “the caregiver’s perception that their caregiving responsibilities are interfering with their daily life and other responsibilities” (Savundranayagam et al., 2011, p. 322).

Primary caregivers “those individuals who, on behalf of the care-recipient, performed the majority of caregiving tasks and spent more time performing those tasks than any other person” (Lund, 1993; as cited in Lund et al., 2009).

Social network consists of the sum of all of a persons social relationships.

Social support **“**the network of relatives, friends, and organizations that provide both emotional support, such as making the individual feel loved or comforted, and instrumental support, which refers to help in managing activities of daily living” (Quadagno, 2008, p. 180).

Stress (1) “…an experience arising from transactions between a person and the environment” (Aldwin, 2007, p. 27). (2) As such, stress is not linked to a negative experience or outcome, but an outcome is determined by the specific interactions of the person and his or her environment, suggesting an infinite number of outcomes, which may be agreeable or healthy (eu-stress) or disagreeable or pathogenic (di-stress) (Selye, 1976).

Subjective burden “the caregiver’s perceptions, attitudes and emotions about caregiving” (Koerin & Harrigan, 2003, p. 66).

Surveillance zone	“space within the visual field of home, [that] may become an increasingly significant source of support (...) as people grow older and spend more time at home” (Rowles, 1981a; as cited in Rowles, 1983, p. 120).
Volunteer activities	distinctly formal in definition and not bound to personal connections, but to the “existence of formal organizations and infrastructures” (Rozanova et al., 2008, p. 76).
Welfare	(1) “well-being, happiness; health and prosperity (of person, community, etc.” (2) “financial support from state” (Oxford Dictionary, 2001, as cited in Greve, 2008, p. 51).

Abbreviated Terms

ADL = Activities of Daily Living

AHCS = Antalya Home Care Survey

CG / CGs = Caregiver / Caregivers

CG$_B$ / **CG burden**= Caregiver burden

CR / CRs = Care-recipient / Care-recipients

IADL = Instrumental Activities of Daily Living

Para. (para.)= Paragraph

PCG = Primary Caregiver

QoR = Quality of Relationship

CHAPTER 1

THE DEMOGRAPHICS OF AGEING AND THE GROWING IMPORTANCE OF ELDER CARE

1.1 International Perspective

1.1.1 Population Growth

In 1999 the United Nations proclaimed it to be "The Year of the Older Person" in recognition of the trend towards global population ageing (Kinsella & Velkoff, 2001). Today we are witnessing rapid improvements in life expectancy worldwide and to an extent never before seen in human history. This unprecedented growth in population ageing around the globe has thrust this demographic change into the forefront as a major economic, social and political issue for many countries. Consequently, new challenges arise for key stakeholders including policy makers, scientists, health professionals, educators and governments at the international, national and local levels.

Nyce and Schieber (2005, p. 9) refer to Massimo Livi-Bacci's historical view of the world's populations between the years 10,000BC and AD2000 (See Table 1). While there was a sizeable increase in world population growth between 1750 and 1950, it was the dramatic increase from 2.5 billion to well over 6 billion during the 50-year period from 1950 to 2000 that posed a myriad of challenges requiring urgent attention in both developed and developing countries. Additionally, while life expectancy at birth increased by 8 years from 27 to 35 years of age over the two hundred years spanning 1750-1950, it was the life expectancy increase of 23 years between 1950 and 2000 that emerged as a preeminent worldwide phenomenon. In particular, Kinsella and Velkoff (2001, p. 23) show that "From 1900 to 1950, people in many Western nations were able to add 20 years or more to their life expectancies".

Table 1

World Population, Total Births, and Years Lived, 10,000BC to AD2,000

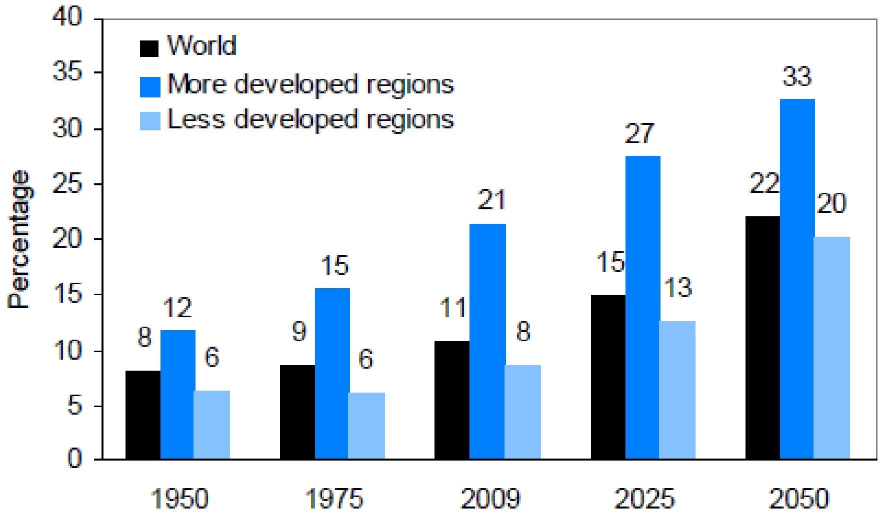
Demographic Index	10,000 BC	0	1750	1950	2000
Population (Millions)	6	252	771	2,530	6,235
Annual Growth (%)	0.0008	0.037	0.064	0.569	1.812
Doubling Times (yrs.)	8,369	1,854	1,084	116	38
Life expectancy at birth	20	22	27	35	58

Source: Massimo Livi-Bacci, *A Concise History of World Population* (1989, p. 31).

Factors influencing this sizeable increase in life expectancy included provision of public health services and control and eradication of many communicable diseases. At the same time, many developing countries since the end of World War II have also experienced upward trends in life expectancy (Kinsella & Velkoff, 2001). While increases in population ageing may be seen as a remarkable human achievement, it is now recognized, more than ever, that all societies throughout the 21st century will have to face the daunting challenge of anticipating and planning for the diverse needs and desires of their respective ageing populations. A particular concern relating to increasing life expectancy is that many older people in advanced old age face the prospect of living with chronic illness and disability and loss of independence. While marked differences exist between developed and developing countries in terms of the availability and access to health and community support services, the predominant form of care for vulnerable older persons remains primarily with family caregivers (Lynn & Adamson, 2003).

1.1.2 Population Ageing

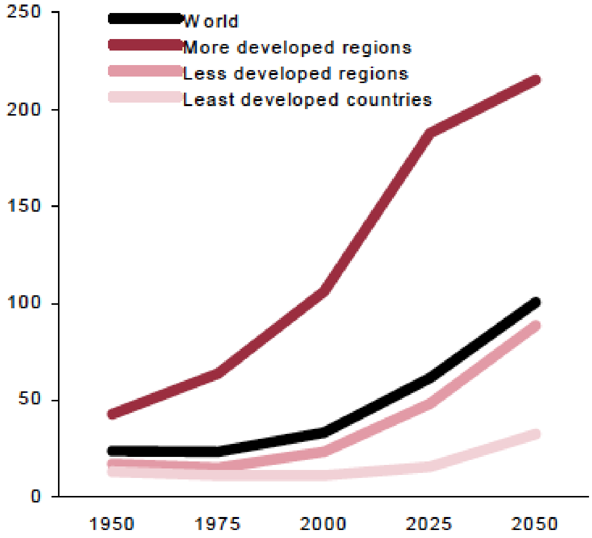
At the pinnacle of interest related to demographic change are the growing numbers and proportions of older populations in most societies throughout the world. Until the twentieth century, older adults aged 60 and over had never accounted for a significant proportion of the world's population. Dr. James Vaupel, Director of the Max Plank Institute for Demographic Research has pointed out that in 1840, Sweden held the record of longest life expectancy at a little more than 45 years for females. Today, adds Dr. Vaupel, the record held by Japanese women is just over 85 years (Nyce & Schieber, 2005, p. 13). In fact, the number of adults aged 60 and over worldwide is expected to increase to such an extent so as to exceed the population of children (under age 15) in 2045 for the first time in history~~.~~ (United Nations [UN], 2010a, p. xxiv). *Figure 1* shows the spectacular world based increases in the proportion of people aged 60 and over including the expected continued growth across developed and developing regions through to 2050.



Source: Department of Economic and Social Affairs, Population Division, (2010). "World Population Ageing 2009", United Nations, p.13.

***Figure 1*. Proportion of population aged 60 or over: World and development regions, 1950-2050**

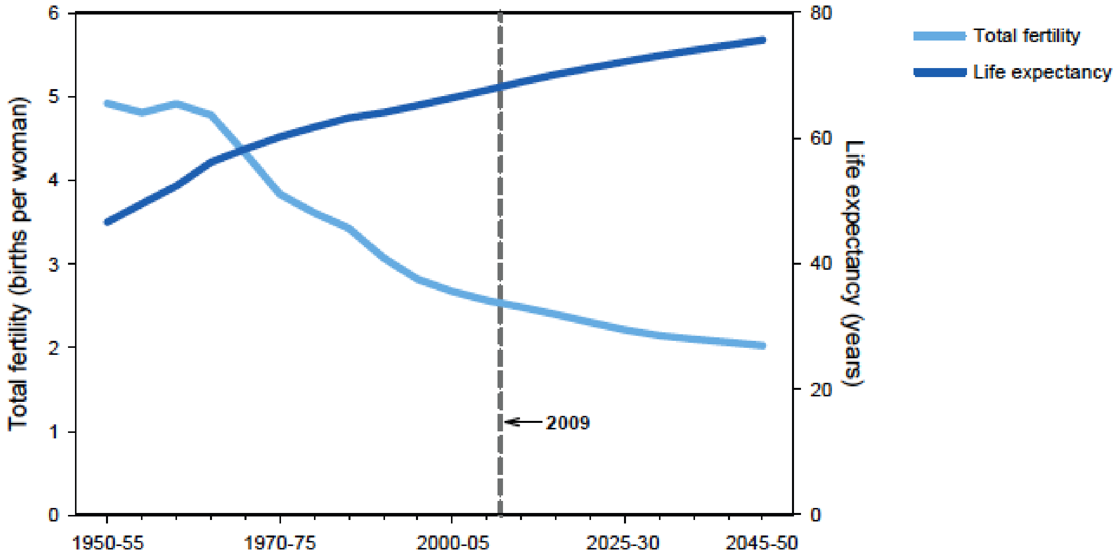
Figure 2 highlights another dimension surrounding the demographics of ageing by way of showing a progressive increase in the number of persons aged 65 and over per hundred children aged under 15 years for the world as a whole and according to level of regional development.



Source: Department of Economic and Social Affairs, Population Division, (2009). "World Population Ageing 1950-2050", United Nations, p.16.

***Figure 2*. Number of persons 65 or over per hundred children under 15: World and development regions, 1950-2050**

Declining fertility rates, the result of changes in reproductive behavior, combined with higher life expectancies also help to explain the increasing numbers of older people across world populations (See *Figure 3*). While for many countries there has been an epidemiologic transition from infectious or communicable diseases to chronic illnesses, essentially known as non-communicable diseases, mortality rates have generally declined due to innovative medical interventions (WHO, 2002). So the combined forces of people living longer and having fewer children are working together to increase the median age of populations– resulting in population ageing –in 'virtually all countries' of the world (Bloom, et al., 2011, p. 3). Thus, current and future demographic projections make it clear that population ageing will be a

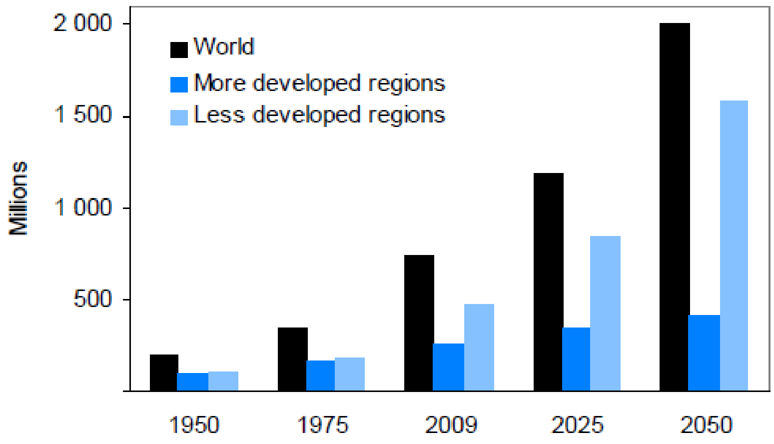


Source: Department of Economic and Social Affairs, Population Division, (2010). "World Population Ageing 2009", United Nations, p. 13.

Figure 3. **Total fertility rate and life expectancy at birth: World, 1950-2050**

significant demographic issue facing all developed as well as most developing nations during the 21st century (Nugent & Seligman, 2008; Kinsella & Velkoff, 2001).

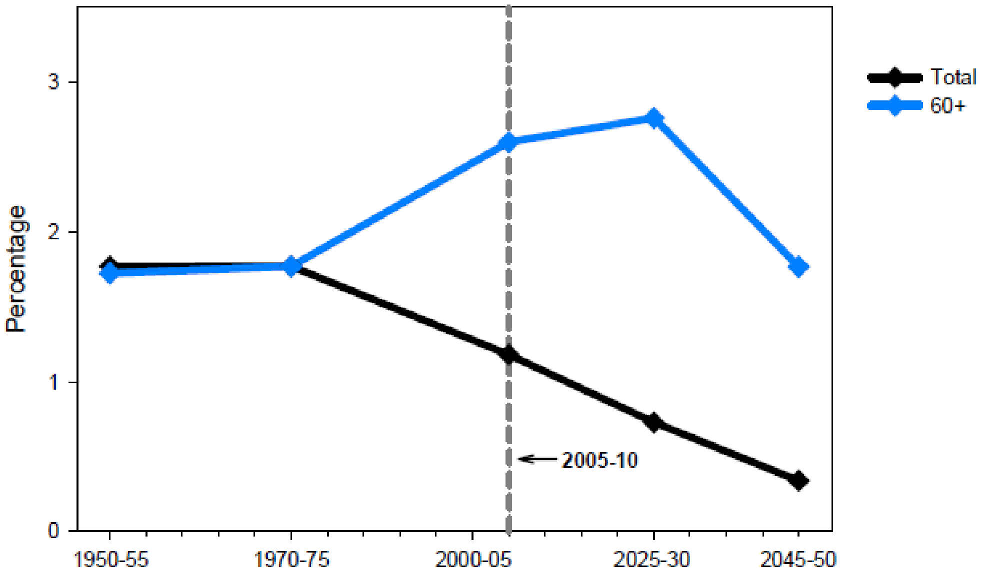
Even more dramatic than the overall population increase has been the concomitant rapid increase in world populations of older cohorts since the 1970's. In 1950, only some 205 million adults aged 60 or over were living worldwide. By 2009, the number of persons aged 60 and over had increased to 735 million – more than a three and a half fold increase in less than 60 years. By the year 2050, the number of adults 60 years or more is expected to increase almost threefold to 2 billion. (UN, 2010a, p. 11).



Source: Department of Economic and Social Affairs, Population Division, (2010). "World Population Ageing 2009", United Nations, p.11.

Figure 4. **Population aged 60 or over: World and development regions, 1950-2050**

An initial glance at *Figure 4* would seem to suggest that the increase in populations of older cohorts is merely shadowing world population growth. However, a closer look (*Figure 5*) comparing annual population growth with that of older adults is needed. As indicated in *Figure 5*, in 1950-55, the annual growth rate of 1.7% among adults 60 and over was slightly behind the annual population growth of 1.8%. In 2005-2010, annual growth in older adults (60+) was 2.6%, more than 2 times the 1.2% growth seen in the total population. Demographic projections for 2025-30 predict 2.8% annual growth among older adults of 60 years and older - four times that of the 0.7% annual growth expected in the total population. In 2045-2050, an annual increase of 1.8% for older adults (60+) is expected to be roughly six times that of the projected annual growth of 0.3% in the world population (UN, 2010a, pp. 11-12). Clearly, while the numbers of older cohorts aged 60 and over have begun to increase at a rate beyond that of the total population, we have not yet witnessed the full extent of future population ageing.



Source: Department of Economic and Social Affairs, Population Division, (2010). "World Population Ageing 2009", United Nations, p.12.

***Figure 5.* Average annual growth rate of total population and population aged 60 or over: World, 1950-2050**

At present, population ageing is most evident in the developed countries of the world, especially in Europe and Japan. Indeed Japan, Germany and Italy are among the nations riding on the front edge of the great population-ageing wave.

At the top among countries experiencing population ageing, Japan is considered a 'super-ageing' society. Life expectancy at birth is highest in Japan at 86 for women and 80 for men (World Health Organization 2009, as cited in Muramatsu & Akiyama, 2011, p. 426). Parallel to its increase in life expectancy, Japan is experiencing a rapid decline in fertility, which is the critical contributor to population ageing. Japan's total fertility rate has been consistently low since the late 1990s (1.37 in 2009), considerably below the replacement level for a sustainable population. While total population peaked in 2004 at 128 million, projections suggest that by 2050 Japan's population will have shrunk to 75% of its peak size (Muramatsu & Akiyama, 2011). In 2009 29.7% of Japan's total population was 60 years of age or older. By 2050, this percentage is expected to increase to 44% (Pirkl, 2009).

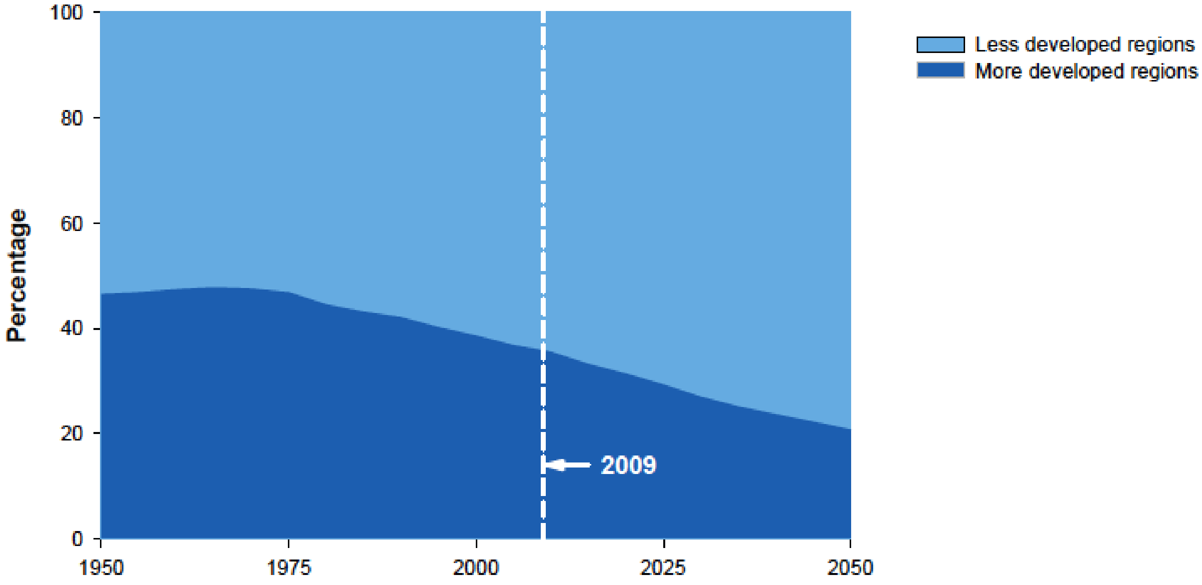
In reference to older cohorts, Germany's population is not much different than that of Japan. In 2009, Germany's aged 60 and over population was 25.6% – roughly one in four people. In 2050, nearly two out of every five individuals (38.1%) in Germany is expected to be aged 60 and over (UN, 2002). Between the years 2000 and 2050, Germany is expected to incur population attrition of nearly 4% resulting in a drop from 82.3 million down to 79.1 million (UN, 2004).

With a very similar profile to that of Germany, 26.4 % of Italy's population was 60 years of age or older in 2009. In 2050, the number of older cohorts aged 60 and over in Italy is expected to climb to over 42% (UN, 2002). Based on United Nations projections, Italy's population is expected to shrink from 57.5 million in 2000 to under 44.9 million in 2050 – a net loss of 22% (UN, 2004).

While Japan, Germany and Italy are examples of more developed countries that have experienced rather acute population ageing to date, underdeveloped and developing countries are at different stages in relation to their projected trajectories for population ageing. In fact, annual growth rates of older cohorts in less developed regions and least developed countries are expected to be considerably higher than those in more developed countries.

Though the annual growth rate of older cohorts (60+) has most recently peaked during the past few years at around 1.9% in more developed countries, annual growth rates in less developed regions are roughly 3.0% and are expected to steadily increase through 2025-2030 to 3.4%. While both developed and less developed regions are projected to experience decreases in annual growth rates from roughly 2030 to 2050, less developed regions are projected to have growth rates of over five times that of developed regions in 2045-2050 (2.1%

compared with 0.4%). Annual growth rates of older cohorts in least developed countries, on the other hand, are expected to increase through to and peaking around 2040 and dropping ever so slightly to 3.5% by 2045-2050 (UN, 2010a, pp. 13-14).



Source: Department of Economic and Social Affairs, Population Division, (2010). "World Population Ageing 2009", United Nations, p.15.

***Figure 6*. Distribution of world population aged 60 or over by development regions, 1950-2050**

While annual growth rates for older cohorts are higher in less developed regions and least developed countries when compared with more developed countries, the issue of population ageing is not so evident in many such countries due to rapid and in some cases, greater increases in overall population growth. However, based on extrapolations of current trends, by the year 2050 nearly 80% of the world's older population (60+) is projected to reside in developing countries (UN, 2010a, p. 14) (See *Figure 6*).

1.2 Turkey's Demographic Transition: Past, Present, and Future

In the year 1935, just 12 years after it's inception as a nation, 76% of Turkey's 16 million people lived in rural environments while the remaining 24% of the population lived in urban settings (TurkStat, 2010a, p. 10). In line with global trends today, these figures have since reversed. Based on 2010 data, 24% of Turkey's population lived in rural environments while the remaining 76% lived in urban environments. Again based on 2010 data Turkey recorded a population of 73.7 million – representing an overall increase of more than four and a half times it's population three quarters of a century ago. With a 2010 annual growth rate of 1.60% (TurkStat, 2011a), medium course projections suggest that Turkey's population will continue to grow through 2050 to 97.8 million people (UN, 2004, p. 23).

A look at literacy records dating back to 1935 to the present reveals that females have historically had lower literacy rates and show 20-25 years lag behind male literacy figures in Turkey. As of the end of 2009, males recorded a literacy rate of 97.0% while 87.9% of females were literate (TurkStat, 2010a, p. 21).

According to World Bank data, Turkey's fertility rate in 1960 was 6.31 (World Bank, 2011). Over the last half century this figure has steadily declined reaching a 2009 recording of 2.06 (TurkStat, 2010b, p. 22). Referring to the importance of infant mortality rates as an indicator of socio-economic development, Kröhnert (2010) points out that while in 1965 166 babies out of 1.000 died in Turkey, this figure fell to 20 out of 1.000 in 2008. While having improved greatly in recent years, compared to 3.54, 3.38 and 2.78 per mille for Germany, Italy and Japan respectively (CIA World Factbook, 2011), Turkey's infant mortality rate is still on the high side.

Along with decreases in fertility and mortality rates, Turkey has seen considerable increases in life expectancy since the middle of the twentieth century. In 1960, average life expectancy was 50.3 years. As of 2009, life expectancy in Turkey was 72.1 years (World Bank, 2011). According to an OECD report, during the 25-year period between 1983 and 2008, life expectancy in Turkey increased by 13.9%, which was the highest for OECD countries – and second only to Indonesia on a global scale (OECD, 2011; as cited in Arun, 2011, p. 1522).

In global rankings of the number of older cohorts, Turkey ranked 90th among 196 nations with 8.8% of it's population aged 60 and over. Based on the same data, Turkey registered a median age of 28.0 years (UN, 2010, pp. 70-71). Table 2 depicts TurkStat figures for 2008-2010, while varying slightly from UN figures for the same period, also show median age on the rise.

Table 2

Median Age and Dependency Ratios, Turkey, 2008-2010

Parameters	2008	2009	2010
Median age	28.47	28.77	29.22
Total age dependency ratio	49.51	49.25	48.89
Elderly dependency ratio	10.23	10.46	10.76
Youth dependency ratio	39.28	38.79	38.13

Source: TurkStat, Turkey in Statistics, ABPRS, 2011.

While total dependency ratios have lowered from 49.51 to 48.89 between 2008 and 2010, this is due to the youth dependency ratios drop of more than one point from 39.28 in 2008 to 38.13 in 2010. The elderly dependency ratio, on the other hand, has increased by more than half a point between 2008 and 2010

(TurkStat, 2011a). So while her people are quick to point out her relative youthfulness among the nations, Turkey's median age is clearly on an upward trajectory. The combination of ongoing decreases in fertility rates and sizeable increases in life expectancy are producing significant trends towards population ageing in Turkey.

1.2.1 Province of Antalya: An Emerging Opportunity for Ageing Research

Of Turkey's 81 provinces, the Province of Antalya (*Figure 7*) is ranked 5th in regards to land mass occupying 20,723 km^2 (half the size of Switzerland). According to the 2010 census, the Province of Antalya is ranked 7th in Turkey's population with 1.98 million persons (TurkStat, 2011b). Of this population, roughly half are situated in the city of Antalya located on the northern most coastal inlet. During the 2009-2010 period, the Province of Antalya recorded the second highest in-migration in Turkey with a net migration rate of 12.84% (TurkStat, 2011a, p. 15).

Source: www.formdaş.net(accessed 14.09.2011)

***Figure 7*. The Province of Antalya demarcated within the country of Turkey**

Source: http://en.wikipedia.org/wiki/File:Antalya_districts.png (accessed 14.09.2011)

Figure 8. **The nineteen districts of the Province of Antalya**

The Province of Antalya is comprised of nineteen districts (*Figure 8*). Of these, Ibradı, Gündoğmuş and Akseki districts in the eastern part of the Province recorded the highest percentage of older cohorts (60+) with 28.8%, 25.3% and 22.4% respectively. On the other end of the spectrum, Kepez, Kemer and Aksu districts– located in close proximity to the provincial center of Antalya – recorded the fewest number of older adults per population with 6.4%, 7.0% and 7.5% respectively (See *Figure 9*). Antalya's mean age was 30.8 (TurkStat, 2009a) compared to Turkey's overall mean age of 28.8 (TurkStat, 2009b). During the same time period the number of adults aged 60 and over residing in the Province of Antalya was 9.46%, below the national average of 10.26% [1] (TurkStat, 2009c/d).

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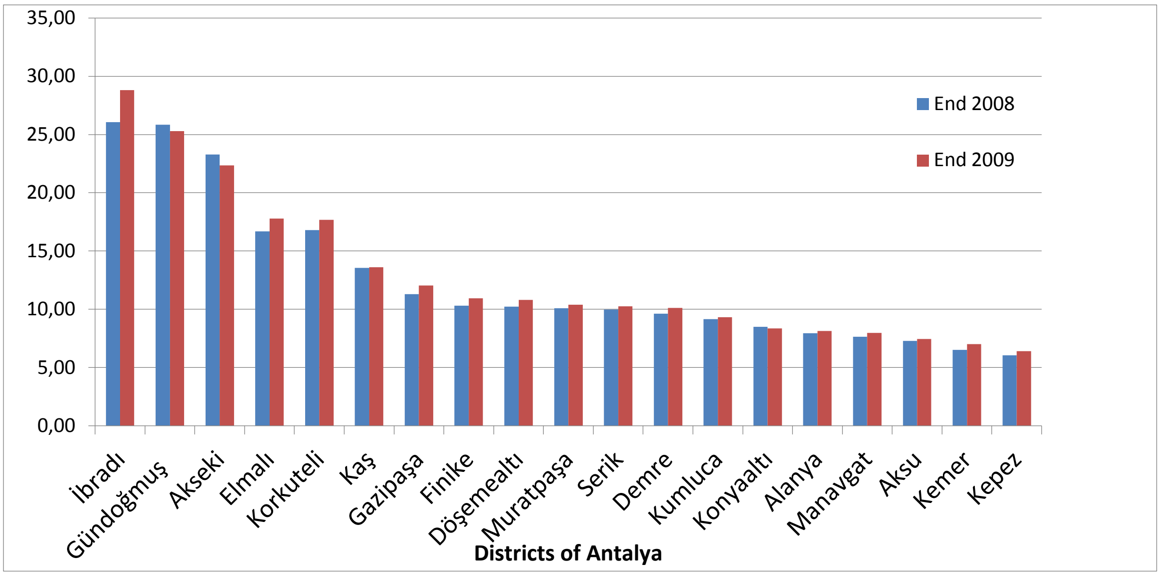
[1] All calculations in this paragraph made by the principal investigator using excel spreadsheet. Data source: Population-Based Record System data, Turkstat, 31.12.2009.



Source: Turkstat, 31.12.2009; Calculations and table made by principal investigator.

***Figure 9*. Percentage of older cohorts (60+) per population for districts in Antalya, Turkey**

As of the end of 2009, 68.5% of Antalya Province's population resided in the provincial or district centers while 31.5% were located in villages and towns (Tuik Verileriyle Antalya, TUIK). As such, the Province of Antalya has a larger portion of its residents in rural settings (villages/towns) when compared with the national average of 24.5% (Turkstat, 2011a, p. 11).

The growing importance of the city of Antalya and its surrounding provincial regions and the present beginnings of a transition from a relatively young to an older population profile offers important and timely research opportunities on a range of age related issues. In particular, the present study has seized upon the opportunity to focus primarily on familial care provision surrounding community dwelling dependent older persons living in rural and urban settings.

CHAPTER 2

A PRELIMINARY ANALYSIS OF CARE PROVISION IN TURKEY

2.1 Introduction

With increased life expectancy worldwide, there will be many older adults who will have multiple chronic and acute medical conditions making the planning and delivery of health care needs and services complex and challenging for both developed and developing countries alike. In this regard, Turkey is no exception as it currently faces a major challenge in dealing with the generally poor and unequal access to health services and infrastructure. In particular, there is the unequal access to health care services in which urban areas are seemingly more favored than rural regions (WHO, 2006). With the demographic trend towards population ageing in Turkey, there are an array of questions and issues regarding the care of older dependent persons. Is it better for dependent older persons to receive care in the home, or is care better provided in a nursing home or through assisted living arrangements? There are also economic and health issues relating to the provision of older person care that have particular implications for a) family caregivers b) health care workers and c) allocation of central and local government resources. The following section provides a preliminary analysis of how care provision is organized in Turkey in order to place the current study into the existing health and welfare care system. In this regard, special emphasis will be given to welfare and care regimes in order to 'locate' Turkey in respect to its place among existing European welfare and care regime typologies.

2.2 Welfare Regimes: Concepts and Models

Greve (2008, p. 51) provides an initial entry into understanding the concept of a 'welfare state' by pointing out the Oxford Dictionary's (2001) definition of welfare as follows: “welfare **1** well-being, happiness; health and prosperity (of person, community etc. **2 (Welfare)** financial support from state.” At the societal-macro level the term ‘welfare state’ can be associated with notions of social justice (George & Page, 1995) and more generally with economic and political decisions whereby a central government assumes a measure of responsibility for the provision of the social and economic security of its population, usually through unemployment insurance, old age pensions, health services and other social-security measures. According to Greve (2008) any serious analysis of a welfare state is best “understood in the historical and cultural context within which it is embedded” (p. 51).

In his landmark text, *The Three World’s of Welfare Capitalism*, Esping-Anderson (1990) presents three different welfare regimes namely, *social democratic*, *liberal*, and *conservative-corporatist*. Esping-Anderson described the social democratic regime as generous in its inclusion of universal benefits typified by Northern European nations such as Denmark, Norway, Sweden, and Finland. He described liberal regimes as generally providing limited and restrictive benefits as currently offered in Ireland and the UK, in Europe and, in the case of the non-European context, the USA, Australia, and Canada. Lastly, he identified France, Germany and Italy as operating conservative-corporatist welfare regimes based upon stratified benefit allocations. While serving as a very useful typology, Esping-Anderson’s categorization of welfare state regimes has received much criticism (Lewis, 1997; Arts & Gelissen, 2002; Hicks & Kenworthy, 2003; Hoff & Hamblin, 2011). Critics focused, among other issues, on lack of gender consideration, unbalanced focus on markets and decommodification, including the omission of southern and eastern European nations from classification.

By portraying men as the traditional “bread-winners” and women as “carers”, Esping-Anderson has been criticized by feminists as lacking gender-sensitivity by failing to recognize women’s experiences in the welfare state. Meulders et al. (2007) argue that European women in some countries have increasingly entered the 'work force' since the 1970s and especially during the 1980s and 1990s. Esping-Anderson's concept of decommodification which places the provision of welfare entitlements as a right and independent of market participation has been criticized on the basis of overlooking the role of the family as a major provider of care in modern welfare societies. As a response, Mclaughlin and Glendinning (1994) introduced the concept of "defamilialisation" (a parallel concept to decommodification) derived from a primary focus on the family (as opposed to the market) that denotes the extent of an individual's independence of the family (Hoff & Hamblin, 2011). In a later publication, Esping-Anderson (1999) responded to some of the criticism. For example, he brought clarity to some key concepts used in his earlier writings such as *familialistic welfare regime* and *defamilialization*. According to Esping-Anderson a welfare regime is essentially "one that assigns a maximum of welfare obligations to the household" while he saw defamilialization as an outcome of policies that reduced dependency on familial support by maximizing the "individuals' command of economic resources independently of family or conjugal reciprocities" (Cited in Leira, 2002, p. 41).

While Esping-Anderson's innovative welfare state typology has served as a very useful model for cross-national comparisons, Bambra (2007) proposes that recent classifications by Ferrera (1996) and Bonoli (1997) are better placed in terms of providing a theoretical framework for understanding the concept of welfare state regimes. Ferrera (1996) constructed a four-type typology, the basic details of which are illustrated in Table 3. In addition to Bambra's recommendation of this typology, Ferrera's model has been judged to be more balanced and inclusive by incorporating a Southern Model (Arts & Gelissen, 2002).

Ferrera has distinguished between the four welfare regime types, *Anglos-Saxon*, *Bismarkian, Scandinavian* and *Southern* countries. Anglo-Saxon countries typically have 'highly inclusive social security coverage', though only in regards

Table 3

Ferrera's European Welfare State Regime Typology

Model	Anglo-Saxon	Bismarkian	Scandinavian	Southern
Principles of welfare provision	Individualistic Basic insurance	Insurance Subsidiarity	Citizenship Collective	Subsidiarity Basic insurance
Extent of outside intervention (primary actors)	Low	Medium (State/ corporatist actors)	High (State)	Low
Typical Unit	Individual	Family	Individual	Family
Average skill level (workforce)	Low	High	High	Low
Typical countries	United Kingdom	Germany	Sweden	Greece

Source: Adapted from Hillmert's (2001) *"General principles of welfare-state regimes and some examples"* (Welfare state regimes section, para. 5).

to health care is coverage universal. Flat rate benefits and means testing are also important in this group. In Bismarkian countries, social security entitlements are still clearly tied to labor market participation and the role of an individual within the family. Various health and related welfare services and supports are derived from contributions and eligible persons have social insurance via personal or kin coverage. Scandinavian countries typically offer universal coverage for life risks and social protection is provided as a right of citizenship. Ferrera describes the Southern group of countries as highly fragmented in regards to social services, though particularly generous in provision of old age pensions. Health care is a right of citizenship, but the state, in general, provides very little welfare intervention. Also within the Southern group of countries, high levels of particularism regarding allocation of cash benefits and finances find expression in high levels of clientelism. (Arts & Gelissen, 2002).

Within the framework of Ferrera's typology, Turkey's welfare regime "clearly shows that Turkey fits the key characteristics of the ideal type of the Southern European Model" (Grütjen, 2008, p. 128). According to Grütjen (2008), a cross-national comparison revealed "only a few deviations from the Southern European Model", namely, "the low impact of civil society, market actors and regional authorities in Turkey and its non-universalistic health system" (p. 128).

2.3 Care Regimes: Concepts and Models

Beginning in the mid-1990s, there was a growing debate and critique surrounding Esping-Anderson's three-type typology, and in particular, European care regimes became a focus of intense scrutiny (Hoff & Hamblin, 2011). Major demographic, societal and cultural changes in post-industrialized European societies such as population ageing, the growing role of women in the work force, and breakdown of the traditional family model ushered in the need for serious dialogue concerning the roles of family, market and state in regards to welfare provision.

Among the various care regime constructs found in the care literature, the care regime by Bettio and Plantenga (2004) was considered to be highly relevant to the focus of the present study. Bettio and Plantenga in particular, investigated the level of adult involvement in care activities among 14 European countries namely, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, the Netherlands, Portugal, Spain, Sweden, and the United Kingdom. Based on the care of both children and older adults, an index was created showing level of informal care. The following five (5) clusters were identified by the preceding researchers: (1) Greece, Italy, Spain, Portugal, and Ireland represent low formal care and high informal care, and the family at the center of care. (2) The UK and the Netherlands represent importance given to informal care with distinction made in level of support offered to carers of either children or older adults. In the Netherlands, families care for children and the state cares for older adults, while in the UK, the state provides care for older adults only in instances where care is unavailable from other sources. (3) Austria and Germany represent the third cluster of private and informal care, where income protection is offered and the state encourages reliance on the family for care while providing indirect interventions in what Bettio and Plantenga have referred to as a "publicly facilitated, private care model" (p. 101). (4) Belgium and France rely on formal care as a strategy rather than offering carers leave from the labor force. (5) Lastly, Bettio and Plantenga identify Denmark, Sweden, and Finland as representing moderate to high universal formal care services where the state assumes direct intervention in care rather than supporting families in their role as carers.

Based on the preceding categorization, Turkey's provision of pensions, reliance on the family for care, and lack of services clearly fits Bettio and Plantenga's cluster one typology with Greece, Italy, Spain, Portugal, and Ireland. In agreement with this assessment, Grütjen (2008) concludes that the state penetration level is low in Turkey regarding matters traditionally left to the family. As an example, Grütjen points out that, based on the principle of subsidiarity[2], care services for children and older adults in Turkey are left to the family. Bettio and Plantenga (2004) argue that a country's care strategy has direct effects on social and economic outcomes. They offer cluster one, represented by Greece, Italy, Spain, Portugal, and Ireland [and Turkey] as an example, arguing that given the lack of family care services, females are effectively prevented from entering the labor market. Bettio and Plantenga contend that this lack of care provision is counter-productive with respect to the creation of jobs (for both women who might otherwise enter the labor force and replacement caregivers who would then provide care in their stead). Bettio and Plantenga argue that the potential for care support services to replace the

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[2] *Subsidiarity* is defined as, "the principle of devolving [passing on] decisions to the lowest practical level" (Collins Online Dictionary, n.d.).

work of family caregivers is likely to be jeopardized where care workers are under-skilled and in receipt of low income earnings. In other words, the only realistic option available to the majority of primary family caregivers is to continue providing care for an older dependent family member.

2.4 Religion as a Social Determinant

Undoubtedly, one of the major factors in the shaping of values and cultural attitudes in a society is the impact of historical and traditional religious beliefs. The Library Congress (2008) on the Country Profile of Turkey reports, "more than 99 percent of the population is Muslim, mostly Sunni. Christianity (Greek Orthodox and Armenian Apostolic) and Judaism are the other religions in practice" (p. 10). With regard to the care of older adults, two questions follow: (1) What are the values upheld in Islam that have played a role in shaping the views of Turkish citizenry regarding the place of the elderly in society and family? and (2) According to Islam, what level of responsibility do the family and state have in providing support services for older people, particularly dependent older adults?

Apart from considerations given to special circumstances and allowances made for the elderly in regards to fulfilling the commands of Islam, Ali Mustafa Ali Al-Qudah (2012) provides a range of vignettes outlining the importance given to the care of the elderly within family and community from the Islamic perspective. For example, the Prophet Mohammed, when asked, "What actions are best and most suitable to please God?" is reported to have responded, "Praying on time, caring about parents and then fighting for the sake of God." When asked what the worst deeds are, the Prophet Mohammed is reported to have given the following four examples: 1) not believing in God, 2) not caring for parents, 3) murder, and 4) false testimony. With these and other examples, Al-Qudah (2012, p. 242) argues that the Prophet Mohammed's sayings "insisted on caring about parents". Based on this rendering of the *'expectations'* of Islam, caring for parents is among the most highly valued 'duties'; from the flip side, failing to care for parents is among the deeds (omissions) that most displease God. The role of the elderly in society, in Al-Qudah's article, primarily revolves or relates to the older person in the context of carrying out the commands or duties of Islam such as prayers, fasting, and doing pilgrimage to Mecca. Based on a number of verses from the Quran and Hadith, Al-Qudah argues that according to Islamic teaching, "the elderly should be first in talking, drinking, eating, and being an Imam in words and in actions" (2012, p. 242). The expression of each of these teachings then may be placed in the context of community action – establishing a set of basic but potentially influential values to be adopted by both family and community alike.

With regards to the role of the state Al-Qudah (2012, p. 243), citing a colleague, argues that based on the Prophet Mohammed's dedication and guarantee to care for "every believer's children and pay his debt when passing away", that the state [assumedly as the authority figure over the people] has a responsibility to provide comprehensive care for the elderly 'in the community' in a like manner.

Based on Al-Qudah's rendering of the teachings of the Quran and Hadith, Muslims then have a responsibility, at the family, community, and state levels to provide care for the elderly. At the present time, the care of the elderly in Turkey at the levels of family, community and state requires clarification and evidence based research to ascertain the overall influence of traditional Islamic teachings found in the Quran and Hadith. The present study has the potential to shed some light on this important area of inquiry.

CHAPTER 3

REVIEW OF LITERATURE:
FRAMING INFORMAL FAMILY CARE IN AN INTERNATIONAL CONTEXT

3.1 Introduction

The intention of this review of the literature is to place the present study within the context of established international understandings, insights and research findings relating to caregiving for older people. In essence, this review of the literature is intended to cast light on the notion of family care in other societies other than Turkey alone, and by so doing, offers an important means for grounding the current research study as well as providing opportunities for comparative purposes. Notwithstanding the value of the preceding endeavour it must be recognized that the overall integrity of the current research focus and its subsequent findings requires an approach that acknowledges a) the place of informal family caregiving within Turkey, particularly in relation to the Province of Antalya and b) its cultural significance within the existing Turkish welfare system in which it is embedded. While the notion of care is now an acknowledged component in welfare state research (Graham, 1991; Greve, 2008), Daly and Lewis (2000) argue for a transformation in thinking by offering the concept of "social care – that presents and develops care as an activity and set of relations lying at the intersection of state, market, and family (voluntary sector) relations" (p. 281).

3.2 Family Care of the Dependent Aged: Historical and Contemporary Developments

Human history shows that "adult children have taken on the primary responsibility of caring for older parents with acute needs" (Silverstein & Gans, 2006, p. 1068). The work of Himes (1994) and Sorenson and Zarit (1996) confirms that informal family caregiving of older parents has been accepted as a normative component of the life course. More recently, the phenomenon of increased life expectancy across most societies has added additional periods of time to the role of family care for ‘at risk’ older family members (Cicirelli, 1990). Connell (2003), using the example of modern social systems, illustrates the following evolutionary process surrounding elder caregiving:

> A hundred or even fifty years ago families both nuclear and extended lived in proximity and had kinship support; families are now often spread geographically. Elders in need, once cared for by a kinship of family are now relegated to being cared for in more formal settings such as assisted living facilities and nursing homes. (p. 2)

It is important to take note of a report by the Institute of Medicine (2008, p. 241)) that “Family members, friends, and other unpaid caregivers provide the backbone for much of the care received by older adults in the United States” (cited in NASW, 2010, p. 5). While medical advances have helped to extend life expectancy there is now the trend towards delayed fertility, which has increased the likelihood of dual caregiving responsibilities for many families (Himes, 1992; Schumacher, 2010). The informal or family related care of the frail and dependent older population is now a major research focus, with a growing list of “published studies carried out by researchers from all of the social-science and many of the health-science disciplines” (Schultz & Martire, 2004, p. 241). Research studies on dementia caregiving undertaken by families represent a significant focus in caregiving literature (Schultz, 2000). Damron-Rodriguez and Lubben (2007) make the critically important observation that policy makers and health professional’s need to appreciate:

> Time is an important element in the differentiation of informal and formal support. Informal caregivers are not “on the clock” as formal caregivers are. Time commitment of informal caregivers requires that they respond to unpredictable demands at all hours of the day and night, such as incontinence. (p. 83)

Today we find an increasing number of policy makers recognizing the need to address the emerging dynamics of population ageing and caregiver vulnerabilities associated with the care of older people with chronic diseases and physical disabilities. A two volume series on "Lessons On Aging From Three Nations" edited by Carmel, Morse and Torres-Gil (2007) involving Australia, Israel and the United States demonstrates that family caregiving of disabled older people is, and will continue to be an area of great concern for both welfare policy makers and social service providers. Raveis (2007) in an examination of the demands upon family caregivers of cancer patients highlights the likelihood for 'cancer-caregiving burden' made more so when cancer diagnosis is combined with other co-morbid conditions of the care-recipient. For Raveis "The cumulative effect of all these stresses and burdens over time may diminish caregivers' ability or willingness to continue this role" (p. 91). In trying to understand aspects of contemporary family caregiving within specific cultural contexts, it is perhaps important to appreciate the following insight provided by Silverstein and Gans (2006):

> The intergenerational solidarity paradigm has firm roots in role theory, emphasizing the relatively static role structures and behavioral expectations of role incumbents; however, it has evolved to include interpretive theories that emphasize the latent and probabilistic nature of family relationships. (p. 1071)

The preceding researchers argue that improved understandings are necessary to gain an appreciation of the respective social forces that "enhance or inhibit the assumption of caregiving duties by adult children" (p. 1082). In other words, for some families the complex mix of life circumstances and lifestyle aspirations may weaken the normative expectation of providing informal family care for dependent older parents. The need to understand the dynamics of informal family caregiving is well articulated by Schultz and Martire (2004) in the following statement:

> Addressing the challenges of caregiving in American society now and in the future will require not only innovative research and clinical applications but also macro-level social experiments to support and motivate caregivers, as well as changes to healthcare policy that fully recognize the caregiver as a healthcare resource. (p. 248)

3.3 The Gendered Nature of Caregiving

A universal value transending national borders is the innate responsibility of parents to provide care for their children. Parents care for their children, providing for their needs into adulthood. As such, the seasons of life do not stand still and parents eventually grow old just as their children grow-up. Historically, in what may be described as a reversal of roles, children have gone on to provide care for their ageing parents when they are no longer able to meet all of their own basic needs. It can be expected that most families will be faced with caregiver decisions for an ageing parent, and in some cases, for both parents due to the onset of frailty and chronic illness. While there will be different configurations of care provision within a family, it is also clear that:

> Many families choose to play a central role in providing long-term home-based care. Usually family members want to take on the responsibility, and in any case recognition is usually given to the reality that no society can afford to look to the state to provide for all of the long-term care needs of frail older people. (Feldman & Seedsman, 2005, p. 189)

Of course, elder care is not only provided by adult children, but by spouses, daughters-in-law, other relatives, and neighbors or friends. In addition to family or informal care, formal caregivers may provide care for those older adults who are able to afford their services or who are fortunate enough to benefit from some form of private or public social insurance.

The mix of societal and cultural values will invariably influence both expectations and ultimately the role of family and state in the provision of care for dependent older adults, including the extent of available options and level of access to care-related resources. Societies in Northern Europe, for example, will inevitably approach the question of who is responsible to care for it's older citizens differently than is the case for Eastern Asia or the Middle East. As outlined in the preceding chapter, welfare state systems around the world utilize differential models and approaches in the provision of care support and related services. Irrespective of the welfare system in question, the availablity of care and support options (either provided or withheld) are generally a reflection of societal priorities and cultural values upheld by the state. In accepting that there are different interpretations and understandings relating to the concept of "welfare" across developed and developing countries, it should also be expected that culture can influence family caregiving to older persons due to differing values, attitudes, norms and meanings relating to care (Dilworth-Anderson & Gibson, 2002; Dilworth-Anderson et al. 2002; Werth et al. 2002). Mestheneos and Triantafillou (2005) offer the following perspective which helps to explain the contextual or cultural basis for diversity among family caregiver orientations, practices and commitments:

> Family carers of all kinds and all ages, grow up with their society's social norms, and obligations. They also belong within a larger value and ideological system of political and religiuos belief (...) which enshine in certain dogma the values attached to care for one another, the role of the family and of women. (p. 17)

On the national level, there are no official statistics or figures to present a profile of caregivers in Turkey. Tufan (2008), however, argues that we must assume that *only* women look after the aged in Turkey. In the light of a caregiver data vacuum, Tufan argues that this assumption holds weight as it is based on socio-cultural factors and on the fact that Turkish women are economically bound to men as the breadwinners. The Turkish Statistical Institute (2010) reports that in terms of Turkey's workforce participation for 2010 under 28% of women of working age (15+ years) were in the workforce compared to 70% of eligible working age men. Of the women not in the work force (N ~ 19.4 mil.), nearly 12 million (~ 62% [3]) stated the reason as *being busy as a housewife*. Additionally, of the men and women not working, more than 1 in 3 men (2.85 mil.) in 2010 reported *retirement* while only 1 in 16 women (0.73 mil.) reported retirement as their reason for not participating in the work force. The large percentage of women functioning as housewives, combined with comparatively low numbers of women in the labour force and not reporting retirement supports Tufan's argument. Accordingly, given their role in society, ascribing caregiving as *women's work* (Kruse, 1994; as cited in Tufan, 2008, p. 32) in Turkey seems consistent with reality in terms of both historical and present cultural and societal expectations.

Research by Arber and Ginn (1991) highlights that early feminist research efforts were focused upon the gendered nature of informal care of older dependent people. According to Bitman et al. (2004) the feminist critque of social policy "led to the 'discovery' of the informal care routinely supplied by women in families" (p. 69). The same writers described informal care by women as "the submerged portion of the iceberg of welfare" (p. 70). Either way, Daly and Lewis (2000) make the point that "care has long been a woman specific concept" (p. 283).

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[3] Compared to Eurofamcare's 23 country profiles, Turkey's figure of nearly 62 % (carers not in the labor force due to housewife status) is higher than Greece's 54% (the highest among Eurofamcare's results) and dwarfs the lowest - Sweden's 1% (Triantafillou & Mestheneos, 2006).

3.4 Family Caregiver Profile

3.4.1 Issues of Gender, Age, Marital Status and Employment

As recognized in the literature, care work is carried out primarily by women, the majority of whom are spouses[4] (Daly & Grant, 2008). Concern has been expressed by Brody (1981) and Hooyman and Lustbader (1986) for women in the middle generation, the *sandwich generation*, who have multiple role responsibilities such as wife, mother, and caregiver to an older parent or in-law (Biegel & Blum, 1990; Feldman & Seedsman, 2005; Phillips, 2007). While women are the dominant providers of informal family care for dependent older family members, this study recognizes that the *sandwich generation* is also inclusive of both middle-aged men and women who care for both dependent children as well as an older dependent parent or family member. The 'sandwich' phenomenon is highlighted by the fact that "Women contribute more unpaid work (care for others, volunteer work, domestic work, childcare, self-care) than men across the lifespan, often with profound implications for care providers' health" (Armstrong & Kits, 2001; as cited in Daly & Grant, 2008, p. 18). For women in particular, there is what Feldman and Seedsman (2005) term the 'priority shuffle' whereby they are having to maintain a sustained and skilful balancing of energy, focused attention and time management in the provision of multiple care roles for family members including, for some women, the added responsibilities of care for older parents and parents-in-law. Some caregivers, while providing unpaid care to others, are also employed in a paid position. In a report on women and informal caregiving in Australia, Rice, Walker and Main (2008) emphasize the difficulty of women carers' (35-64 years) ability to participate fully in paid work. They further state: "As a

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[4] In contrast to Daly et al.'s US-based findings, Eurofamcare study results suggest that, in general, a larger proportion of caregivers in Europe (among 23 countries studied), are children. Sweden is reported as an exception with a high proportion of spouse CGs (Triantafillou et al., 2006).

consequence of their caring responsibilities women are often compelled to work fewer hours, choose jobs primarily for their flexibility rather than job satisfaction or not at all" (p. 5).

Eurofamcare study results report 41% of family carers interviewed were employed (Triantafillou & Mestheneos, 2006). Interestingly, in a Canadian study of 55 rural women caregivers, employed caregivers were more likely to report good health than those who were not employed (Blakely & Jaffe, 2000). It should be noted that in this study it was the employed women who had the assistance of family members that were most likely to report that caregiving had not adversely affected their health (Wagner & Niles-Yokum, 2006, p. 151). Balancing work and family responsibilities for women is difficult enough but even more so when they have the added responsibility of providing long-term home-based care for an older family member. Indeed, it is well to bear in mind that long periods of informal family caregiving for an older dependent adult can create tensions and stressful situations that can result in chronic fatigue and heightened probability of ill-health for the primary caregiver (Mestheneos & Triantafillou, 1993; Cooke et al. 2001; Hooyman & Kiyak, 2002). Earlier research work by Archbold (1983), Baines (1984), Barusch (1988), and Cantor (1983) identify a range of negative outcomes and strains (i.e. emotional, physical, financial & family) while Baillie, Norbeck and Barnes (1988) provide valuable insights into caregiver depression. More recently Schultz and Sherwood (2008) report that informal family caregiving fits the criteria for chronic stress and that increased risk of detrimental effects to caregiver health status represents a major public health issue. On the other hand, research also indicates that for some family caregivers the caregiving experience, at least in the short-term, results in no serious strain or lowered health outcomes and may provide a positive sense of self-worth and life purpose (Kinney & Stephens, 1989; Lawton et al. 1989; Tarlow et al. 2004). While negative consequences of caregiving have been well documented, it is important to take note of what Lawton et al. (1989) report as caregiving *'uplifts'* and the experience of caregivers with small but meaningful daily events that were identified by Hirschfield (1978) as providing caregiver satisfaction, pleasure and affirmation of the caregiving role. It is therefore important to recognise that understanding the true 'lived experience' and nature of a caregiver's perceptions, meanings, behaviours and well-being in relation to the caregiver role is only possible when considered within the context of a caregiver's frame of reference.

While women are recognized as the frontline in caregiving, the number of male caregivers is on the rise in the United States. Up from 26% in 1989 and 36% in 1999 (Wagner & Niles-Yokum, 2006), 37% and 33% respectively of caregivers in the U.S. in 2004 and 2009 caring for adults aged 50 years and older were men,[5] of which 2 in 3 (in 2004) also held a full or part-time job (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2004 & 2009). Men in the 2004 study, however, were found more likely to provide care at the lowest level of burden (performing no ADLs and giving just a few hours per week care) compared to women who were most likely to provide care at the highest level of burden (typically help with 4 ADLs[6] and 6 IADLs[7] with constant care)(NAC & AARP, 2004).

The report *Caregiving in the U.S.* provides us with a general profile including marital status of caregivers caring for adults aged 50 and over. The majority of caregivers at 64% were married or living with a partner, far fewer at 15% were single, while 14% were divorced or separated and 7% widowed. In this report, the typical caregiver is female and 48 years of age (NAC & AARP, 2009).

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[5] Representing most of Europe, Eurofamcare findings show 24% of primary caregivers were men (Triantafillou et al., 2006). Note: While the NAC & AARP studies reported findings from caregivers in general, the Eurofamcare finding above refer only to *primary* caregivers.

[6] ADLs stand for *Activities of Daily Living.*

[7] IADLs stand for *Instrumental Activities of Daily Living.*

The Eurofamcare study conducted in 23 European countries found the average family caregivers of older adults to be women (76%), 55 years of age and providing care for care-recipients over 80 years of age (53%). On average, nearly half of the caregivers were adult children (Triantafillou & Mestheneos, 2006).

3.4.2 Spouses, Adult Children, and Daughters-in-Law as Caregivers

While it's been established that women typically function as the major source of informal family caregiving, it is nevertheless important to have some understanding of the types of informal caregivers within specific social- cultural contexts. So while the literature typically reports spouses, adult children and daughters-in-law among those most likely to provide care for dependent family members, societal values or expectations play a critical part in influencing who is deemed to be primarily responsible for both the care of dependent family members as well as organizing and managing overall living arrangements. While spouse caregivers appear throughout the international literature, the inclusion of adult children versus daughters-in-law serving as caregivers seems a function of established societal obligations. For example, Johansson and Sundström (2006) report that in Sweden, daughters-in-law are seldom involved in the *panorama of care*. According to Johansson and Sundström, frail older adults in Sweden are generally cared for by one family member: a spouse, a daughter, or a son. In contrast, Isaac, Stewart, and Krishnamoorthy (2011) report that in India there are more daughters-in-law caring for older people. They add that daughters-in-law, presumably in line with cultural expectations, view their role as providers of care for their in-laws *as a duty.* Feldman and Seedsman (2005) report "That it has been established by Australian researchers that a substantial amount of informal assistance is also provided to frail and disabled older Australians by family members who are not co-resident" (p. 189).

In Sweden and Denmark, only 2% (Johansson & Sundström, 2006) and 3% (Kahler, 1992; as cited in Stuart & Hansen, 2006), respectively, of adult children live with their elder parent(s). Fewer adult children co-residing with elderly parents is a general trend in most European countries, with the apparent exception of Italy (Johansson & Sundström, 2006). Johansson and Sundström (2006) also report that in Sweden, 2 out of 5 older adults aged 65 and older live alone or just with their spouse or partner, while solitary living is not uncommon in the Nordic countries, the Netherlands and Britian.

According to the Center on an Aging Society at Georgetown University, Washington, D.C. (2005), 41% of family caregivers in the U.S. are spouses and 44% are adult children. Wives and husbands provided an average 28 and 15 hours of care per week, while daughters and sons provided 13 and 10 hours of care per week, respectively. These figures confirm Wagner and Niles-Yokum's (2006) suggestion that spouses and adult children account for the largest informal care networks for older adults in the U.S. The caregiving literature is inconclusive, however, as to which group (adult children or spouse caregivers) suffers most from caregiver burden. Kahana and Young (1990) refer to research suggesting spouse caregivers as less likely to suffer from caregiver burden when compared with adult child caregivers. Referring to research by Johnson (1983), while more than 80% of spousal caregivers accepted the caregiver role without reservation, comparatively fewer adult child caregivers (56%) could say the same. Additionally, while older care-recipients reported greater levels of satisfaction with spousal caregivers, spousal caregivers also appeared less stressed than child caregivers (Kahana & Young, 1990). More recent research supports Johnson's conclusions, finding adult child caregivers to experience greater burden, especially those who co-reside with the care recipient and have other family duties (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010). Conde-Sala et al. reason that spouses view caregiving as part of their marital obligation, while adult children view caregiving as ushering in major restrictions and unwelcome changes to their lifestyle. Byrd, Spencer, and Goins (2011), on the other hand, present research results showing spousal caregivers to experience higher levels of burden than other caregivers. Byrd et al. list several possible explanations, including changes in the marital relationship due to the demanding caregiving tasks, which in turn, precipitate within the caregiver a feeling of increased burden and stress, leading to an increased risk of neglecting his or her own needs to fulfill the [marital] commitment relating to the ongoing care for their spouse. Additionally, Byrd et al. (2011) refer to research stating that spousal caregivers, as a result of "taking over responsibilities that were once handled solely by their ailing spouse," in effect must take on "more duties beyond the caregiving situation" (p. 417). Wagner and Niles-Yokum (2006) join the debate pointing out that spouses report giving more time to caregiving activities and are at higher risk of reporting negative health effects of caregiving compared to adult children.

Interestingly, Johansson and Sundström (2006) suggest that, "counter intuitively, men care for wives about as much as women care for husbands" (p. 14). They reason that, apparently in contrast to women, men often require little to no help before they die (Sundström et al., 2003; as cited in Johansson & Sundström, 2006). Brown et al. (2007) provide some valuable insights into help-seeking approaches taken by older husbands of wives who had dementia related illnesses. Findings from the preceding research showed husbands tending to use action/interactionist strategies that resulted in attitudinal responses such as 'Staying Together', 'Staying at Home' and 'Taking Care of Myself '. It was also concluded that interventionist strategies to assist carers should be gender specific.

3.4.3 Main Care Tasks and Amount of Care

In the report *Caregiving in the U.S.* the typical caregiver was employed[8] and spending an average of 22 hours per week providing care and support for her parent(s) (NAC & AARP, 2009). According to findings from the Eurofamcare study, family caregivers spent an average of 45.6 hours a week caring for their dependent family member (Triantafillou &Mestheneos, 2006).

The roles and responsibilities of family caregivers will vary based on the needs of the care-recipient. Caregivers may be required to provide companionship and emotional support, including (a) *hands-on care* such as feeding, dressing, bathing or incontinence-related cleaning, and transfering or maneuvering of the care-recipient (b) *household chores* such as general cleaning, cooking, laundry, and home repairs, as well as (c) *out-of-home tasks* such as shopping, meetings/coordinating transportation needs, financial management and arranging doctors visits (Gitlin & Schulz, 2012; Quadagno, 2008). However, distinction is made in the literature regarding the relationship between caregiver gender and roles typically assumed. Daughters [female caregivers] are reported more likely to address more intimate *hands-on care* needs, while sons [male caregivers] are more likely to do those tasks associated with the categories *household chores* and *out-of-home tasks* (Chang & White-Means, 1991; Stoller, 1994; as cited in Quadagno, 2008, p. 232-233). While the type of caregiving tasks which are spread across male and female family members present a range of research challenges, it is interesting to note that Montgomery, Gonyea and Hooyman (1985) pointed out that it may be more a case of the variety or mix of caregiving tasks rather than the actual duration of caring responsibilities that may help to explain the intensity of the caregiving experience. By way of illustration, intensity-related outcomes of care provision

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[8] It should be noted that primary as well as non-primary caregivers were included in this report. Non-primary caregivers were more likely (66%) to work than primary caregivers (50%). These figures include male and female CGs.

for a family member with Alzheimer's Disease is best considered as showing differential impacts due to a combination of the "physical, psychological or emotional, social and financial problems experienced by family caregivers representing both subjective and objective aspects of the impact of care" (George & Gwyther, 1986; cited in Acton & Kanga, 2001, p. 350). While subjective and objective aspects of caregiver burden are addressed in sub-section 3.6.7, it will presently suffice to recognize that as the nature, types, and extent, and/or mix of care needs change from situation to situation, so also the differential impacts faced by caregivers will also vary according to a multiplicity of diverse and interactive factors.

3.5 Motivation to Care and Positive Aspects of Care

In day-to-day life, most of us are accustomed to using the term *stress* to refer to negative or distressful situations. But stress need not produce only negative outcomes. A definition of stress is "…an experience arising from transactions between a person and the environment" (Aldwin, 2007, p. 27). In this definition, stress is not necessarily linked to a negative experience or outcome, but an outcome is determined by the specific interactions of the person and his or her environment, suggesting an infinite number of outcomes, which according to Selye (1976) may be agreeable or healthy (eu-stress) or disagreeable or pathogenic (di-stress). Selye understood that how a person responds to change or how a person accepts change determines in a very important way whether or not a person can adapt successfully to major life related stresses.

Consistent with the assertion that stress can be either negative or positive, caregiver research supports negative as well as positive effects of stressors on caregivers. However, according to Kramer's (1997) critical review, the benefits of caregiving only began to surface in the literature during the 1990s (with the exception of a handful of publications in the 1980s). So while the concept of negative and positive stressors was identified in the mid-1970s, it was not until the 1990s that this concept was readily applied to the field of caregiving.

Results from a number of studies (Foley et al., 2002; Miller & Lawton, 1997; Brown et al., 2009) have found that caregiving may lend to "positive psychological and health benefits for some caregivers" (as cited in Roth, Perkins, Wadley, Temple, & Haley, 2009, p. 680). Research has shown that positive outcomes in the caregiver– care-recipient relationship often stem from (a) provision of meaningful "company for the caregiver" (Schulz, Tompkins, & Rau, 1988; as cited in Schulz, 1990, p. 43) and (b) finding "meaning in providing care to a loved one" (Roth et al., 2009, p. 680). U.S. national estimates report that three-quarters of caregivers *feel useful* as a result of providing care (Stone et al, 1987; as cited in Schulz, 1990; Roth et al., 2009). Eurofamcare study results show that 4 in 5 family caregivers interviewed reported that caring was worthwhile and that they were able to cope well even under difficult or stressful circumstances (Triantafillou & Mestheneos, 2006). Singer, Bachner, Shvartzman, and Carmel (2005) report on findings by Herth (1993) that suggest both positive and negative outcomes for effects of caregiving including "high rates of anxiety, exhaustion, stress, and decline in health status, a positive sense of challenge, more purpose to life, and achieving family closeness." (p. 73).

From another perspective it is important to note that when consideration is given to the cultural context, the notion of distress (or burden) in relation to caregiving may be perceived by the caregiver as a blessing or grace from God. From a theological perspective, stress may not always be interpreted by the caregiver as a negative feeling of suffering but also as a positive feeling or expectation of compensation or reward in the next life.

3.6 Caregiver Burden: Theoretical Constructs and Models

3.6.1 Historical Beginnings

While the study of ageing in the broadest sense can be traced back to references in the Bible and classical literature (Achenbaum, 1995), Russian scientist Elie Metchnikoff is credited in 1903 with coining the term *gerontology*. Since it's inception as a scientific field of study, the research focus of gerontology has been concerned with the study of older adults themselves and ageing processes per se. On the other hand, the needs and issues related to family caregivers have only been a topic of serious research for the last 25-30 years (Knight & Losado, 2011; Savundranayagam, Montgomery, & Kosloski, 2011).

In particular, as demographic ageing trends have given way to an increase in numbers of older adults living into their 80's, 90's and beyond, the number of care-dependent older adults has also risen. On a global level, increases in numbers of dependent older adults have produced increasing need for assistance from, in most cases, family members. Proliferation in numbers of family caregivers experiencing burden as a result of care provision has brought the realities of their often-unrecognized needs to the attention of researchers and policy makers. In the caregiving literature, the burdens associated with care responsibilities have been found to influence the quality of interpersonal relationships, caregiver health, and the decision to institutionalize the care-recipient (Pinquart & Sorenson, 2007; Schulz & Martire, 2004). From a socio-economic standpoint, these are indeed significant reasons to invest in caregiver burden research.

3.6.2 Theoretical Framework/Construct: An Introduction

A critical aspect of the current study concerns the need to untangle the complex nature of 'caregiver burden' while all the time being sensitive to cultural influences that impact the overall experience and meanings attached to informal family caregiving. The preceding challenge involves a recognition of the unique experience of each caregiver and the differential contributions to 'caregiver burden' arising from the complex mix of a) the socio-cultural context b) physical environment c) socio-economic circumstances d) physical and psychological health factors and e) relationship of the caregiver to the older care-recipient. Equally important is the need to disentangle influences from outcomes, if the nature and characteristics of caregiver burden is to be understood. Attaining better understanding of the influences and outcomes of caregiver burden is essential to the creation and implementation of effective interventions aimed at mediating care-induced burden. In turn, family caregivers with appropriate support systems will be in a stronger position to continue their caregiving role while at the same time enabling their older dependent family member to remain "ageing in place' [9] for as long as possible.

3.6.3Theoretical Framework/Construct

Sebern and Whitlatch (2007) note that medical and nursing sciences typically focus on the patient (care-recipient) while gerontology and caregiving literature tend to focus on caregiver outcomes. It seems relevant, therefore, that the study of family care would benefit from including inquiry into both sides of the dyadic relationship, that is, caregiver and care-recipient. On the international scene, caregivers and the care dyadic relationship as well as caregiver burden in more recent decades have been topics of considerable research within the gerontological and caregiving literature. In the country of Turkey, however, the first and only Gerontology Department[10] to date was established in 2006 and very little gerontological research has been conducted. The Antalya Home Care Survey (AHCS) represents the first major research study in Turkey to address

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[9] "Ageing in place" is synonymous with ageing/remaining at home – the place where most dependent older adults wish to live and age.

[10] At Akdeniz University in Antalya, Turkey.

the perspectives of both family caregivers and community-dwelling dependent older adults 'ageing in place'.[11]

Early caregiver research focused exclusively on the negative stress or burden provoking outcomes associated with care provision. Based on the Transactional Stress Theory of Lazarus and Folkman (1984), Pearlin et al. postulated the Pearlin Stress Process Model (Pearlin, Turner, & Semple, 1989; Pearlin Mullan, Semple, & Skaff, 1990) that maintains the influence of socio-demographic characteristics of caregivers and care-recipients in adaptation to the stress processes of care (as cited in Carretero, Garces, Rodenas, & Sanjose, 2009). Pearlin's model suggests the role of subjective and objective primary stress factors that can spawn secondary stress factors that may further produce negative objective outcomes (e.g. lose of free time, disruption of employment) that may lead to negative subjective assessments (e.g. decreased self-esteem, etc.) (Carretero et al., 2009).

As referred to in sub-section 3.5, Kramer (1997) pointed out that only as recently as the 1990's have *benefits* of caregiving found a firm place in the literature. In fact, Kramer's critical review in 1997 helped to give birth to the *gain and strain theory of caregiving*, which maintains that family caregivers experience both positive and negative reactions though reflecting different aspects of the caregiving experience. (Iecovich, 2011).

3.6.4 Burden: Concept and Definition

So exactly what do we mean by the terms *burden* and *caregiver burden*? The Webster's Dictionary defines burden as "that which is borne or carried; a load" (Webster's Online Dictionary, n.d.). As it relates to caregiving, burden refers to the time and effort given by an individual to address the needs of another

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[11] In this study however, the primary focus is on the caregiving perspective, though some descriptive socio-demographic care-recipient data is presented.

(Schultz, 1990). Providing a little more specificity, Hooyman and Kiyak (2002, p.279) define caregiver burden (CG burden) as, "The personal energy, time restrictions, financial strains, and/or psychological frustrations associated with assisting persons with long-term care needs." [12]

The concept of burden was first cast by Zarit et al. in 1985 as a theme uniting diverse caregivers (CG) to diverse groups of older care-recipients (CR) (Kahana & Young, 1990). Caregiver burden as a concept has been a subject of considerable interest and research in the family caregiving context (Butler, Turner, Kaye, Ruffin, & Downey, 2005). However, while some researchers approach the conceptualization of burden from a narrow viewpoint, looking at the tasks associated with caring for a relative, others look more broadly at burden as incorporating issues of general well-being or any one of numerous dimensions assessing the caregivers' situation (Shultz, 1990).

3.6.5 Multidimensionality

Caregiving is a multidimensional construct (Savundranayagam et al, 2011) involving complex interactions (Kahana & Young, 1990) that are not single events but entail a long and complex process wherein many problems, temporary or lasting, may be encountered at any given moment (Chiriboga et al, 1990). Kahana and Young detail some of the *complex interactions* contributing to the complexity and diversity in any care situation, including, caregiver characteristics, their resources, specifics of the caregiving situation, care-recipient characteristics, and their resources. Consistent with the discourse in sub-section 3.5, *Motivation to Care and Positive Aspects of Care*, Kahana and Young (1990) add that these complex interactions may result in positive or negative consequences for caregivers as well as for care-receivers.

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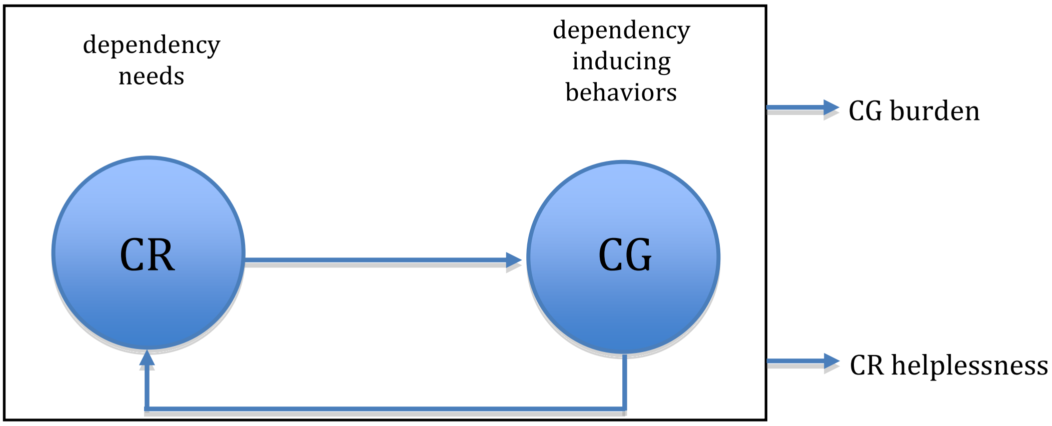
[12] As noted in sub-section 3.2, while the definition of burden, as an outcome of time and effort given in caregiving, is cast in a negative vain by Hooyman and Kiyak, it may well be interpreted by the individual as a positive, agreeable or healthy outcome.

3.6.6 Caregiver Models

While a number of different caregiver models have been addressed in the literature, the primary model focusing on the determinants of caregiver burden, the *two-person dyad model* (Cantar, 1983; Caserta, Lund, Wright, & Redburn, 1987; Johnson & Catalano, 1983; as cited in Kashner, Magaziner, & Pruitt, 1990), has focused on the care-recipient and the primary caregiver. Also relevant to the CR-CG relationship, the *contingency model of caregiver/care-recipient interaction* emphasizes the reinforcement of dependency, which in turn may result in learned dependence and ultimately may increase CG burden (Kahana & Young, 1990). Kahana and Young (1990) refer to care-recipient dependency as the element that initiates or activates a cycle where CGs by their "dependency-inducing behaviors" begin and continue to 'do for' care-recipients (p. 85). Dependent behaviors may result among CRs who in turn become increasingly helpless which may lead to increased CG burden. A helpful visual depicting a nonrecursive or feedback model of caregiving and dependency is provided in *Figure 10*.



Source: Kahana & Young, 1990, p. 85. Based on Blalock's (1971) nonrecursive model of caregiving and dependency. Reproduced by principal investigator.

***Figure 10*: Feedback model of caregiving and dependency**

3.6.7 Objective and Subjective Measures

Montgomery et al. (1985) were the first to make the distinction between objective and subjective caregiver burden in relation to outcomes of caregiving (as cited in Kahana & Young, 1990). When it comes to measuring burden, Schulz (1990), based on the observation that most researchers agree that burden is a "subjective state reflecting perceptions of the individual caregiver", suggests that the appropriate source of felt burden should be the caregiver (p. 37).

There appears to be no consensus, however, as to what measures represent an objective versus subjective perspective of burden. As Acton and Kanga (2001) point out, "there is a lack of conceptual clarity about what actually differentiates subjective from objective burden" (p. 356). In recognizing the preceding conceptual dilemma, Koerin and Harrigan (2003) suggest that "caregiver burden has two dimensions: objective burden refers to the time, efforts, tasks services, and financial supports, while subjective burden refers to the caregiver's perceptions, attitudes and emotions about caregiving" (p. 66).[13] Schumacher (2010) contends that "subjective burden of caregiving is difficult to comprehend and measure through quantitative studies. Subjectiuve burden is analagous to pain, everyone has a different threshold and it is contingent on factors confounded by objective burden" (p. 5).

Recent research by Savundranayagam et al. (2011), on the other hand, has conceptualized burden in a different framework composed of three types of burden: stress, relationship, and objective burden where stress burden refers to *tension and anxiety*, relationship burden to *changes in dyadic relationship* and

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[13] Still it would appear that not all researchers agree as reflected in the view by Schultz (1990), who has suggested that measurements such as types of tasks performed and amount of time spent caregiving are best viewed as caregivers' subjective perspective due to the plausibility of distortion.

objective burden to *time infringements*. Objective burden is further defined as "the caregiver's perception that their caregiving responsibilities are interfering with their daily life and other responsibilities" (Savundranayagam et al., 2011, p. 322).

3.7 Empirical Findings I: What Impact can Caregiver Burden have on Caregiver's Life?

Note: As explained in sub-section 3.6.2, the task of disentangling factors that influence caregiver burden from outcomes can be daunting. Despite the blurring of borders between cause and effect, effort has been made to primarily refer to findings related to *outcomes* in the present sub-section, *3.7 Empirical Findings 1*, and *influences* in sub-section *3.8 Empirical Findings 2.*

3.7.1 Impact on Physical and Psychological Health and Well-Being

Early research of care burden mostly focused on the impact of family and informal care settings of mentally ill relatives transitioning from institutions back into the home. These studies did not generally look at the physical or mental health outcomes of caregivers (Raveis, Siegel, Sudit, 1990). But since that time, researchers have gathered an increasingly large pool of evidence that for some caregivers, particularly those providing care to a chronically ill family member (Pinquart & Sörensen, 2003; Schulz, O'Brien, Bookervale, & Fleissner, 1995; as cited in Roth et al., 2009; Chang, Chiou, & Chen, 2010), there may be psychological as well as physical consequences (Butler et al, 2005; Chang et al., 2010). For half a century now, exposure to stress has been associated with a number of physical and psychological problems (Chiriboga, Weiler, & Nielsen, 1990). In particular, dementia CGs and male CGs are identified at higher risk of negative physical consequences due to caregiving stressors as compared to women (Knight & Losada, 2011). Among the health consequences that may be associated with caregiving aredecreased levels in preventive health behaviors, immunity, and wound healing, and increases in cardiovascular reactivity, risk of serious illness, and risk of mortality (Schulz & Beach, 1999; as cited in Butler et al., 2005).

Recent research supports the physical-psychological health link connection, which proposes that mental health influences caregivers' physical health (Chang et al, 2010; Savundranayagam et al., 2011; Knight & Losada, 2011). Knight and Losada point out that psychological burden is associated with negative physical outcomes for caregivers, including lower antibody and higher stress hormone counts. They argue that these negative outcomes may cause mortality among caregivers reporting strain (Knight & Losada, 2011).

Some researchers suggest that the most significant negative (Raveis et al., 1990) and pervasive (Stuart & Hansen, 2006) consequence associated with caregivers may be in the emotional or psychological domain. Based on research, Raveis et al. (1990) document a variety of potential psychological outcomes for caregivers, including increased levels of depression, anxiety, helplessness, hopelessness, emotional exhaustion, low morale, distress, feelings of isolation, guilt, and anger.In particular, potential sources of stress include competing demands, childrearing and employment (Stone, Cafferata, & Sangl, 1987; as cited in Stuart & Hansen, 2006). Stressors evoked in social relationships in general have been found significantly related to levels of psychological well-being (Chiriboga et al, 1990). Knight and Losada (2011) argue that convenience samples provide consistent evidence of stronger effects on the mental health of caregivers caring for individuals with dementia.

As has been supported in previous research (as referred to in sub-sections 3.4.1 and 3.7.1), there is a high correlation between caregiver burden and depression (Butler et al., 2005). Butler et al. report high correlations of both caregiver burden and depression with study measures including, isolation, knowledge of CG tasks, CG task difficulty, and family support. In the sample, however, there did not appear to be a strong correlation between demographic variables and caregiver burden or depression (Butler et al., 2005). Contrary to earlier results (Anthony-Bergstone, Zarit, & Gatz, 1988; as cited in Butler et al., 2005), Butler et al. (2005) findings[14] attest that demographic variables (including age, gender, education and employment) do not predict depression, but "suggest that caregivers across age, gender, and education categories are vulnerable to caregiver burden and depression" (p. 59). Proposed intervention would aim at decreasing CG burden and depression through the provision of training to caregivers regarding knowledge of caring tasks (Butler et al., 2005).

Some research, on the other hand, suggests that caregiving for some caregivers may lend to positive psychological and health outcomes (Foley, Tung, & Mutran, 2002; Miller & Lawton, 1997; Brown et al, 2009; as cited in Roth et al., 2009).

Research by Chiriboga et al. (1990) found strong correlation between both care-specific and general caregiver stressors and caregiver well-being. Results revealed that general stressors, particularly those perceived as a hassle and related to work and social relationships, were strongly correlated to indices of well-being. Caregiver well-being and health have been found to be influenced by several factors, including CG and CR demographic characteristics, care-related stress levels, and quality of resources available to assist caregivers in coping with stress (Dilworth-Anderson, Goodwin, & Wallace, 2004; as cited in Byrd, Spencer,& Goins, 2011).

The combination of caregiver tasks and stress may lead to compromised health among caregivers (Schulz & Beach, 1999; as cited in Butler et al., 2005). Caregiver research identifies possible adverse affects of stress upon both the psychological and physiological health of caregivers. Saldaña, Dassori and Miller (1999) cite research showing rural caregivers, in particular, as being succeptible to poorer psychological and [physical] health outcomes due to

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[14] It should be noted that Butler et al. conducted research on a relatively small (n = 62), non-representative sample.

stress resulting from relative isolation and decreased available supports. Chiriboga et al. cite evidence that stress has been linked to depressed immune systems and interferon production, which may precipitate increased risk of numerous health problems including cancer (Stein & Schleifer, 1985; as cited in Chiriboga et al., 1990). Casado, van Vulpen, and Davis (2011) cite research associating behavioral problems of care recipients with negative effects on caregiver well-being, including psychological and emotional distress, increases in caregiver burden and risk of illness, and general physical health problems. The link between caregiver and care-recipient well-being, however, "is not well established, especially in countries with more family-oriented care structures" (Clark et al., 2004; as cited in Isaac, V. et al., 2011, p. 644), which is typical of Eastern and Middle Eastern countries such as Turkey.

3.7.2 Impact on Family and Social Life

The family, as well as practical assistance given by designated others, may have an important role in informal caregiving (Kashner et al., 1990). The paradoxical 'catch' however, is that "as care needs increase, support networks become smaller and more focused on close kin" (Wenger & Keating, 2008; as cited in Keating, 2008, p. 125). For primary caregivers, this may translate into a reduction of potential resources in care provision at thevery time when additional help is most needed – when care needs have increased. This observation, that care support becomes more focused on close kin as care needs increase, may also have an enormous impact on the family and on the social life of caregivers.

In a study by Hoff and Hamblin (2011), employed family caregivers consistently reported significant consequenses of combining work and care duties on both their family and their social life. Hoff and Hamblin (2011) reported that a lack of: (a) time, (b) freedom to leave home (the care setting), and (c) family or friends to provide respite lent to caregivers having little available time with family members as well as to the exclusion, for many, of any social life. Some caregivers, however, managed to make the transition from a social life as they once knew outside of the home to a social life within the home (Hoff and Hamblin, 2011). Among the detrimental effects on family reported by caregivers combining employment and caring were increased conflicts with children, spouses, siblings and children or grandchildren. Among married couples, a lack of time together, attention, or intimacy, were commonly reported and sometimes resulting in "dramatic implications" for the relationship (Hoff & Hamblin, 2011, p. 52). While the study mentioned above focused on caregivers combining care with employment, similar time constraints on non-employed caregivers and consequenses for family and social life may be faced by caregivers. Factors include: (a) providing high levels of care, (b) caring for challenging individuals (care-recipients with behavioral or mobility issues), (c) having limited or no care support, (d) residing together with care-recipients, (e) providing/balancing other care duties within the family, and anyone of a number of other issues such as, (f) transport limitations.

3.7.3 Impact on Caregiver–Care-Recipient Relationship

In her recent study, Iecovich (2011) found that among the multitude of factors tested, QoR between CG-CR had the most significant impact on caregiver burden.[15] Iecovich delineates between a *present and past perspective* and *present perspective only* regarding the dyadic quality of relationship (QoR). She postulates that where the present only perspective is concerned, a closer CG-CR relationship may contribute to higher CG satisfaction, in turn leading to lower care induced burden. From the present and past perspective, Iecovich argues that the past dyadic QoR may affect CG burden, suggesting that a good pre-dependency relationship may reduce burden while a poor pre-dependency QoR

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[15] Iecovich's finding extended to caregiving satisfaction as well as CG burden. While Ieocovich and Snyder (later in this section) evaluate CG burden and CG satisfaction together, the focus here will be limited to quality of the dyadic relationship as it promotes or mediates CG burden.

including unresolved conflict may increase CG burden (Iecovich, 2011). Snyder's findings (2000) support CG burden having an effect on dyadic QoR and conversely, QoR having a strong influence on CG burden – thus suggesting a two-way or bidirectional relationship between dyadic QoR and CG burden[16] (as cited in Iecovich, 2011).

3.7.4 Institutionalization and Maltreatment of Care-Recipients

Caregiver burden not only impacts the CG, but may adversely affect the CR. Two of the most serious negative consequences of CG burden on the CR are institutionalization and maltreatment. Carretero et al. (2009) cite findings that suggest emotional discomfort and caregivers' poor health status as predictors of CG abandonment of the care role and subsequent institutionalization, as well as CR variables that lend to increased risk of institutionalization, including disease advancement, behavioral problems, cognitive alterations, and difficulties in performing ADLs (Logdson, Gibbons, McCurry, & Teri, 1999). Additional findings suggest that CG employment, dyadic QoR, and availability of financial resources are correlated to an increased risk of institutionalization of the CR (Brodaty & Donkin, 2009).

While there is considerable variation in estimates and some variation in definitions of maltreatment, a World Health Organization (WHO) report estimates that roughly 4-6% of older adults have experienced some form of maltreatment at home. (WHO, 2011a). According to the same report, *elder maltreatment* is defined as "a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm and distress to an older person" (WHO, 2011a, p. 1). Another WHO report brings further clarification, defining elder maltreatment as

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[16] Based of this finding, a bidirectional arrow was placed between CG burden and QoR in *Figure 12*. Basic research model, and *Figure 19.* Theoretical research model with caregiver burden components.

"physical, sexual, mental and/or financial abuse and/or neglect of people aged 60 years and older" (2011b, p. viii). Based on WHO population projections of older adults for the year 2025,[17] and assuming 4-6% elder maltreatment, suggests that between 48 and 72 million older adults will experience maltreatment by 2025. In Europe, it is estimated that at least 4 million older adults experience abuse and/or neglect annually and that caregivers who are partners, offspring, or other relatives are most often the perpetrators of maltreatment (WHO, 2011b).

Based on results from the nation-wide longitudinal study Geroatlas, Tufan (2011) published the first empirical-evidence-based report to address the issue of violence, abuse and neglect among older adults in Turkey.[18] From a randomized sampling of 3,510 interviews in 7 cities throughout the country, roughly 3 in 100 (3.1%) older adults were 'willing' to acknowledge[19] being subject to violence, abuse and/or neglect and answer related questions. Projected onto the population of Turkey, this approximates the number of older Turkish adults at 200,000 who are subject to periodic or constant abuse of some form (Tufan, 2011a). Key findings include: (a) more than 2 in 3 (71%) older adults reporting violence, abuse and/or neglect were female, (b) nearly 1 in 2 (48%) adults reporting violence, abuse and/or neglect were age 80 or over[20], (c) 2 in 3 (66%) of the respondents reported psychological violence in the family, (d) while 1 in 5 reported exposure to violence with bodily injury, (e) and

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[17] Calculations based on: (a) number of older adults defined as age 60 and over, (b) projected by WHO in 2025 to be 1.2 billion in number.

[18] It should be noted that this segment of the Geroatlas study on violence, abuse, and neglect was conducted in 2005.

[19] Tufan suggests that fear and shame might prevent older adults from reporting instances of violence, abuse or neglect. Because Turkish culture (closely associated with Eastern cultural values) is considered a shame-based society, one may easily reason that the occurrence of maltreatment may very well be higher than the reported findings.

[20] Tufan suggests a correlation between loss of physical functioning and violence against older adults.

1 in 10 older respondents from the sub-sample reported exposure to corporal violence[21] (Tufan, 2011a).

3.7.5 Impact on Employment and on Financial Situation

As reported in sub-section 3.4.1, some caregivers concomitantly juggle the responsibilitiy of unpaid family care and employment in the work force. Figures from the Eurofamcare study report more than 2 in 5 family carers interviewed were also employed (Triantafillou & Mestheneos, 2006). Findings regarding the affect of employment on caregivers, however, are inconclusive. Some studies show carers also employed in the work force experience less caregiver burden (Stoller & Pugliesi, 1989; as cited in Edwards, Zarit, Stephens, & Townsend, 2002: Jaffe & Blakely, 2000) while other research suggests that employment (especially full-time) among caregivers, lends to greater levels of burden (Scharlach &Boyd, 1989; as cited in Edwards et al. 2002; Wang, Shyu, Chen, & Yang, 2011), and still other research found no significant differences between strain in employed and non-employed family caregivers (Edwards et al., 2002). As Edwards and colleagues have cautioned, the contradiction of findings may be due to the inclusion of differing variables in measures used to compare employed and non-employed caregivers (Edwards et al., 2002). Jaffe and Blakely (2000) in their rural-based Canadian study, found family help and outside employment as the most significant variables in explaining caregivers' self-assessment of present health and change in health projection. Caregivers employed outside the home were found much more likely to assess themselves as healthy than their non-employed counterparts. Many non-employed family caregivers who assessed their health as poor received no assistance from family while caregivers receiving help from family were more likely to assess themselves as healthy and less likely to feel their health to be deteriorating (Jaffe & Blakely, 2000). Edwards et al. (2002) notes that employment in and of

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[21] Corporal violence is defined in this study as being attacked with an instrument such as a stick or knife.

itself may not equate with disadvantage to caregivers, rather specific experiences related to the employment role may lend to greater or lesser overall role strain.

The report, *Caregiving in the U.S.* (NAC & AARP, 2005) found level of burden and whether caregivers felt they had a choice in taking on caregiving responsibilities to be the two greatest predictors of caregivers' financial hardship. Caregivers reporting higher levels of burden and who felt no choice in whether to take on caregiving responsibilities reported greater financial hardship. Caregivers' age, health, living arrangements, and income were also found to contribute to financial hardship. More specifically, the older the CG, the poorer the self-assessed health, co-residence with the CR, and having a lower income all increased the reported level of financial hardship (NAC & AARP, 2005). Additionally, Mears (1998) suggests the possibility that financial hardship may increase with the prolonged period of care, increased seriousness of CR illness, and depending on whether the CG is a female and of advanced age (as cited in Carretero et al., 2009).

3.8 Empirical Findings II: What Factors Influence the Extent of Burden Experienced by Caregivers?

3.8.1 The Role of Caregiver's Socio-Demographic Variables

As reported in sub-section 3.4.1, caregiver well-being and health have been found to be influenced by demographic characteristics of the caregiver, among other factors (Dilworth-Anderson et al., 2004; as cited in Byrd, et al., 2011).The following findings are presented to provide an overview of some of the specific correlations identified between socio-demographic variables and CG burden.

According to a study by Kim, Chang, and Rose (2010), correlations between age, gender, kin relation and living arrangements were found to influence extent of burden such that caregivers who were older, female, a spouse, or lived together with the CR were found to have greater levels of burden than their counterparts. Interestingly, findings by Navaie-Waliser, Spriggs, and Feldman (2002) correlate young CGs with significantly higher levels of CG burden than older caregivers (as cited in Carretero et al., 2009). Caregivers' self-rated health was found to have a significant influence on CG burden such that the poorer the self-rated health, the greater the perceived burden (NAC & AARP, 2004; Iecovich, 2011). Education level of CGs has been shown to have a significant negative correlation with CG burden where the lower the educational attainment the higher the burden reported by caregivers (Cameron, Franche, Cheung, & Stewart, 2002; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; as cited in Byrd et al., 2011; Iecovich, 2011).

3.8.2 The Role of Care-Recipient's Health Status

In her study, Iecovich (2011) found significant correlation between the care-recipients' self-rated health and CG burden such that the lower the reported health of the CR, the greater the level of burden reported by the CG. In addition to the subjective self-rated health measure, care recipients' health status may be gauged according to assistance with activities of daily living (ADL), which refers to needs related to basic functions of day-to-day life. Caregiver assistance with ADLs has been linked to greater objective burden (Savundranayagam & Montgomery, 2010; as cited in Savundranayagam et al., 2011). A positive correlation between CG assistance with instrumental activities of daily living (IADL[22]) has also been found significantly related to burden. Thus, where IADL items increased, so the level of reported burden increased (Byrd et al., 2011).

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[22] IADLs are indirect care tasks such as grocery shopping, financial management, provision of transportation, preparation of meals and clean-up, and housework.

3.8.3 The Role of Caregiver– Care-Recipient Relationship: Dependency, Interdependency, Reciprocity and Altruism

Dependency, as a construct, is multidimensional (Kahana, Kahana, & Riley, 1989; as cited in Kahana & Young, 1990). As Baltes (1996) has pointed out, dependency is not only a construct of old age, "but of all life stages" (p. 9). Dependency is therefeore not simply influenced by biological, but also environmental and societal conditions (Baltes, 1996). The gerontological literature addresses a wide range of dependencies including "structured [social], mental, physical, economic, social, emotional, cognitive, real, pseudo, or neurotic dependencies", analyzed from different perspectives, be it "at the behavioral, personal, situational, or interpersonal level" (Baltes, 1996, p. 8-9).

Looking from a psychological perspective, dependency may be a form of coping or a means of attaining "passive control over one's environment" (Kahana & Young, 1990, p. 88). Kahana and Young (1990, p. 88) point out that this perspective is "consistent with Goldfarb's (1969) typology where an older patient may seek control over those around him or her by exhibiting passive and dependent behaviors." In this way care-recipients, who may otherwise be perceived as weak or helpless, may effectively gain power or influence over caregivers upon whom they are dependent. Passive and dependent behavior, for example, may be used by care-recipients to gain attention.

The literature regarding the relationships of the aged point to persuasive evidence of social interactions formed on the basis of reciprocity, interdependency and altruism[23] (Kahana & Young, 1990). Kahana and Young suggest that interdependency may be all the more relevant in situations where physical illness, as opposed to mental illness, is the reason for need of care. In care relationships wherecaregiving paradigms involve terminal or dementing illnesses, a dependency model may be more appropriate (Kahana & Young,

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[23] A concern for the welfare of others.

1990). Accordingly, to the extent that the care relationship can be a *two-way* as opposed to *one-way street*– that is, where CGs and CRs both have something to give or offer –the opportunity for interdependence in the care relationship exists. Kahana and Young provide three explanations as to why interdependence in caregiving relationships may exist, namely (a) ongoing reciprocity, (b) anticipation of future reciprocity, and/or (c) acknowledgement of past reciprocity (Kahana & Young, 1990).

3.8.4 Dyadic Quality of Relationship

A recent study found a significant correlation with dyadic QoR between CR-CG and CG burden (Iecovich, 2011). In fact, of the multiple variables analyzed in this study, dyadic QoR showed the strongest correlation with caregiver burden. These findings support similar results by Steadman, Tremont, and Duncan-Davis (2007), who also found correlations between pre-care-dependency quality of relationship and CG burden. Steadman et al. concluded that intervention might focus on addressing attitudes and behaviors that may have contributed to the pre-care-dependency quality of relationship. Modification of the caregivers' longstanding perceptions and behaviors might then lead to positive changes in the present relationship and consequential reduction in CG burden (Steadman et al., 2007).

3.8.5 The Role of Coping Strategies and Social Supports in Mediating Caregiver Burden

3.8.5.1 The Role of Coping Strategies as Mediators of Caregiver Burden

In the literature, coping strategies are listed as one of two types of mediators of CG burden (Carretero et al., 2009). In their model of stress and coping, Lazarus and Folkman (1984) conceptualized coping as a reaction – an appraisal of stress as a threat or a challenge (as cited in Sun, Kosberg, Kaufman, & Leeper, 2010). In a study measuring coping styles, Lazarus and Folkman (1980) found that their study sample could be divided into one of two coping types: behavioral (or problem-focused) and psychological (or emotion-focused) (Cited by Sun et al., 2010). In 1994, Carver and Scheier, as a component of their Coping Orientations to Problems Experienced (COPE) scale, introduced a third subjective and controversial type of coping strategy, *dysfunctional*, which the authors suggested as characterized by denial, mental disengagement, behavioral disengagement, and the use of alcohol (as cited in Sun et al., 2010; Li, Cooper, Bradley, Shulman, & Livingston, 2012). Since Folkman and Lazarus' landmark work in 1980, studies assessing stress and coping have been adapted to and carried out in family caregiving research. While results show possible correlations between coping styles and caregiving outcomes, there is general disagreement as to which coping styles offer the most benefit to caregiver outcomes (Sun et al., 2010).

3.8.5.2 Definitions of Social Network and Social Support

Social supports are listed in the literature as the second of two types of mediators of CG burden (Carretero et al., 2009).However, prior to addressing social supports, it is necessary to first distinguish between social networks and social supportsin order to understand the relation of one to the other. A social network consists of the sum of all a person's social relationships. The social support system, on the other hand, may be defined as "the network of relatives, friends, and organizations that provide both emotional support, such as making the individual feel loved or comforted, and instrumental support, which refers to help in managing activities of daily living" (Quadagno, 2008, p. 180). As such a person's social support, from which care potential may be realized, is a sub-group of their larger social network.

3.8.5.3 The Role of Social Networks and of Informal and Formal Social Support in Mediating Caregiver Burden

3.8.5.3.1 Informal Caregiver Support: Family and Community-Based Support

3.8.5.3.1.1 The Role of the Family

In Europe, as in the rest of the world, care for older adults is primarily provided by informal sources – meaning by family and other members of their social network (Suanet, Van Groenou, & Van Tilburg, 2012). The extent of available family-based social support in society today is diminishing as a result of several key changes, including: breakdown of the nuclear family, urbanization, and the phenomenon sometimes referred to as the *bean pole family structure* (Novak, 2009).

The support and care provided by family members are essential resources in enabling persons with chronic illness to remain in the community (Gonzalez, Polansky, Lippa, Walker, & Feng, 2011). However, as recognized among many societies in the world today, the traditional nuclear family (consisting of a husband, wife, and children) is no longer the assumed 'norm'. In many countries, in addition to heterosexual relationships, homosexual partnerships appear to be openly pursued and in some cases ratified by the laws of certain jurisdictions. Today divorce rates are histoically higher than ever, fertility rates in many countries have dipped below the rate of replacement, and many children are raised in one parent, single-salary households.

At an unprecedented rate, urbanization is affecting many countries around the world, particularly developing nations where youth (and in particular young men) move to the cities to find work and older cohorts remain behind in rural areas. Some studies have attested to comparatively higher percentages of married couples and men in rural as compared to urban areas (Dwyer, Lee, & Coward, 1990; Glasgow, 2000; as cited in Wagner & Niles-Yokum, 2006). This being the case, Wagner and Niles-Yokum (2006) suggest the likelihood in rural contexts of increased numbers of spousal caregivers and fewer numbers of adult children as primary caregivers compared to urban contexts.

As discussed in chapter one, massive demographic changes in large part are a result of increases in life expectancy and decreases in birth rates. The bean pole family structure– a reference to the elongated vertical structure of the family –is the result of these two major demographic changes. The image of a lengthy bean pole, as opposed to the traditional family tree with narrow top and wide base, reflects the fact that more generations (three or four) tend to be alive at the same time due to increases in longevity. The implications are that increasingly within the family, there will be larger proportions of older compared to younger people and therefore fewer caregivers to meet the care needs of dependent older adults of the future (Ajrouch, Akiyama, & Antonucci, 2007). Because each generation [has and] will have fewer members upon which to rely on for support, Novak (2009) suggests that family members will increasingly need rely on support from across the generational lines.

All of these factors– breakdown of the nulear family, progressive urbanization, and bean pole family structure –lend to an ever growing global decline in family-based support networks.

3.8.5.3.1.2 The Role of Neighbors, Friends, and Volunteers

Older adults, compared to other age cohorts, are most prone to the loss of social support due to the "normative experiences of death of parents, retirement, loss of a partner or close friend, or chronic illness" (Wenger & Keating, 2008, p. 33). In addition to chronic illness, declines in or loss of mobility and cognitive functioning may render older adults in need of care. These findings are most relevant for the fastest growing age cohort– older adults aged 80 and over (UN, 2002) –in that they are most at risk of chronic illness or disability (Martel & Malenfant, 2007; as cited in Fast & Gierveld, 2008), as well as loss of social support.

Stuart and Hansen (2006) refer to literature suggesting that social supports may lessen the negative effects of stressors associated with caregiving.Social supports are recognized in the literature as stress mediators (Pearlin, 1982; as cited in Chiriboga et al., 1990; Carretero et al., 2009) and directly associated with well-being (Chiriboga et al., 1990; Mockus Parks & Novielli, 2000; as cited in Carretero et al., 2009). In a similar way, caregiver support may be perceived as "a buffer or mediator of illness-induced stress for the care-recipient" (George, 1990; as cited in Kahana & Young, 1990, p. 79). Social supports or support networks may play an important if not crucial role in assisting family caregivers of dependent older adults, especially where the care-recipients needs are many and the caregivers' resources are stretched beyond capacity. In fact, support to caregivers has been conceptualized as a way of preventing care-recipients from being institutionalized (Lavorie, Grand, Guberman, & Andrieu, 2003; as cited in Guberman et al., 2006).

Support networks, from which psychological and hands-on help may be attained, are a functional subset of social networks (Keating, Otfinowski, Wenger, Fast & Derksen, 2003; as cited in Wenger & Keating, 2008). As such, network resources may be understood to be the bi-product of "relationships developed across the lifecourse" and "not universally available" (Aartsen, Van Tilberg, Smits, & Knipscheer, 2004; as cited in Wenger & Keating, 2008, p. 34). But as Nolan, Grant, and Keadt (1996) warn, assessed availability of care does not guarantee receipt of care. Theyrefer, rather, to a persons care potential as an *opportunity framework* from which care may be derived but is not guaranteed (Nolan et al., 1996). Nolan et al. (1996) warn that while the assessment of a persons support network may serve as "an initial guide" as to possible care resources, it should not be assumed that the existence of human supports be “immediately equated with the actual provision of care” (p. 11).As older care recipients in rural environments may have less access to both their adult children and public services, the need for support from neighbors in the local community increases. The term “fictive kin” has been used to describe “individuals who, while not related, are imbued with the same rights and responsibilities as kin” (MacRae, 1992; as cited in Wagner & Niles-Yokum, 2006, p. 150). Barker (2002) has estimated 5-10% of older adults are recipients of informal assistance from a friend or neighbor (as cited in Wagner & Niles-Yokum, 2006).

In a more general sense, informal help tends to be enmeshed in interpersonal relationships (Rozanova et al., 2008). According to study results by Chapman and Peace (2008), though communities are changing, “community cohesiveness can support older adults”(p. 31). However, the authors astutely identify the changing nature of populations through population exchanges (especially between rural and urban populations), as threatening the existence of cohesiveness in communities (Chapman & Peace, 2008). Loss of relationships and, thus, cohesiveness undoubtedly may result in negative effects for care-recipients and caregivers including low care and informal respite potential.

Drawing on results from The Bangor Longitudinal Study of Ageing (Wenger, 1989) in North Wales, Wenger and Keating (2008) identify five types of care networks, namely *family dependent*, *locally integrated, wider community focused, locally self-contained,* and *private restricted.* The first two care network types consist entirely or in part of family support, the third network of friends and others with regular contact with family from a distance. The fourth type tends to be somewhat solitary, while the final type is more socially isolated. Wenger and Keating point out that the last two network types, *locally self-contained* and *private restricted* receive little practical support, have no identifiable network wherein tasks and services are exchanged, and have low care potential (Wenger

& Keating, 2008). Comparing the percentage of most limited support networks at the start and end of the 20 year study, Wenger and Keating (2008) identify “a shift from *local self-contained* to the more solitary *private restricted* network type” (p. 40). While at the start of the study, only 6 % (the lowest representation) of respondents were *private restricted*, 20 years later while the number of *locally self-resricted* types had fallen from 21 to 13%, the number of private restricted had increased almost five-fold to 29% - the highest percentage among the five network types (Wenger & Keating, 2008). Thus, the view that social network size is an important determinant of care potential (Wenger & Keating, 2008) is indirectly supported by these findings.

Two broad categories of community participation are described in the literature: *helping others* and *volunteer activities* (Rozanova et al., 2008). Helping others is distinctly informal in definition, as it refers to help based on relationship between family member, friend, or neighbor and the care-recipient, and is typically based on historical patterns of reciprocity and sense of obligation(Rozanova et al., 2008). Volunteer activities, on the other hand, are distinctly formal in definition and not bound to personal connections, but to the “existence of formal organizations and infrastructures” (Rozanova et al., 2008, p. 76). Research suggests that individuals possessing a post-secondary degree or diploma are more likely to volunteer and provide informal help to others (Wilson, 2000; Perren, Arber, & Davidson, 2003; as cited in Rozanova et al., 2008).

3.8.5.3.2 Formal Caregiver Support: The Role of Professional Helpers, Respite Services and Models

> All things may be endurable if the demands are finite in depth and time. But a future that offers no exit at all, even if the burden on a daily basis is not utterly overwhelming, can be an obvious source of sadness and depression... No burden can be greater than trying to imagine how one

> can cope with a future that promises no relief. (Callahan, 1988; as cited in Schulz, 1990, p. 35)

When informal caregivers are overstretched and in need of respite, formal caregiver support may play a role in mediating CG burden.More than two-thirds of countries included in the EuroFamCare study reported experiencing problems in recruitment and retention of care workers in either the public or private sector. Among the main difficulties cited in the national reports were (a) understaffing leading to unacceptable shift work and overtime, (b) low status and heavy (tiring) work load, (c) lacking career identity and promotion opportunities, and (d) low pay[24] and prestige (Mestheneos & Triantafillou, 2005). Suggested interventions for recruitment and retention of care workers have included training and development of a career structure for caregivers, modernization of services, and improvement in employment conditions (including flexible and/or part time work opportunities) (Mestheneos & Triantafillou, 2005).

Of the 23 nations participating in the EuroFamCare study, 13 national reports[25] specifically reported the roles of migrant and foreign care workers in domestic care or nursing positions. Lack of language competency and lack of training in care work were listed as two difficulties associated with migrant care workers (Mestheneos & Triantafillou, 2005). The authors suggest that many governments have effectively placed migrant workers in danger of exploitation

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[24] The EuroFamCare study being no exception, care work being predominantly performed by women is a characteristic almost always associated with lower pay (Mestheneos & Triantafillou, 2005).

[25] While 13 nations made specific mention of the inclusion of migrant and foreign workers in domestic and/or nursing positions, only 5 countries specifically reported that migrant labor was not important. Of the remaining 5 silent countries, the authors note that in 2 countries, migrant workers were important in one or both sectors (domestic care and/or nursing sector) (Mestheneos et al., 2005).

as illegal aliens, by not directly addressing the issue of legality. Suggested interventions include legalization of migrant workers, care worker and language training, and (where feasible) their inclusion into a caring career (Mestheneos & Triantafillou, 2005).

Informal caregivers of dependent older adults may, at intermittent periods or on an ongoing basis, feel the need for respite from their care dutiesas a result of associated burden or stress. Stoltz reports that, "the need for a break is one of caregivers' most frequently expressed needs" (Stoltz, Uden, & William, 2004; as cited in Chappel, Schroeder, & Gibbens, 2008, p. 53). The same concept, taking a break, has also been referred to in the literature as *stolen moments*, that is, short periods for the caregiver to step aside from the regular routine of caregiver tasks (Chappel et al., 2008). Lund et al. refers to findings from a recent study of more than 3,700 CGs in Australia that rated respite as "the most important service for caregivers" (Cummins & Hughes, 2007; as cited in Lund, Utz, Caserta, & Wright, 2009, p. 114).

Three respite services typically offered in developed nations are in-home *sitter attendance services* that free the caregiver to engage in non-caregiving tasks; *adult day care* or *day hospital* where care-recipients are taken from a few hours to one or two days a week;and *respite care beds* where care-recipients stay for a few to several days (Chappel et al., 2008). Adult day care/respite has been identified by CGs as "one of the most seriously needed caregiver services"and will likely be among the most widely available services in the future (Caserta et al., 1987; Gottleib & Johnson, 2000; Kirk, 2002; as cited in Lund et al., 2009, p. 115). Among benefits of adult day respite cited by Lund et al. (2009), are (a) possible reduction of negative effects on families and caregivers via restructuring caregiver time, (b) provision of flexibility in engaging in a variety of activities over a relatively large window of time, and (c) provision of regularity in engaging in activities both in and out of the home.

Among the current respite services and programs offered internationally, Wagner and Niles-Yokum (2006) identify two U.S. respite services; mobile adult day services of Georgia's Central Savannah River Area Rural Day Care Services, which serves low-income elders as far as 50 miles (80 kms.) away with day services and respite services several times weekly. The second service, the Project Care Option & Public Education (COPE) provides low-income and minority families caring for older adults with dementia in-home respite care as well as information and assistance via telephone by ElderLink, Inc.

Chappel et al. (2008) challenge the notion of respite being perceived as a service. Results of their qualitative study "confirmed the notion of respite as an outcome rather than a service and demonstrated the importance of caregivers' own meanings when thinking about respite" (Chappel et al., 2008, p. 55). The people and activities involved in offering respite, argues Chappel et al. (2008) are not respite. Rather, "whether a caregiver receives a break depends on their frame of mind" (Chappel et al., 2008, p. 61). Recognizing that no two caregivers are alike, Chappel et al. (2008) recommends that service providers inquire of caregivers what a break looks like to them and how they might receive one that is meaningful. For some caregivers, the need is not necessarily to get away from the person for whom they provide care, "but opportunities to participate in rituals or traditions that connect them with others" (Chappel et al., 2008, p. 61). Furthermore, citing Strang and Haughey, Chappel et al. suggest that caregivers must recognize their need for and give themselves permission to take respite and benefit from available social support to facilitate it (Strang & Haughey, 1999; as cited in Chappel et al., 2008).

Lund et al. (2009) suggest that *continuity theory* may help direct caregivers in choosing beneficial activities for their respite time. Continuity theory (Atchley, 1989, 1999) posits that "most people find satisfaction in being able to maintain specific personal traits, interests, and activities throughout their life course" (Atchley, 1989, 1999; as cited in Lund et al., 2009, p. 126). Caregiving tasks and duties can hinder caregivers from maintaining continuity in day-to-day life (Lund et al., 2009). The tenets of continuity theory seem consistent with a number of research findings in the literature on CG burden. Lund et al. (2009) report on the research results of Cummins and Hughes (2007) which found the most effective way to improve caregivers' well-being is to facilitate their satisfaction with leisure time. Citing the REACH I studies, Lund et al. highlights the finding that a "*one-size-fits-all* approach is likely to be ineffective and that more successful interventions are those that are responsive to individual risk profiles (Schulz et al., 2003) and each caregiver's unique needs" (Beauchamp, Irvine, Seeley, & Johnson, 2005; Kelly & Williams, 2007; as cited in Lund et al., 2009, p. 111).

Lund et al. (2009) suggest that if CGs are indeed undergoing considerable stress due to discontinuation of previous facets of their lives and personhood then respite may offer the very best means of re-establishing continuity, particularly through engaging in activities enjoyed prior to becoming a caregiver. Important research regarding effectiveness of respite services has posited that caregivers need regularly use respite a minimum of two days per week in sufficient, uniterrupted, pre-planned blocks of time (Zarit, Stephens, Townsend, & Greene, 1998; Lund et al., 2009).

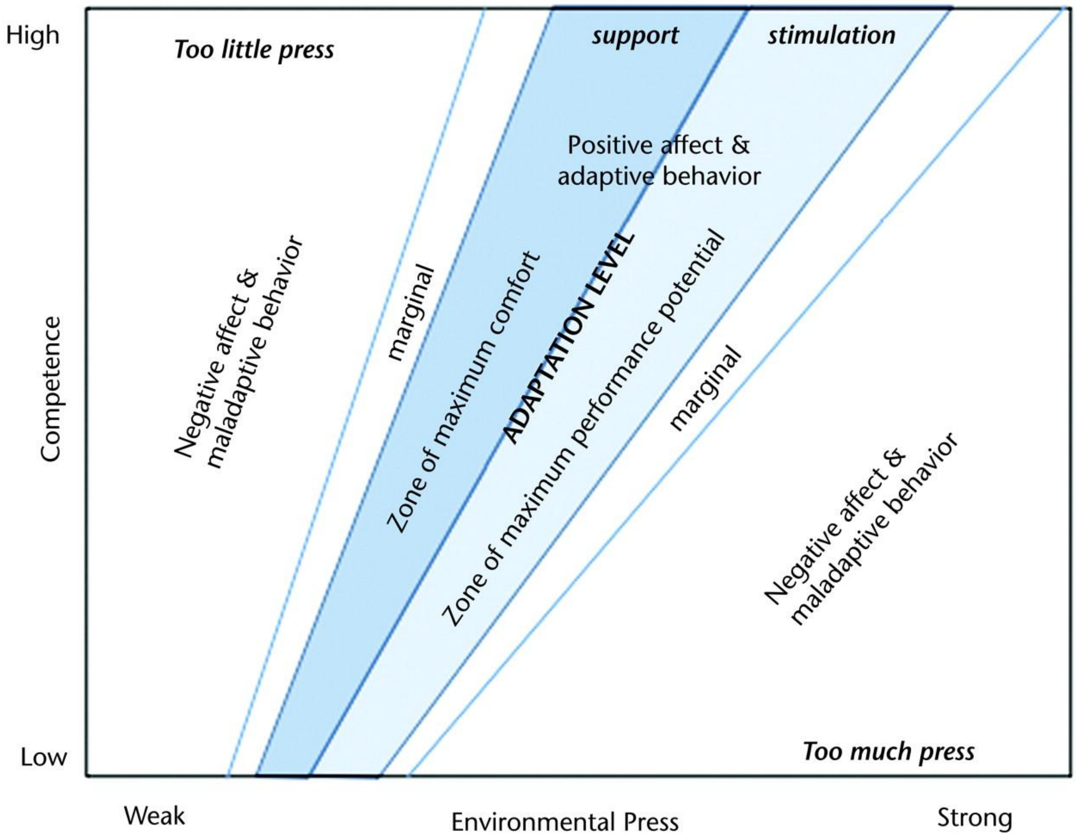
Furthermore, Lund et al. (2009) suggest a model for making respite services more person-centeredand effective. They recommend the employment of consultants, facilitators, or existing respite staff in assessing particularly problematic burden types encountered by caregivers and identification of goals to relieve specific difficulties (Lund et al., 2009). By individualizing respite through matching specific needs, such as physical or social burden, with specific goals for alleviating the particular difficulties, Lund et al.(2009) suggest that respite services will be more effective.

Despite the volume of literature suggesting the need for and benefits of respite care, Chappel et al. (2008) warn that respite service research is inconclusive inasmuch that some studies report benefit to respite for caregivers based on satisfaction with services (Gottlieb, 1995; Zarit, 1998), while other studies report no benefits (McNally, 1999; Lee and Cameron, 2004; Lund et al., 2009). It is hypothesized that CGs receiving*no benefits* from respite care do not experience a break because mentally they continue to think about and be concerned for the care-recipient (Watts and Teitelman, 2005; as cited in Chappel et al., 2008).

3.8.6 The Role of the Spatial Environment

3.8.6.1 Person-Environment Model

A psychologist named Kurt Lewin (1951) was the first in his field to try to conceptualize the person-environment relationship. He put forward the ecological equation **B=f(P,E)**, where *behavior* (B) is the result of both the *person* (P) and the *environment* (E) (Cited by Lawton, 1980). What Lewin's bare-bones formula lacked, Lawton and Nahemow (1973) sought to bring into the world of the tangible by defining the person (P) and environment (E) elements. They described the person element as "a set of 'competences' (Lawton & Nahemow, 1973, p. 11)in the domains of biological health, sensorimotor functioning, cognitive skill, and ego strength" (Lawton, 1972; as cited in Lawton, 1980, p. 11). To address the environment element, Lawton and Nahemow (1973) borrowed a term from psychologist Henry Murray (1938), *environmental press*, which may be defined as "the demands that social and physical environments make on the individual to adapt, respond, or change" (Hooyman & Kiyak, 2008, p. 9). In their ecological model of ageing (*Figure 11*), Lawton and Nahemow reasoned that the combination of a persons given competence level weighed in/against a given (environmental) press level may be charted on a continuum or axis where *x* represents competence and *y* represents environmental press,



Source: Lawton, M. P., & Nahemow, L. (1973). Reprinted with permission of the American Psychological Association.[26]

***Figure 11*: Lawton's press-competence model**

and positive and negative affect and behavior may be measured (Lawton & Nahemow, 1973; as cited in Lawton, 1980). Based on Lawton and Nahemow's person-environment model, behavior is not simply a function of the indiviual or of the environment alone, but of the "unique interactions between what is inside and what is outside the person" (Lawton, 1980, p. 9). It reasons then that the environment is not a "static backdrop but changes continually as the older person takes from it what he or she needs, controls what can be modified, and adjusts to conditions that cannot be changed" (Hooyman & Kiyak, 2008, pp. 8-9).

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[26] See APA's Copyright Permissions Information, http://www.apa.org/about/contact/copyright/index.aspx).

According to Lawton and Nahemow's *person-environments fit* theory (1973), as people move through the lifecourse, needs for more or less space may require a change of location (Phillips, 2007). Seen through the lens of care "a 'lack of fit' or appropriateness of the physical environment may require a change of place and readjustment of space" (Lawton, 1980; Cited by Philips, 2007, p. 105). Phillips keenly points out that, "this assumes that people have 'agency' in relation to their environments and can mould and shape them to suit their needs; this, however, may not be possible in relation to some people in need of care" (2007, p. 105).

An example of Lawton and Nahemow's person-environment model may be seen in the social connection preferences of two broad types of older adults in a given community. Manthorpe, Malin, and Stubbs (2004) describe stoic and activeseniors in rural England wherein some, preferring connectedness to others, maintain close relationships while others value their privacy above social interactions, preferring to keep fewer social connections (as cited in Eales, Keefe, & Keating, 2008).

3.8.6.2 The Micro Level Environment: Housing

> For the vast majority of older people and their family caregivers, the home is the preferred residence in which to grow old. (Gitlin, 2003, p. 635)

In the context of homecare and home support, Sims-Gould and Martin-Matthews (2008) describe a *human ecological framework* as a perspective – giving attention to dimensions of the environment and relationships between providers and receivers of homecare. Research findings support a *critical human ecology perspective* where the environment that older adults live in and receive care are deemed of particular importance (Keating & Phillips, 2008; as cited in Chadiha, Feld, & Rafferty, 2011).

Researchers have repeatedly proven that older people spend the majority of their day within the home, and this pattern is especially true for the oldest old (Baltes, Maas, Wilms, & Borchelt, 1999; Baltes, Wahl, Schmid-Furstoss, 1990; Wahl & Weisman, 2003). Because of this, the home comes to have increasing significance and the spatial context becomes a means of maintaining independence and offsetting possible decreases in function and increases in disability (Oswald & Wahl, 2005; Sixsmith & Sixsmith, 1991; as cited in Tanner, Tilse, & de Jonge, 2008).

As Rowles (1983) has said, it is clearly within the home that the most intensive forms of social support are available. Especially in situations where caregivers reside with older adults, practical assistance and companionship are available to the care-recipient at all times (Rowles, 1983). Perhaps for this reason, caregivers who reside together with those older adults for whom they provide care are at increased risk of CG burden (Kim et al., 2010), because they are essentially on call at all hours and may be unable to really experience a mental or even physical break[27] from caregiving (Chappel et al., 2008).

In the literature, home modifications, defined as "conversions or adaptations to the permanent physical features of the home environment" (Fange & Iwarsson, 2005; Pynoos, 1993; as cited in Tanner et al., 2008, p. 197) are suggested as a form of intervention. Reduction of physical environment demands through home modification aims to "make tasks easier, reduce accidents, and support independent living (Tanner et al., p. 197). By supporting independent living, home modifications may offer benefits to care-recipients and caregivers alike because increases in independent living for care-recipients should translate into decreases in both care demand and burden for caregivers.

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[27] This topic is also addressed, in reference to respite care, in sub-section 3.8.5.3.2.

3.8.6.3 The Meso Level Environment: Rural Versus Urban Regions

In the context of "apocalyptic demography" (Gee, 2000, p. 5) rural environments, due to their accelerated rate of population ageing, have been viewed with particular concern (Wagner, 2006; as cited in Eales et al., 2008). In the literature, accelerated population ageing in rural environments is attributed to out and in-migration, and ageing in place. In England and Canada, for example, evidence for working-age youth migrating from rural to urban centers in search of employment, older adults choosing to age in place, and some retirees moving to rural environments are reported (Statistics Canada, 2001; Rothwell, Bollman, Tremblay, & Marshall, 2002; as cited in Chapman & Peace, 2008).

In contrast to urban settings, growing old and providing care in rural environments is associated with a number of disadvantages in the literature. While access to traditional health care services, as a result of physical frailty, financial limitations, and lack of available transportation, may be a problem for both older adults or disabled persons in urban and rural communities, these barriers are magnified by geographical distance and lack of health care infrastructure in rural environments (Redford & Spaulding, 2006). In contrast to older adults in suburban and urban settings, Kerschner (2006) cites research findings that suggest older adults living in rural settings are typically older, have lower incomes, and have poorer health compared to older adults in suburban and urban settings. Scharf and Bartlam (2008), citing findings from North American and Australasian studies, show rural residence to be associated with both lower income and higher-than-average poverty. Goins and Krout (2006) point out that poverty rates have been shown to increase as rural settings become more remote (Miller, Crandall, & Weber, 2002; as cited in Goins & Krout, 2006).Furthermore *persistent poverty* has been identified as a predominantly rural problem (Mosley & Miller, 2004; as cited in Goins & Krout, 2006). Based on US statistics dating from 1959, 95% of the poorest counties are consistently rural (Miller, Crandall, & Weber, 2002; as cited in Goins & Krout, 2006). In addition to findings that income in rural settings are comparitavely lower than in urban settings, research shows that income decreases incrementally as the cohort ages (Fry, 2001).

Lower incomes, poorer health, and increased percentage and persistency of poverty among older adults in rural settings may introduce increased risk of burden for caregivers of rural dwelling seniors. Recent findings support a health disadvantage among nonmetropolitan caregivers who report having more medical conditions than their urban/metropolitan counterparts. (Jones, Parker, Ahearn, Mishra, & Variyam, 2009; as cited in Byrd et al., 2011).

Some researchers, however, offer a word of caution to those quick to make generalizations concerning the disadvantages associated with living in a rural community. Keating (2008) suggests that in regards to resources, while many rural communities are in decline, “rural communities are not uniformly resource-poor” (p. 127). She argues that the number of “well-resourced communities is growing” (Keating, 2008, p. 127). Goins, Spencer, and Byrd (2009) maintain that research findings do not consistently equate poor health outcomes for caregivers living in a rural environment. They argue that, beyond rural CGs/CRs being more likely to use informal supports while their urban counterparts tend to have the option/predisposition to use formal services, further research must be conducted to better understand if and how residence influences the caregivingexperience (Goins et al., 2009).

In conclusion of this section, the preceeding sections have offered numerous findings from the international scientific community related to outcomes and influences of caregiver burden. Attention has been given to these findings so as to establish a baseline or series of reference points for comparative purposes with the findings to be addressed in this study. Appendix A offers in table format a comprehensive summary of reported findings in the review of literature related to factors influencing or impacting caregiver burden.

3.9 Summary: Which Kinds of Support are Most Efficient in Reducing Caregiver Burden?

A study by Singer et al. (2005, p. 73) supports the pivotal role of "availability of adequate support systems" in meeting both physical and emotional caregiver needs in defusing the negative and facilitating the positive outcomes of caregiving. The form that support takes may be formal and systematic or informal and relationally-based. The various types of support referenced as a means of reducing CG burden in chapter three as well as additional supports will be summarized below under these three forms: *individual, public* and *societal*.

3.9.1 The Individual Level

Some researchers have underlined the important role that caregivers themselves may have in using personal resources to mediate care-induced burden. Based on interviews from national reports in Germany, Italy, Poland, and the United Kingdom, Hoff and Hamblin (2011) point out the necessity of caregivers to pursue or ask for help when needed. They refer to an Italian-based report of an only child (adult) caring for a parent, advising other caregivers to "get help from someone…to ask…around" (p. 58). Caregivers may pursue assistance lending to an alleviation of physical and or emotional burden, by such means as seeking out advice or information for care tasks, health promotion or counseling resources, and the setting aside of discretionary time where possible. Hoff & Hamblin (2011) point out the importance of would-be supporters in having both knowledge of the care-context and an appreciation for the care offered as a prerequisite to being able to truly offer caregivers emotional support.

In addition to caregivers themselves, other individuals– whether family members or designated others, including neighbors or concerned members of a community –may offer practical support (Kashner et al., 1990) to help alleviate the load or burden borne by caregivers. However, as Wenger and Keating (2008) have pointed out, as the needs of the CR increase, support networks tend to become smaller and composed of close kin (as cited in Keating, 2008). As Hoff and Hamblin (2011) put it, friends and neighbors might possibly be relied on as help "of last resort" though not too often (p. 61). It goes to reason that a narrowing of one's support network as care needs increase would naturally lend to an increased risk of decreased health and emotional status among caregivers – variables found to be good predictors of institutionalization of the care-recipient (Logdson et al., 1999: as cited in Carretero et al., 2009). Additionally, WHO (2011b) has found that caregivers who are family members or relatives are most often the perpetrators of maltreatment of care-recipients. Thus, especially in situations where the extent of one's support network rests solely on the family, availability of non-family support– from public and societal sources –may determine the ultimate fate of care-recipients and caregivers alike.

3.9.2 The Public Level

Caregiver well-being and health have been found to be influenced by the quality of resources available to assist caregivers in coping with stress (Dilworth-Anderson et al., 2004; as cited in Byrd et al., 2011). Johansson and Sundström refer to the increasing research evidence regarding "the crucial role of families, their care commitments, and their ensuing need for support." They likewise note an increasing awareness that caregivers need be supported as "…a necessary precondition to mobilize carers in the future" (Johansson& Sundström, 2006, p. 13). Thus, when the informal resources of family and one's support network are not sufficient to alleviate undue burden, the availability of public resources may be the only remaining hope of assistance for struggling caregivers in the present and safeguard for the availability of caregivers in the future.

Among interventions in the literature aimed at minimizing caregiver burden at the public level are: (a) modification of longstanding perceptions and behaviors between CG-CR so as to increase QoR and reduce care-induced burden (Steadman et al. 2007), (b) provision of respite services for caregivers, especially adult day care services (Cummins & Hughes, 2007; Caserta et al., 1987; Gottleib & Johnson, 2000; Kirk, 2002; as cited in Lund et al., 2009), (c) adopting a person-centered approach to intervention (Lund et al., 2009), and (d) provision of resources for home modifications to meet care needs (Fange & Iwarsson, 2005; Pynoos, 1993; as cited in Tanner et al., 2008). These intervention types are summarized below.

In a recent study, dyadic quality of relationship between CG-CR was found to have the strongest correlation with caregiver burden (Iecovich, 2011). Proposed intervention in this area includes addressing and modifiying attitudes and behaviors of the pre-care-dependency QoR. Researchers suggest that modification of the longstanding perceptions and behaviors might lead to positive changes in the present dyadic relationship and translate into a reduction in CG burden (Steadman et al., 2007).

As previously addressed,[28] respite care services are recognized as a needed form of support for family caregivers.In fact, provision of respite care and especially adult day care services which have been identified as the “most seriously needed caregiver service” are referred to in the literature as among the forms of respite care likely to be most widely available in the future (Caserta et al., 1987; Gottleib & Johnson, 2000; Kirk, 2002; as cited in Lund et al., 2009, p. 115). The literature offers several guidelines, however, to keep in mind

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[28] See sub-section 3.8.5.3.2 for further details.

regarding the approach to and implementation of respite care, namely (a) a sensitivity to the individual caregivers sense of what constitutes a break (Chappel et al., 2008), (b) the important role that respite may offer in providing caregivers the opportunity to re-establish continuity, especially with regards to activities enjoyed prior to becoming a caregiver (Lund et al., 2009), and (c) the need for respite to be used a minimum of twice weekly in adequate blocks of time to be most effective (Zarit, Stephens, Townsend, & Greene, 1998; Lund et al., 2009) (See sub-section 3.8.5.3.2 for a fuller address of these topics).Caution is offered, however, that effective approaches to respite will be *person-centered* (Lund et al., 2009) and not *one-size-fits-all* (Schulz et al., 2003). To ensure this, it is recommended that consultants and facilitators be employed to identify specific goals to address specific burdens (Lund et al., 2009).

Home modifications, addressing conversion or adaptations to physical features of the home (Fange & Iwarsson, 2005; Pynoos, 1993; as cited in Tanner et al., 2008, p. 197) are a suggested means of intervention. Reduction of physical environment demands through home modification are reported as a means of simplifying tasks, reducing accidents, and supporting independent living (Tanner et al., 2008). It reasons that by supporting independent living, home modifications would benefit care-recipients as well as caregivers because increasing independent living for care-recipients should result in decreased care demand and burden for caregivers.

Germany's Social Long Term Care Insurance, serves as a good example of intervention in the area of home modifications, providing up to 2,557 Euro's for use in home modifications[29] (Heinicke & Thomsen, 2010). Provision of such resources make modifications of the primary care environment– the home – possible for those who would otherwise be unable to substancially adapt the physical features of their home environment according to care needs.

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[29] It should be noted that support of up to €2,557 is provided with co-payment of the insured depending on income.

3.9.3 The Societal Level

The need to recognize the invaluable role that family caregivers play is being addressed by researchers in both health (Haley, 1997;Mitnick, Leffler, & Hood, 2010; Tataru & Dicker, 2011) and social (Ehlers, 2010; Chappell, 2012) care settings. Mitnick et al. (2010) note that physician recognition of the value of the caregiver role may contribute to a positive caregiving experience as well as decreased rates of care-recipient hospitalization and institutionalization. Furthermore, Mitnick et al. (2010) suggest that by recognizing and addressing the physical, psychological, spiritual, and emotional needs of caregivers, physicians can positively affect the caregiving experience. Research by Ehlers (2010) among family carers of persons with dementia cites many carers expressing both disappointment that no one appreciates what they're doing and a desire for recognition from politicians and society. Chappell (2012), in a review of international literature in assisting caregivers, lists several interventions related to valuing the role of caregivers, including, (a) early and continual assessment of caregivers by trained assessors, (b) allocation of sufficient resources to adequately address identified needs, (c) development, together with caregivers, of person-centered, multidimensional, and flexible intervention-based programs, and (d) the training of caregivers to self-identify and recognize their own needs. For Eurocarers (n.d.), a European association working for carers, the issue of recognition is so important that they have placed it as their top agenda item or guiding principle, as reflected in the following statement, "Carers should be recognized for the central role they play in community care, and this recognition should be reflected in all policies having effect on carers" (p. 1).

3.10 Care Support: Societal Preferences and Issues of Accessibility

3.10.1 Formal Versus Informal Care Support

In Singapore, by way of public appeal, families are reminded that they "should be" the "first line of support" in caring for their older family members (Mehta, 2006, p. 45). This is consistent with the filial care norms of children caring for their parents in the Asian cultural context (Mehta, 2006). In Singapore, the older person's family is the first line of support, while the second line of support falls to the community, which may include assistance from NGO's, associations, private foundations, and religious charities (Mehta, 2006). As a last resort or "safety net", the state will step in where necessary to provide support where neither family nor sufficient levels of family assistance are available (Mehta, 2006, p. 45).

In contrast to Singapore and it's traditional Asian filial influence, the inhabitants of Northern Europe, in particular, prefer public services to family providers, especially for chronic or long-term care (Johansson & Sundström, 2006). Professional care is preferred to family care by many British and Swedish older adults, "especially when they live alone and need intimate, long-term personal care" (Johansson & Sundström, 2006, p. 18).

Results from the OASIS study comparing Norway, England, Germany, Spain, and Israel found that the majority of respondents of all ages preferred responsibilities for the care of older adults be shared by family and state as opposed to falling entirely on one or the other (Daatland & Herlofson, 2003; as cited in Johansson & Sundström, 2006). Johansson and Sundström (2006, p. 22) assert the importance of and relationship between care in old age and security. Providing a definition in relation to service usage, they suggest that "security is not to *use* a service, but to *get it*, reliably and swiftly, *when it is needed*." Johannson and Sundström (2006) further suggest that, based on this perspective [availablilty as needed], if public services can establish a feeling of security, then “actual use of services may be low”(p. 22).

3.10.2 Urban Versus Rural Accessibility Issues

The common trends of population ageing and a strong desire to ‘age in place’ are making homecare the likely choice of many older people (Sims-Gould & Martin-Matthews, 2008). In less populated rural communities, declines in once staple industries such as mining, forestry, or family farms has “led to out-migration of younger people and loss of service infrastructure” (Horton, 2005: as cited in Rozanova et al., 2008, p. 75). Less densely populated areas may be unable to provide services commonly available in more densely populated communities such as postal delivery, public transport and fire fighting due, in part, to the relatively large size of the area in respect to its property tax base (Woods, 2006; as cited in Rozanova et al, 2008).

It is not surprising then, that the residents of rural communities depend upon one another for support (Rozanova et al., 2008). In view of the shortfall of public infrastructure and services in rural contexts, social participation is all the more important in sustaining the social fabric of the community (Bull, 1998; Shortall. 2004; as cited in Rozanova, 2008). Research in rural Minnesota provides an example of older women “embedded in networks of mutual support as providers and recipients of care” (Shenk, 1998; as cited in Fry, 2001, p. 898). Other researchers have found rural residents to be more “intensely involved in helping others” than their urban counterparts, “regardless of age or presence of activity limitations” (Fast & Gierveld, 2008, p. 69). Comparisons of urban and rural service availablity in the US have found that rural areas consistently have “fewer home-and community-based services and a lack of health care options” (Glasgow, 2000; as cited in Wagner & Niles-Yokum, 2006, p. 152). For this reason, Wagner and Niles-Yokum (2006) point out the particular importance of caregiving support provided by families and friends in rural areas.

Research by Kincade, Rabiner, Nelson, and Salmon (1998) found severly-impaired older adults residing in non-metropolitan areas less likely to receive formal support and more likely to receive informal caregiver support exclusively when compared with urban counterparts. In another study, solo primary caregivers were found to be more prevelant in rural contexts, where caregiving tasks may be very demanding and care recipients lacking sufficient informal supports in meeting their regular assistance needs (Chadiha et al., 2011). In addition to potentially greater caregiver responsibilities, studies in rural regions found caregivers "reluctant to seek assistance unless there is a crisis, or finding existing services too geographically distant to be helpful" (Buckwalter & Davis, n.d.; as cited in Butler et al., 2005, p. 51).

CHAPTER 4

AIM AND RESEARCH QUESTIONS

4.1 Introduction

As established in chapter one, population ageing– resulting from decreases in fertility rates and increases in life expectancy –is a global phenomenon in progress. Along with an increase in life expectancy, the number of care-recipients and the average length of their care-dependency is increasing. While most people in Turkey choose to care for their older care-dependent relatives at home, caregivers may experience positive aspects but also burden[30] as a result of providing care. Together with demographic trajectories in Turkey that clearly project a considerable rise in the number of care-dependent-seniors over the next 40 years, the ratio of potential caregivers to care-recipients is also projected to concomitantly decrease. This means that there will be fewer available caregivers to care for the increasing number of care-dependent seniors in the future. It is thus deemed prudent that issues related to caregiver burden in Turkey be identified and addressed. Turning a blind eye to the issue of caregiver burden in Turkey may jeopardize the future availability of both healthy caregivers and quality care of dependent community-dwelling older adults. As the needs of caregivers are recognized and addressed, on the other hand, both caregivers and the seniors they care for stand to benefit.

4.2 Objectives, Research Questions and Hypotheses

This dissertation was done in the framework of a bigger research project – the Antalya Home Care Survey (AHCS). Utilizing standardized questionnaires in the form of the AHCS, research was conducted in rural, quasi-rural and urban environments in the Province of Antalya, Turkey. The AHCS was designed to

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[30] For a definition of *burden*, see chapter 3, sub-section 3.6.4.

better understand the situation of both dependent older adults (care-recipients) living at home and their primary caregivers.

An important aim of this study is to build a contemporary knowledge base on informal family caregiving of dependent community-dwelling older adults in Turkey, and to subsequently disseminate the research findings in the interest of improving the situation for both caregivers and older dependent people. More specifically, this dissertation aims to (a) understand the extent to which caregiver burden is experienced by primary caregivers in different environments and (b) to identify which factors show significant correlation to burden experienced by family caregivers in Antalya, Turkey. Furthermore, it is the authors hope that this project will effectively establish a reference point, based on empirical findings, for comparative provincial, regional and national-based caregiver research and serve the eventual development of a *national* policy to support family caregivers.

Informed by the pilot study, general observations, and the caregiving literature, the **main research question** was constructed:

1. What is the nature and extent to which primary family caregivers of community-dwelling older adults in the Province of Antalya, Turkey experience caregiver burden?

The following **additional research questions** were also constructed according to observations and the literature:

1. What is the role of socio-demographic variables of the caregiver, such as gender and age, for caregiver burden?
2. Does the motivation to care have an influence on caregiver burden?
3. Does self-rated health of the caregiver have an influence on caregiver burden?
4. What is the role of quality of relationship between care-recipients and caregivers on caregiver burden?

5. What is the role of social support on caregiver burden?
6. Does living in the same household with the care-recipient have an influence on caregiver burden?
7. Does physical environment (geography) have an influence on caregiver burden?
8. Do caregivers who help their care-recipient with five or more Activities of Daily Living experience higher levels of burden than those who help with less than five Activities of Daily Living?

Given the aim of this study, the following main hypothesis and additional hypotheses were constructed in line with the aforementioned research questions.

Main Hypotheses:

1. Primary family caregivers in the Province of Antalya, Turkey experience differential expressions of caregiver burden.
2. Primary family caregivers in the Province of Antalya, Turkey experience high levels of caregiver burden

Additional Hypotheses:

1a. Older caregivers experience more caregiver burden than younger caregivers.

1b. Women experience more caregiver burden than men.

1c. Caregivers with higher education experience lower care-induced burden.

2. Caregivers who provide care by their own free will experience lower caregiver burden.
3. Caregivers who rate their health as poor experience more caregiver burden.

4a. The better the present quality of relationship between care-recipient–caregiver, the less caregiver burden experienced.

4b. Where the dyadic quality of relationship has improved for the better (comparing present with pre-care-dependency relationship), less caregiver burden is experienced.

5a. The more assistance provided by a caregiver's family members, the less caregiver burden experienced.

5b. The more assistance provided by the caregiver's neighbors, the less caregiver burden experienced.

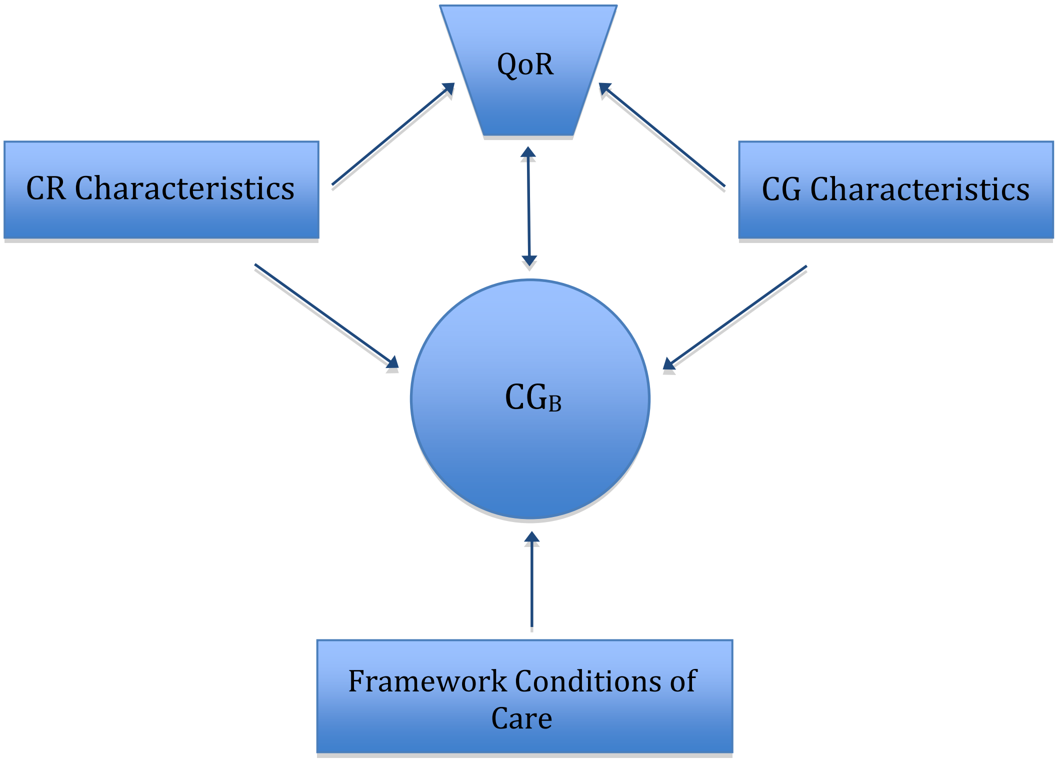
6. Caregivers who live in the same house with care-recipients experience greater caregiver burden.
7. Caregivers who live in rural areas experience more burden than those living in urban environments.
8. Caregiver burden is higher for those caregivers who perform five or more Activities of Daily Living tasks for the care-recipient.

In the event that high levels of caregiver burden are identified, the following questions were constructed to be addressed in the Conclusions Chapter of this dissertation:

1. What *framework* conditions minimize caregiver burden with regards to:
    - Caregiving families?
    - Care and social services?
    - Public policy?
    - Further research?

4.3 Research Model

The model represented in *Figure* 12, is a modified version of Ieocovich's (2011) research model and also reflects findings reported in the review of literature and the orientation of the research questions and hypotheses of the study.



Key: CR = care-recipient; CG = caregiver; CG_B = caregiver burden; QoR = quality of relationship

***Figure 12*: Basic research model**

This research model suggests that four sets of variables are associated with promoting and/or mediating caregiver burden: (a) caregiver characteristics, (b) care-recipient characteristics, (c) the past and evolving quality of relationship (QoR) between the dyads, and (d) framework conditions of care.

CHAPTER 5

METHODS

5.1 Sample Description

5.1.1 Definition of Care-Recipient and Primary Caregiver in the Study and a Description of the Sampling Method

The profile of care-recipients (CR) sought out in this study was 60 years of age and older, care-dependent [e.g. requiring assistance in activities of daily living (ADL) and/or instrumental activities of daily living (IADL)], and having cognitive health sufficient to reliably respond to questionnaire inquiries. Primary caregivers, on the other hand, may be described as those individuals who, on behalf of the CR, performed the majority of caregiving tasks and spent more time performing those tasks than any other person (Lund, 1993; as cited in Lund et al., 2009). Note: All references to caregivers (CG) in this study are references to primary caregivers (PCG) unless otherwise noted.

In urban environments, potential respondents were identified and visited randomly with the assistance of a provincial elections committee list, which includes the birth dates and corresponding addresses of the Province's residents. In rural and quasi-rural environments, respondents were identified with the assistance of elected village headmen or their assistants using a convenience sampling approach.

5.1.2 Care-Recipients' and Caregivers' Characteristics

5.1.2.1 Socio-Demographic Characteristics of Care-Recipients

Table 4 shows the characteristics of both groups of respondents according to environment type – urban, quasi-rural, and rural. Assessing the age of care-recipients according to the categories young old (up to 74), old old (75-84), and oldest old (85 & over), the majority of respondents in all three environments/areas consisted of the old old, especially in quasi-rural areas (62.9%) where there were fewer young old (21.3%) and oldest old (15.7%) respondents, respectively. Care-recipients were predominantly female in all three areas, but noteworthy were the large number of male respondents (45.5%) in rural areas. While the majority of respondents in urban (58.0%) and quasi-rural (71.9%) areas were widowed, there was a slightly larger married (50.0%) to widowed (49.1%) ratio in rural areas. Noteworthy were the very low number of single, separated and divorced care-recipients (1.2% combined total) in all three environments. In fact, none of the care-recipients in quasi-rural (n = 89) or rural (n = 112) areas reported being separated or divorced. There were stark differences in educational achievement among care-recipients according to environment type. For example, considerably fewer urban respondents at 58.8% reported no schooling or diploma compared to 93.3% and 84.8% of quasi-rural and rural respondents, respectively. With the exception of one rural respondent, no respondents in rural or quasi-rural areas reported attaining a diploma above the elementary (1-5) level.

Regardless of environment type, the mean age of care-recipients in this study was 78.45 (SD = 8.38) years of age, most were female (62.0%), widowed (58.7%), had received no formal schooling or diploma (76.8%), and had an average of 4.76 children (SD = 2.22). For more details see Table 4.

5.1.2.2 Socio-Demographic Characteristics of Caregivers

Regarding the characteristics of caregivers in the study sample according to environment type, the age of caregivers was broken into two groups: those under 60 and those 60 and over. Roughly two-thirds of urban and rural caregivers were under 60 while nearly 9 in 10 quasi-rural caregivers (88.8%) were under 60 years of age. Roughly 1 in 8 caregivers in urban and rural areas were male compared to only about 1 in 18 male caregivers in quasi-rural areas. The percentage of married caregivers was higher in rural (~89% & 85%) versus urban (~72%) environments. While comparatively higher than care-recipients, the numbers of separated or divorced caregivers was relatively low totaling 1.5% of respondents. The number of widowed caregivers was markedly higher among urban respondents (16.8%) compared to rural respondents (2.7%). While roughly 1 in 5 caregivers in urban and quasi-rural areas reported having no formal schooling or diploma, more than 1 in 3 caregivers (35.7%) in rural settings reported no schooling or diploma. Among caregivers who had children (n = 291), respondents in rural areas on average had the most children at 3.66 (SD = 2.26), followed by urban caregivers with 2.93 (SD = 1.76), and quasi-rural caregivers with 2.66 (SD = 1.44).

Regardless of environment type, the mean age of caregivers in this study was 50.13 (SD = 14.67). Nearly 9 in 10 caregivers were female (89.5%) and just over 8 in 10 were married. While more than 1 in 4 had received no formal schooling or diploma (25.9%), more than 4 in 5 caregivers (85.2%) had completed at most an elementary (1-5) school education. Of those respondents who reported having children, caregivers had an average of 3.09 children (SD = 1.90).[31] For more details, refer to Table 4.

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[31] It should be noted that employment figures were not included among independent variables due to having less than 10% (n = 32) of the whole PCG sample concomitantly working in a paid position.

Table 4

Socio-Demographic Characteristics of 332 Matched Dyads based on Environment-Type in Antalya-Turkey

Variables		Primary caregiver (PCG)				Care-recipient (CR)			
		Region			Total	Region			Total
		Urban n = 131	q-Rural n = 89	Rural n = 112	*N* = 332	Urban n = 131	q-Rural n = 89	Rural n = 112	*N* = 332
Age (PCG)	Under 60	66.9%	88.8%	67.0%	72.8%				
	60 & over	33.1%	11.2%	33.0%	27.8%				
Age (CR)	74 & under					28.5%	21.3%	25.7%	25.7%
	75-84					46.9%	62.9%	48.2%	51.7%
	85 & over					24.6%	15.7%	25.9%	22.7%
Gender	Male	12.2%	5.6%	12.5%	10.5%	38.9%	27.0%	45.5%	38.0%
	Female	87.8%	94.4%	87.5%	89.5%	61.1%	73.0%	54.5%	62.0%
Marital status	Married	71.8%	88.8%	84.8%	80.7%	40.5%	27.0%	50.0%	40.1%
	Single	9.2%	4.5%	10.7%	8.4%	-	1.1%	0.9%	0.6%
	Separated/ Divorced	2.3%	-	1.8%	1.5%	1.5%	-	-	0.6%
	Widowed	16.8%	6.7%	2.7%	9.3%	58.0%	71.9%	49.1%	58.7%
Education (yrs completed)	No schooling/ diploma	20.6%	21.3%	35.7%	25.9%	58.8%	93.3%	84.8%	76.8%
	1-5	47.3%	71.9%	63.4%	59.3%	28.2%	6.7%	14.3%	17.8%
	6-8	9.2%	5.6%	-	5.1%	6.1%	-	-	2.4%
	9-11/12	11.5%	1.1%	-	4.8%	4.6%	-	-	1.8%
	12/13+	11.5%	-	0.9%	4.8%	2.3%	-	0.9%	1.2%
Average no. of children (SD)[a]		2.93 (1.76)	2.66 (1.44)	3.66 (2.26)	3.09 (1.90)	4.12 (2.15)	5.17 (2.06)	5.14 (2.25)	4.76 (2.22)
Average age (SD)[b]		52.69 (15.83)	47.06 (11.16)	49.61 (15.32)	50.13 (14.67)	78.12 (9.73)	78.42 (6.57)	78.87 (8.01)	78.45 (8.38)

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[a] Calculations based on number of PCGs (n = 291) and CRs (n = 323) with children.

[b] Only one person from among PCGs and CRs did not know their age and were without identification. Calculations are based upon the number of respondents providing their age (n = 331) from CGs and CRs.

5.2 A Human Ecological Model: Classification According to Spatial Context and Resource Availability

Rowles in his book chapter, *Geographical Dimensions of Social Support in Rural Appalachia*,(1983), provides us with a helpful human ecological model incorporating 6 spatial zones from which support for older persons [and incidentally, their primary caregivers] may be derived in rural environments. These zones are *Home, Surveillance Zone, Vicinity, Community, Subregion,* and *Region*.Rowles suggests that "as people grow older and spend more time at home the *surveillance zone*, space within the visual field of home, may become an increasingly significant source of support" (Rowles, 1981a; Cited by Rowles, 1983, p. 120). He offers four ways that the surveillance zone provides support, including, "watchful reciprosity" meaning "exchange of visual signals" at regular interval or schedule, "neighbors as intermediaries" helping an older neighbor (Lowenthal & Robinson, 1976; Cited by Rowles, 1983, p. 120), supportive relationships that conjour a "sense of ongoing social involvement", and connection with memories of times past that may be evoked (Rowles, 1983, p. 120). Vicinity, encompassing a larger area around the home of the older individual, may vary in size according to topography and population as offers opportunity for interaction (Rowles, 1983). Rowles argues that this zone is of particular importance to older adults as relationships with others from within their vicinity may offer critical support as they become vulnerable (Rowles, 1983). Community, in Rowles' particular case study, encompasses "the primary domain of the society of the old", while the incrementally larger areas of subregion and region refer to the spatial limits of resource utilization (such as hospitals, doctors, banks and grocery stores) and the zone of infrequent and almost exclusively family-derived-support, respectively (Rowles, 1983, p. 122). Thus, Rowles argues that "a supportive social network emerges as a result of geographical proximity" (1983, p. 121).

With both the primary domain of the aged and spatial limits of resource utilization in mind, particular emphasis was given in this study to establish clear geographical delineations as well as availability of basic resources and services as a basis for the demarcation of assessed neighborhoods and villages as rural, quasi-rural, or urban. The details of place classification in this study are presented in the following section.

5.3 Urban, quasi-Rural, and Rural Respondents

As Goins and Krout (2006, p. 10) have said, "…the growth of suburbia has blurred the lines between rural and urban communities." In this study, the term *quasi-Rural* refers to this blurred parameter as a third and separate classification, a 'buffer zone', identifying those areas of residency that lie between distinctly urban and rural environments. Quasi-Rural environments in our typology have a less distinct though separate identity from her neighbors urban and rural. Thus, in recognition of the processes of urbanization at work in Turkey, I've used the term 'melez' (in Turkish) referring to the 'hybrid' nature of what 'once was' rural but is 'not yet' urban…quasi-Rural.

Classification of a community as rural, quasi-rural or urban was determined on the basis of primary and secondary factors (*Figure 13*). Primary factor refers to the distance[32] of a given community/sampling from the selected *central urban point* (CUP).[33] Ten sub-categories were constructed based on distance from the

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[32] Using the most reliable map we could locate, distance was measured "as the crow flies". Consideration was given in instances where distance via transport routes differed greatly from map measurements.

[33] Selection of the *central urban point* was made on an 'educated assessment' of the city of Antalya's most geographically central location and in regards to accessibility to transport routes (including public transport), health services, and access to other needed services and commodities (e.g., banks and markets/stores).

CUP,[34] beginning with the most central urban location, Urban 1 (U1), and continuing with U2, U3, quasi-Rural 1 (qR1), qR2, qR3, Rural 1 (R1), R2, R3, and ending with the most remote location, fully rural (fR).[35] Secondary factors include nine items from three main categories: health services, environmental factors, and education.[36] Based on field experience, a form with a point system was devised whereby actual conditions as assessed and recorded at field locations correlate to points, which in turn correlate to a range of possible identities (from U1 to fR). Points were assessed separately in each of the three main categories of health, education, and environmental factors and combined into one score, which was used to confirm or challenge the preliminary determination of place identity as per the primary factor of distance. In cases where secondary factors clearly portrayed place identity other than that assessed by distance (primary factor), the preliminary category assignment was adjusted up or down by one step. Given the city of Antalya's small geographical size and limited issues of accessibility relative to more rural settings, those locations rendered urban were not further broken down into sub-categories (e.g. U1, U2, U3). Only locations rendered quasi-rural or rural were divided into sub-categories.

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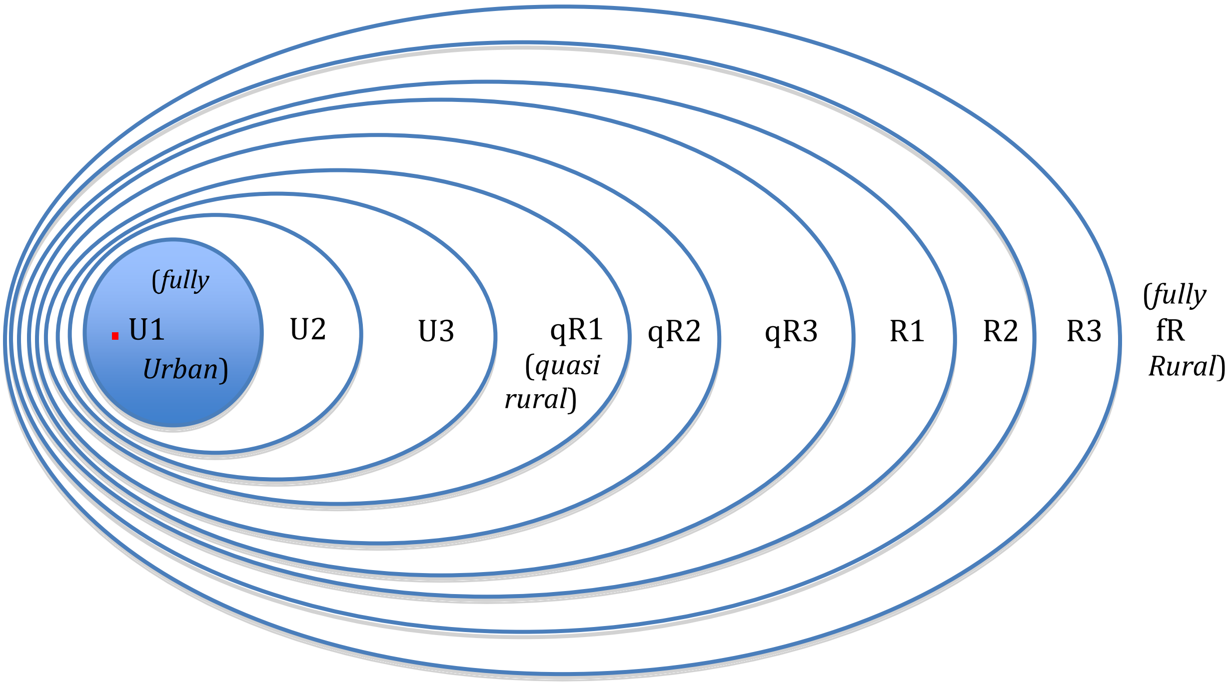
[34] Each of the 19 districts in the province of Antalya has a municipal center wherein medical facilities (of varying capacity), financial institutions, postal service, etc. may be accessed. Thus, for fieldwork carried out in districts far from the city of Antalya, the CUP was measured from a central location in that district's municipal center.

[35] In addition to geographical remoteness, our theoretical classification criteria for fully rural (fR) included residency in an environment without reasonable access to health care, educational institutions, and basic public services such as electricity, sewage treatment and drinking water. We could not identify a location of residency in the province of Antalya that fully fit this classification.

[36] The secondary factors assessment form may be found in Appendix C.



Primary Factor (Distance from CUP)		**Secondary Factors** (Scales & values)	
fR R3 R2 R1	40+ km (+Sec. factors) 40+ km 30-39 km 25-29 km	Health Services	5 points: U1 – U2 3-4 points: U1 – R1 1-2 points: R1 – R3 0 points: fR or R3
qR3 qR2 qR1	20-24 km 16-19 km 12-15 km	Environmental Factors (0-15 points)	13-15 pts.: qR1 – U1 8-12 points: R2 – qR1 1-9 points: R3 – R1 0 points: fR
U3 U2 U1	8-11 km 4-7 km <4 km (from CUP)	Education	3-5 points: R1 –U1 2-4 points: R2 – qR1 1-3 points: R3 – R1 0 points: fR (fully Rural)

Abbreviation Key	Sec. factors = Secondary factors	U = Urban	R = Rural
“▪“=Central Urban Point (CUP)	U1 = fully Urban	qR = quasi-Rural	fR = fully Rural

Figure 13. **Primary and secondary community classification criteria**

5.3.1 Distribution of Respondents According to Environment

Of the 352 households interviewed, 150 were in urban settings, 90 in quasi-rural, and 112 households were in rural environments. An overview of the number of locations (e.g. neighborhoods or villages) and households wherein samples were collected according to urban and non-urban classification are listed in Table 5.

Table 5

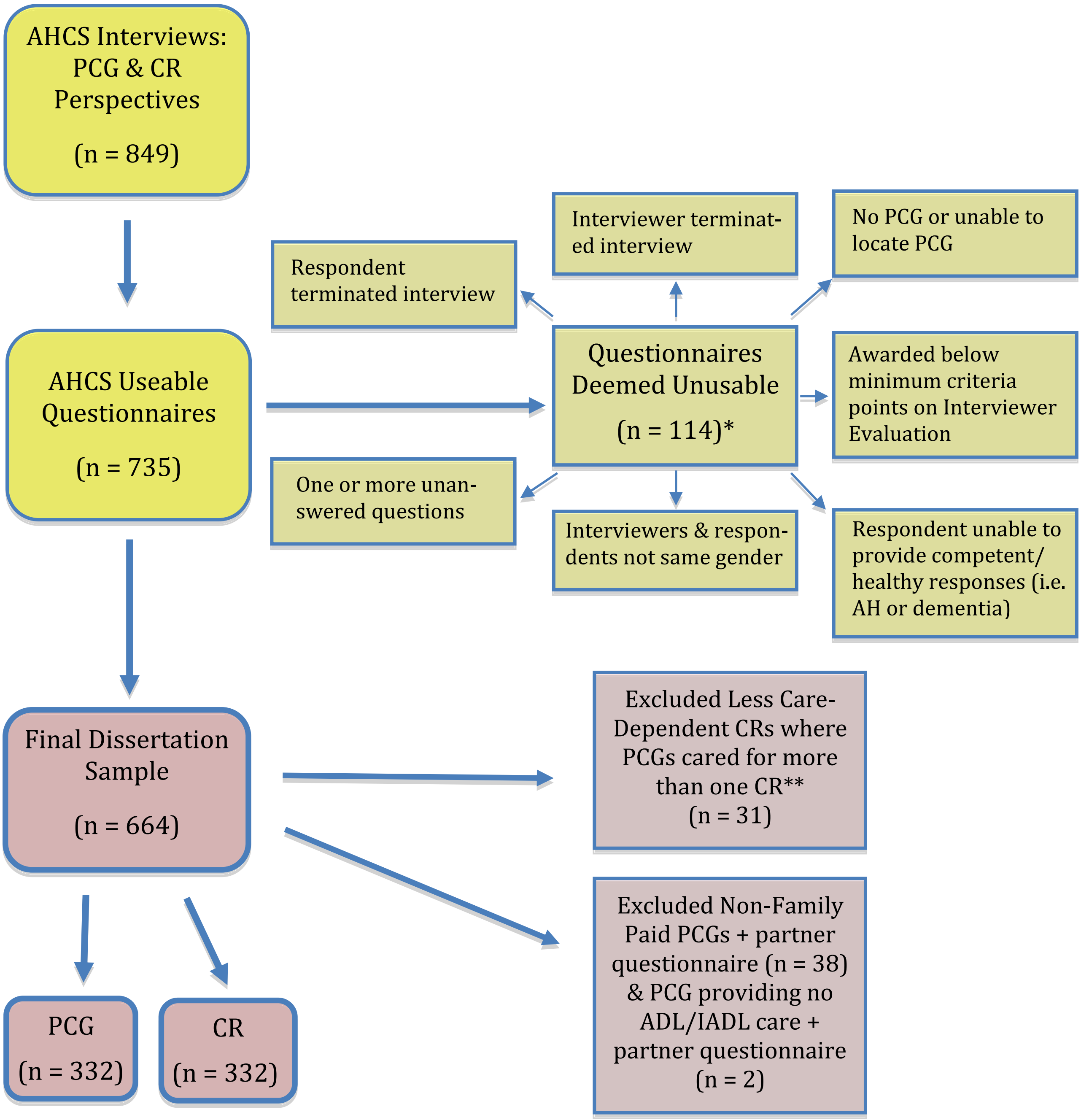
Distribution of Respondents in AHCS According to Environment

Environment Classification	Number of Locations	Number of Households
U sub-Total	**38** (*36*)	**150** (*131*)
qR1	10	40
qR2	12	37 (*36*)
qR3	3	13
qR sub-Total	**25**	**90** (*89*)
R1	7	35
R2	3	11
R3	14	66
R sub-Total	**24**	**112**
Total	**87**(*85*)	**352** (*332*)

Key: “U” = Urban; “qR” = quasi-Rural; “R” = Rural

Note: (a) All figures in *italics* delineate actual numbers included in the sample of this dissertation, and (b) AHCS is an acronym for “Antalya Home Care Survey”

Of the 352 households interviewed, 19 (n = 38) were excluded from the sampling due to the inclusion of non-family paid caregivers and 1 additional household (n = 2) was excluded due to the caregivers not performing any ADLs or IADLs. The updated figures are represented in Table 5 in *italics*. On the next page, *Figure 14* shows in flow chart form the questionnaires excluded from the AHCS, reasons for exclusion, and the remaining proportion of questionnaires included in this study/dissertation sample. A more detailed list of the neighborhoods and villages represented in the AHCS, along with the number of corresponding households and individual interviews may be found in Appendix B.



Key: ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; AH = Alzheimer's; PCG = primary caregiver; CR = care-recipient

Figure 14. **Respondent flow chart and dissertation sample for Antalya Home Care Survey (AHCS)**

* Any questionnaires deemed unusable were excluded together with their partner questionnaire(s)

** In order to be able to compare both perspectives (PCG & CR) at a 1:1 ratio, of all households having two care-recipients, the less care-dependent respondents were excluded from this dissertation sample

5.4 Instrumentation

5.4.1 The Survey Instruments

Distinctly different questionnaires on parallel topics were devised for implementation with care-recipients (CRs) and their caregivers (CGs). Standardized questionnaires consisting of 135 questions for CRs and 176 questions for CGs were employed in this study, in addition to video footage and photos at selected locations and interviews. Topics covered in the two questionnaire types are listed in Table 6.[37] It is worth noting that in this dissertation, only some variables were analyzed. For details of actual questionnaire content, see Appendices F and G.

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[37] Topics are listed as they correlate exactly or in part, with the partner questionnaire. Where no correlation exists with the CG perspective, the adjacent CR item is listed in *italics*.

Table 6

Topics Addressed in Study Questionnaires

CG Perspective	CR Perspective
Demographic profile & general information	Demographic profile & general information
Caregivers' education, experience & income assessment	*Life views measurement*
Environmental perception & CG burden	Ability to meet personal needs (ADL & IADL) measurements (Qc35 only)
Assessment of CG-CR relationship	Assessment of CG, family & institution(s)
CGs' general health	Health condition and hospital evaluation
CGs' attitude & behavior towards senior	-
Satisfaction with institutional support for senior care	-
Adequacy of physical home/ care environment	-
Falls & home accidents	Falls & home accidents
Material & spiritual influences bearing upon CG	Financial/social security
Availability of community resources in meeting seniors medical & social needs	-
Environmental noise & affects on senior	-
Air pollution & effects on senior	-
Government agencies approach to care dependency	-
Views on death and dying	Views on death & dying
Sexuality - assessment of personal & CRs' views	Views on sexuality in old age
Burden of caregiving upon caregiver & impact on family	Care-dependency & impact on family

5.4.2 Evaluation and Modification of the Instruments

Prior to engaging in the pilot project or actual fieldwork, each of the questionnaires was sent to subject experts for review of ethical soundness and changes were made in accordance with their feedback. A pilot study was conducted (but not included in this sample) between February 16, 2009 and March 25, 2009 implementing the prepared questionnaires. Eighty-four interviews (representing approximately 40 dyads) were carried out in predominantly rural but also urban environments in selected districts in the Province of Antalya.[38] A questionnaire for CGs and a separate questionnaire for CRs were tested. Immediately following each outing, interviewers met to discuss perceived strengths and weaknesses of the instruments for purpose of refinement. Between March and mid-April, 2009, questionnaire content was further debated by staff and students of the Gerontology Department at Akdeniz University, together with a handful of invited academics and the members of the fieldwork team. Equipped with insights from the pilot study, a series of meetings totaling some 20 hours was required to debate and refine the soundness and wording of the questionnaires.

Among the most important observations made during the pilot study was the need to develop a system for pairing and identifying questionnaires. The following identification system (*Figure 15*) was developed and printed at the top of the first page of both CR and CG questionnaires for interviewers to fill out for each interview.

S/C	Environ	District	County/Village	Interviewer	Interview #
2					

Figure 15. **Questionnaire identification system for Antalya Home Care Survey – Part 1**

From left to right, the term S/C refers to Senior or Caregiver with the former identified with a “1” and the later a “2”. Each interview was carried out in one of

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[38] Assuming lower rates of education among rural versus urban residents, we deemed rural locations the ideal location to test comprehension of questions related to word selection as well as relevance of topics of inquiry and appropriateness of answer keys.

three environments; urban, quasi-rural, and rural were assigned the numbers "1","2", and "3" respectively.[39] Because research was restricted to Antalya, each of the Province's 19 districts was assigned a number from 1 to 19 and the number entered for the corresponding district.[40] Each county (or neighborhood) and village wherein fieldwork was carried out was assigned a number from 1 to 89.[41] [42] Every individual who worked as an interviewer was assigned an exclusive number, which was entered under the term Interviewer. Each interviewer was also assigned an exclusive range of interview numbers coinciding with their interviewer number (as depicted in Table 7 below).

Table 7

Example of Interviewer and Interview Number System Employed in Study

Interviewers	Interview Numbers
01 Interviewer A	001 – 010
02 Interviewer B	011 – 020
03 Interviewer C	021 – 030
04 Interviewer D	031 – 040
05 Interviewer E	041 – 050
06 Interviewer F	051 – 060

For example Interviewer D, whom we'll call Yilmaz, was assigned interviewer number 04 and his interview numbers ranged from 031-040. In every case, the person interviewing the CR was considered the lead, and as such his/her interview number was assigned to both his CR questionnaire and to that of the

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[39] Because a set of clear criteria for delineating one environment from another had not been established prior to the commencement of research (and would not be established until more than halfway through fieldwork), this section was left blank and filled in at the time that the criteria had been firmly established and the final assessment for each community had been made.

[40] Research was carried out in 15 of the 19 provinces of Antalya. Those provinces not represented are Kaş and Kale in the west and Gazipaşa and İbradi in the east.

[41] Note: Samplings from just 87 neighborhoods and villages were included due to the exclusion of all samplings from two neighborhoods.

[42] A list of neighborhoods and villages represented in this study may be found in Appendix B.

corresponding CG questionnaire.[43] For the first senior interview of the day, the lead interviewer's first interview number was assigned to his questionnaire. The same interview number was also assigned to the corresponding CG questionnaire. For example, on the first senior questionnaire of the day, Yilmaz put 031 for the interview number and the same number was recorded on the corresponding CG questionnaire. During the same day for all subsequent senior interviews, Yilmaz recorded the next number in the sequence (032, 033, 034, etc.) and that number was also assigned to the corresponding CG questionnaire. Inversely, when interviewing the CG, Yilmaz recorded the interview number of the corresponding lead (CR) interviewer. In this manner, all CR and CG questionnaires were effectively paired. Upon returning to the field the next day, when functioning as the lead interviewer, Yilmaz began with his first number–that is, 031 –once more.

On the first page of all questionnaires, directly under the pairing mechanism explained above, interviewers recorded the name of the village or neighborhood, the date of the interview and time that the interview began on a grid identical to the one in *Figure 16*, below.

Name of Village/County	
Interview Start Time	
Date	/ / 2010

Figure 16. **Questionnaire identification system for Antalya Home Care Survey – Part 2**

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[43] In households where two CRs were present, the most care-dependent CR was identified and assigned the lead status meaning all three questionnaires were assigned the corresponding interview number.

Directly below this, space was provided for interviewers to record notes, whether respondent quotations, comments or insights considered worthy of highlighting, additional information not otherwise recorded in the questionnaire, or interviewer comments or impressions related in some way to the respondent or interview environment. At the bottom of the first page, a statement explaining the project's purpose and right of the respondent to terminate the interview at any time was read by the interviewer verbatim or otherwise communicated to the respondent prior to implementing the questionnaire [See Appendix E for a copy of the actual statement].

At the conclusion of each interview, interviewers immediately completed an Interviewer Evaluation Form[44] identical to the form found in *Figure 17*.

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[44] Apart from a few minor alterations, with appreciation the principal investigator acknowledges that the content and design of this Interviewer Evaluation Form was borrowed from Dr. Özgür Arun.

S. INTERVIEWER EVALUATION

To be filled out by Interviewer

Interview end time	
Interview duration	___ hrs. ___ min. [s177]

S1. *During the actual interview was there any individual (family or non-family) in close proximity to the respondent ?* [s178]1.Yes 2. No

S2. What were the terms of completion: [s179] 1. Whole 2. Omission 3. Partial

If omission, portion omitted: ______
If partial, last question completed: ______

Reason uncompleted (explanation):

……

Evaluate this interview according to the criteria below.

S3. *Criteria*	*Good*	*Medium*	*Poor*
Friendliness of respondent [s180]	3	2	1
Percentage of questions completed [s181]	3	2	1
Interview environment [s182]	3	2	1
Sincerity of interview responses [s183]	3	2	1
Approach to questions [s184]	3	2	1
Comprehension ofquestions[s185]	3	2	1

To be completed by those to whom it pertains

	First & last name	*Date*	*Time*
Interviewer			
Field Controller			
Data entry personnel			

Notes:

Figure 17. **Interviewer evaluation form for the Antalya Home Care Survey**

The literature indicates that “rural elders compared to their urban counterparts are (...) less educated, (...) and more likely to live in substandard housing” (Bull, Krout, Rathbone-McCuan, & Shreffler, 2001, p.357). Based on the literature and confirmation through observations in the pilot study, it was determined that results from the six items under "S3 Criteria" and one item[45] under "S1" in the Interviewer Evaluation form above should constitute an aggregate point scale evaluated according to location of the interview.[46] Criteria maintains that of the possible 20 points attainable from both CR and CG Interviewer Evaluations, the aggregate score from the combined seven items in urban-based locations need be 11 points or higher, and 10 points or higher in both quasi-rural and rural locations. In comparison to their urban counterparts, greater leeway was accorded to quasi-rural and rural-based locations due to the increased likelihood of lower (poor) ratings from either or both of the questions s182 and s185 addressing housing situation and educational attainment.

5.5 Interviewers

Between April 25, 2009 and March 11, 2010, a total of 23 (6 male and 17 female) interviewers took part in post-pilot fieldwork. Initial plans for a fieldwork quality control mechanism included having designated field controllers do random face-to-face post-interview visits with respondents (both CRs & CGs). This plan, however, was abandoned due to the decision to collect neither names nor addresses of the participants in an effort to protect their identity. Quality control, pertaining to interviewers and the quality and thoroughness of their work, was monitored by several means. Firstly, theoretical[47] and on-the-job training[48] was provided to 11 of the 23

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[45] This question inquires, "During the interview was there any individual in close proximity to the respondent?" and confers 1 point for "Yes" and 2 points for "No". "No" is assigned to all interviews wherein the respondent and interviewer were alone for more than half the duration of the interview including sensitive questions such as views on death & dying and sexuality.

[46] Note: S2. (s179) was not included in the aggregate point scale because this item is re-addressed and essentially included in question s181 of the 6-item scale.

[47] The first group of interviewers received 5-6 hours of interviewer training in a classroom environment.

interviewers who took part in field work. Each of the remaining 12 interviewers were recruited and trained at various points throughout the fieldwork continuum. Their training consisted of review of the questionnaires, participation in mock interviews[49], observation of actual interviews, assisting seasoned interviewers by recording responses and, when deemed ready, carrying out interviews on their own. Secondly, based on the self-imposed project criteria to exclude all questionnaires and their partner questionnaire that had one or more unexplained missing responses, prior to physically leaving every village or neighborhood the principal investigator personally reviewed every item of every completed questionnaire[50] for questionnable content or missing data, so that as needed, amends could be made[51] and the questionnaire saved from the reject pile. Thirdly, early on in the fieldwork, the principal investigator based on personal observations and interviewer feedback, constructed an interviewer guidebook documenting sometimes misunderstood questions, additional instructions or needed reminders and pointers deemed valuable for carrying out interviews. Each interviewer was given a copy of this guidebook, required to read it and encouraged to have it accessible in the field should it be needed. Fourthly, the fieldwork team consisting on average of 5 to 6 persons, traveled in one vehicle and worked in the same neighborhood or village, having regular contact with the principal investigator. Lastly,

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[48] Experienced interviewers who had participated in the pilot project mentored newcomers during the first one to two fieldwork outings serving as examples for observation and providing oversight during initial implementation of questionnaires.

[49] Not all interviewers participated in mock interviews due to time constraints.

[50] This is true for all interviews carried out after June 1, 2009.

[51] For example, if review of a given questionnaire uncovered a missing response, the interviewer was then afforded the opportunity to return to the respondent and ask the overlooked question.

meticulous review and comparison of data entered into the SPSS database served as a valuable form of quality control.[52]

5.6 Data Collection Process

In urban settings, the initial plan was to obtain interviews using a rendezvous method where a select member(s) of the field team went out into the targeted neighborhood in advance of the field team and with the assistance of the provincial elections committee list[53], located potential candidates, establishing a rendezvous with willing dependent older adults and their caregivers for the next day. Very early on, however, this method was found to be inefficient. In its place, a convenience sampling approach was adopted where the field team, with the assistance of the provincial elections committee list, randomly went door-to-door in an effort to locate and obtain candidates to interview on the spot.

When doing research in non-urban locations, the assistance of the local *elected village headman* (muhtar) was sought out. A designated member of the field team explained to the headman the purpose of the study and type of respondent sought. The headman or one of his assistants (aza) in turn would accompany the field team, by foot or by vehicle, to appropriate households (e.g. having a care-dependent older adult and primary caregiver). An introduction of the purpose of the research was made by the headman and/or designated member of the field team. Where potential respondents were found willing to participate, an informal verbal assessment of the CRs cognitive intactness was made by asking several simple questions such as age or year of birth, number of children, and years of residency in present home. All interviews were carried out in the care environment (e.g. home of the CR or CG) and only with those CRs who were judged to have mental faculties sufficient to reliably respond to the

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[52] Those familiar with SPSS software will be aware of the internal checks and balances that it offers.

[53] This list included the name, age, and address of residents throughout the province of Antalya.

questionnaire. Additionally, interviews were carried out only where both CRs and their primary CGs were present and willing to be interviewed. Interviews were conducted face-to-face and every effort was made to see that no other person besides the respondent was present during the duration of the interview. All interviews were conducted in Turkish, except in a few cases (n = 3 households) where the CR (as well as the CG in one household) did not know Turkish.[54] In each of these instances, a bi-lingual family member served as a translator. Informed consent was attained from all participants in the study. Signed consent forms were obtained in instances where photographs or video footage was taken. The average CG and CR questionnaires took approximately 32.5 and 30 minutes respectively to conduct,[55] as presented in Table 8.

Table 8

Questionnaire Evaluations for the Antalya Home Care Survey: Interview Duration - Minutes

Caregiver Perspective (*N* = 352)		Care-Recipient Perspective (*N* = 383)	
Mean	32.489	Mean	29.932
Median	30.000	Median	29.000
Mode	30.00	Mode	30.00
Std. Deviation	9.876	Std. Deviation	11.062

Due to the inclusion of sensitive topics such as incontinence, views on sexuality and perception of personal security (Arcury, Bell, & Carlton-LaNey, 1998) in the questionnaires, it was deemed prudent in line with Arcury and associates that female CR and CG respondents be interviewed by female interviewers only and male respondents solely by male interviewers.

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[54] In two households the CRs only spoke Kurdish while in one household both the CR and CG only spoke Arabic.

[55] Calculations based on the whole sample from the AHCS.

5.7 Research Model with Components

Based on a modified model of Esther Iecovich (2011), *Figure 18*(below) sums up the most relevant variables identified in this study related to caregiver burden.

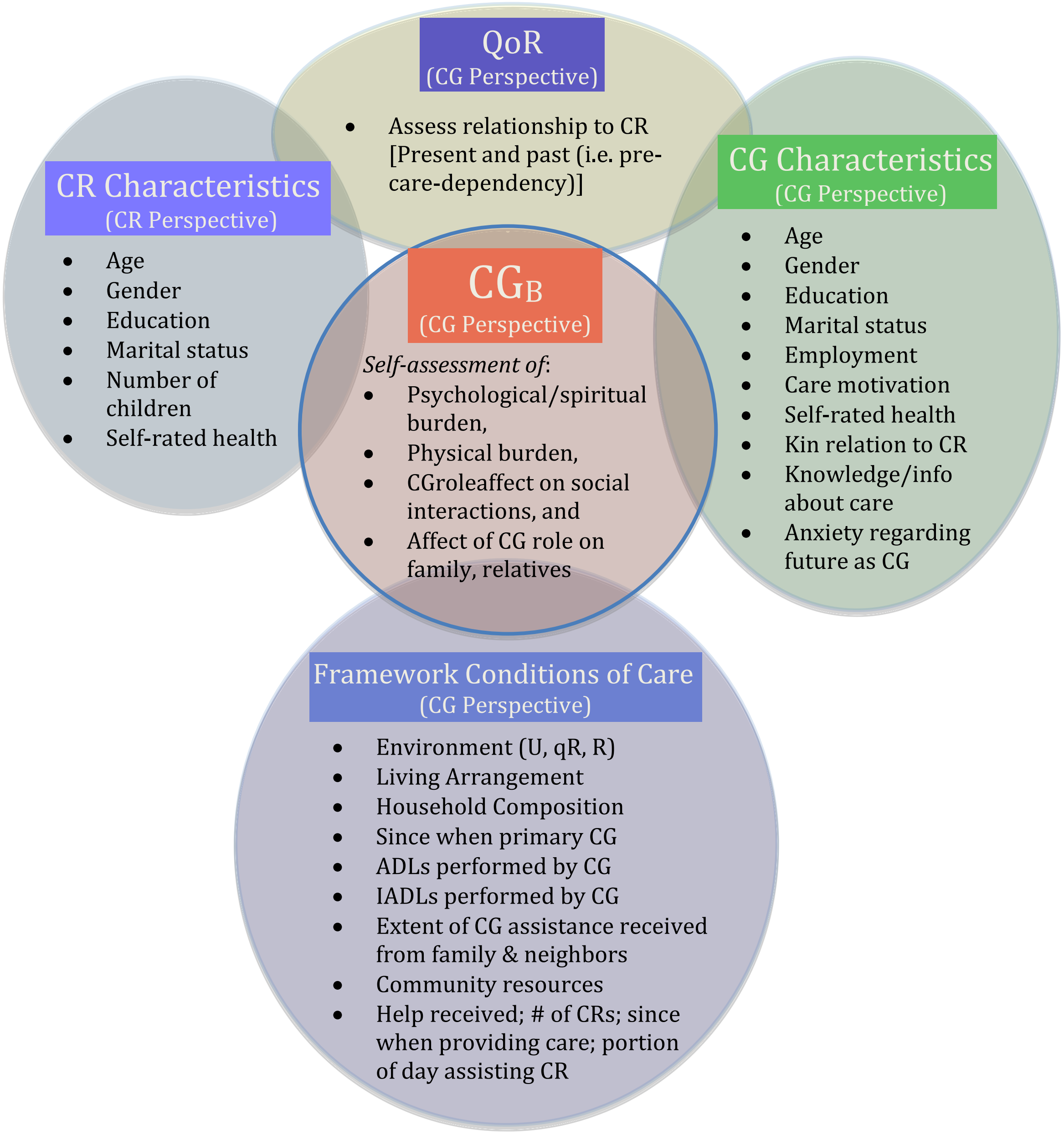

Figure 18. **Research model with summary of caregiver burden components**

CHAPTER 6

DATA ANALYSIS

6.1 Dependent and Independent Variables

Dependent variables (DV) used to construct caregiver burden in the study included psychological/spiritual, social, and physical indicators of burden including psychological/spiritual health, the affect of the CG role on social interactions and on family and relatives, and self-assessment of physical burden. The three components used to construct CG_B were derived from the results of a factor analysis (See 6.3 Construction of CG Burden Measure for details).

Psychological/spiritual burden. Five variables were used to construct this component, namely:

(a) Respondents were asked whether, as a result of caregiving, they were under spiritual/psychological stress. Included five categories (1 = none at all, 2 = no, 3 = sometimes, 4 = yes, 5 = very much).

(b) Respondents were asked how undertaking caregiving affected them spiritually. Included five categories (1 = very positively, 2 = positively, 3 = no affect, 4 = negatively, 5 = very negatively).

(c) Respondents were asked whether they were psychologically/ spiritually unwell. Included two categories (1 = yes, 2 = no).

(d) Respondents were asked if while providing care they'd ever felt angry. Included five categories (1 = exceedingly, 2 = generally, 3 = sometimes, 4 = very seldom, 5 = never).

(e) Respondents were asked whether, in their opinion, caregivers of seniors need psychological counseling. (1 = yes, 2 = no, 3 = I don't know, 4 = perhaps).

Social burden. Three variables were used to construct this component. Respondents were asked how undertaking caregiving affected their (a) social relationships, (b) family relationships, and (c) relationships to their relatives. All three variables included five categories (1 = very negatively, 2 = negatively, 3 = no affect, 4 = positively, 5 = very positively).

Physical burden. Three variables were used to construct this component.

(a) Respondents were asked how undertaking caregiving had affected their physical health. Included five categories (1 = very negatively, 2 = negatively, 3 = no affect, 4 = positively, 5 = very positively).

(b) Respondents were asked during what portion of the day, in general, they need to be at their senior's side. Included ten categories (1 = morning, 2 = afternoon, 3 = evening, 4 = all day, 5 = morning-afternoon, 6 = morning-evening, 7 = morning-afternoon-evening, 8 = there is no set time, 9 = at meals, 10 = afternoon-evening).

(c) Respondents were asked if they have any physical disabilities. Included two categories (1 = yes, 2 = no).

Independent variables (IV) used as control variables included caregiver characteristics, care-recipient characteristics, quality of care, and framework conditions of care. It was deemed helpful that some of the observed variables listed below be recoded. See Appendix D for a listing of recoded variables and justifications.

Caregiver characteristics included indicators such as socio-demographic characteristics, health, employment, kin relation to CR, care knowledge, and anxiety regarding the future as a CG as reported from the caregivers' perspective.

Age. The actual reported age of the CG was entered as is and not into categorical form.

Gender. Included two categories (1 = male, 2 = female).

Education. Included nine categories [1 = I didn't go to school, 2 = reading/writing course, 3 = quit school (no diploma), 4 = night school, 5 = elementary school, 6 = middle school, 7 = high school, 8 = tertiary education/univ., 9 = other].

Marital status. Included 5 categories (1 = married, 2 = single, 3 = separated, 4 = divorced, 5 = widowed).

Employment. Included two categories (1 = yes, 2 = no).

Care motivation. Included six categories (1 = I wanted to, 2 = my family wanted me to, 3 = senior wanted me to, 4 = neighbor wanted me to, 5 = out of obligation, 6 = paid caregiver).

Self-rated health. Included five categories (1 = very good, 2 = good, 3 = neither good nor poor, 4 = poor, 5 = very poor).

Kin relation to CR. Respondents were asked what relation existed between themselves and the senior they provided care for. Included eight categories [1 = spouse, 2 = parent, 3 = parent-in-law, 4 = grandparent, 5 = spouse's grandparent, 6 = other relative (brother, sister, aunt, sister-in-law, etc.), 7 = paid caregiver, 8 = neighbor].

Knowledge/information about care. This measure consisted of three separate variables as follows.

(a) Respondents were asked whether civil institutions (government agencies) provided them with sufficient information on caregiving.
(b) Respondents were asked whether health institutions provided them with sufficient information on caregiving.
(c) Respondents were asked whether there were resources in their immediate community from which they could obtain information on caregiving.

All three variables had 3 categories (1 = yes, 2 = no, 3 = I don't know).

Anxiety regarding future as caregiver. Respondents were asked whether they ever worried about coming to the point where they could no longer continue providing care for their senior. Included five categories (1 = never, 2 = very seldom, 3 = sometimes, 4 = generally, 5 = exceedingly).

Care-recipient characteristics included socio-demographic and health indicators as reported by the care-recipient.

Age. The actual reported age of the CR was entered as is and not into categorical form.

Gender. Included two categories (1 = male, 2 = female).

Education. Included eleven categories [1 = I didn't go to school, 2 = I know how to read/write, 3 reading/writing course, 4 = learned reading/writing in military, 5 = quit school (no diploma), 6 = night school, 7 = elementary school, 8 = middle school, 9 = high school, 10 = tertiary education/university, 11 = other].

Marital status. Included 5 categories (1 = married, 2 = single, 3 = separated, 4 = divorced, 5 = widowed).

Number of children. Based on previous responses and using conditional statements, this measure consisted of three separate variables as follows:

(a) Respondents were asked how many children they still had alive, including children from previous marriages. Secondly,

(b) Respondents were asked how many living children they had from their present marriage. Lastly,

(c) Respondents were asked how many children, at present, were still alive.

The actual numbers of children reported for all three variables were entered as is and not into categorical form.

Self-rated health. Respondents were asked if they could say they are pleased with their health. Included two categories (1 = yes, 2 = no).

Quality of relationship characteristics included an assessment of the present and past (pre-care-dependency) dyadic-care-relationship according to the caregivers' perspective.

Present relationship to CR. Respondents were asked to assess their [present] relationship to their senior. Included five categories (1 = very good, 2 = good, 3 = neither good nor bad, 4 = bad, 5 = very bad).

Pre-care-dependency relationship to CR. Respondents were asked how their relationship with their senior had changed when compared to their pre-care-dependency days. Included seven categories (1 = it's much better, 2 = better, 3 = not changed, 4 = worse, 5 = much worse, 6 = I did not know senior before, 7 = both better and worse).

Framework conditions of care characteristics included environment, living arrangements, extent of CG assistance in ADL/IADL's, extent of assistance received from family and neighbors, and availability of community medical resources from the caregiver's perspective.

Environment (urban, rural, quasi-rural). According to an assessment of primary and secondary determinants, the author labeled each of the completed questionnaires/interviews as having taken place in one of three environment types (1 = urban, 2 = quasi-rural, 3 = rural).

Living arrangements. Respondents were asked whether they live in the same house with their senior. Included two categories (1 = yes, 2 = no).

Household composition. Respondents were asked how many people live in the home in which care is given. Included ten categories (1 to 9 corresponding to a range of one to nine persons, 13 = thirteen persons).

Since when providing care. Respondents were asked how long they have been caring for their senior. Included four categories (1 = number of days, 2 = number of weeks, 3 = number of months, 4 = number of years).

ADLs performed by CG. Respondents were asked with which tasks they assist their senior. Included eleven categories [1 = comb hair, 2 = lay down & raise from bed, 3 = undress and dress, 4 = assist sitting in & standing from chair, 5 = feed food, 6 = take to/from toilet, 7 = bathe, 9 = (If male) shave, 12 = assist going up/down steps, 15 = incontinence-based cleaning, 16 = take outside/bring inside].

IADLs performed by CG. Respondents were asked with which [instrumental] tasks they assist their senior. Included five categories (8 = cook food, 10 =

house cleaning, 11 = dishes & laundry, 13 = shopping, 14 = assist in financial duties).

Extent of assistance received from family. Respondents were asked whether family members assisted them in providing care. Included five categories (1 = exceedingly, 2 = generally, 3 = sometimes, 4 = very seldom, 5 = never).

Extent of assistance received from neighbors. Respondents were asked whether neighbors assisted them in providing care. Included five categories (1 = exceedingly, 2 = generally, 3 = sometimes, 4 = very seldom, 5 = never).

Availability of community resources. Respondents were asked whether they were able to meet their senior's medical needs with the resources available in their community. Included five categories [1 = yes, 2 = partially, 3 = no, 4 = I don't know (paid CG), 5 = senior does not take medication].

Help received. This measure consisted of three separate variables as follows:

(a) Respondents were asked whether, in their family (senior's family), they were the only person who could provide their senior with care. Included three categories (1 = yes, 2 = no, 3 = paid caregiver).

(b) Respondents were asked whether they provide all of the care needs for their senior. Included two categories (1 = yes, 2 = no).

(c) Respondents were asked whether, in the area of caregiving, there was anyone who helped them. Included two categories (1 = yes, 2 = no).

Numbers of CRs. Respondents were asked how many seniors they provide care for. The numerical answer was entered as is.[56]

Portion(s) of day assisting CRs. Respondents were asked during what portion of the day they generally needed to be at their senior's side. Included ten categories [1 = morning, 2 = afternoon, 3 = evening, 4 = all day, 5 = morning-afternoon, 6 = morning-evening, 7 = morning-afternoon-evening, 8 = there is no set time(s), 9 = at meals, 10 = afternoon-evening].

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[56] Numbers of CRs receiving assistance from the CG ranged from 1 to 3.

6.2 Pre-Data Analysis Preparations

Prior to testing the hypotheses, all data was recorded onto SPSS version 20 for Mac. Data entry was performed by four different individuals[57] and checked intermittently on a regular basis by the principal investigator throughout the process for accuracy and internal consistency.[58]

As mentioned previously, the questionnaires and interviews were carried out in the Turkish language. Because the dissertation target language is English, the author translated the questionnaires and key variables in the database from Turkish to English, taking great care to preserve the intended meaning of questions and answer keys.[59]

6.3 Construction of Caregiver Burden Measure

The statistical tool used to measure caregiver burden (CG_B) was constructed from a number of variables recognized in the literature or otherwise identified in the caregiver questionnaire for inclusion in a factor analysis. Prior to doing the factor analysis it was necessary to recode some answer keys for the following two reasons: (1) to change the order of numerical association such that the lower the numerical value, the lower CG_B and conversely the higher the numerical value the higher CG_B, and (2) to consolidate/group responses into more relevant/useful categories (e.g. "very good" and "good" combined to form the response, "good", especially when few "very good" responses were

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[57] In addition to the four individuals, but to a lesser extent, the author also performed some data entry.

[58] At the conclusion of data entry, using a systematic sampling selection method, the author inspected approximately 2,100 combined samples[58] from CG and CR perspectives finding 4 errors in data entries suggesting a data entry reliability rate of over 99.8%.

[59] A copy of the Caregiver and Care-Recipient Questionnaires in English may be found in Appendices F and G.

reported). Recoded variables and their corresponding categories are recorded in Tables 9 and 10.

Tables 9 and 10 (next two pages) identify observed data with original categories and recoded categories where applicable and provide justification for implemented changes.

Table 9

CG BurdenVariables in Original and Recoded Form with Justification - Part 1

Variables	Categories (original)	Categories(RECODED)	Justification
Qb29 As a result of caregiving are you under spiritual/ psychological stress?	1 = None at all, 2 = No 3 = Sometimes, 4 = Yes 5 = Very much	-	-
Qj114 How has undertaking caregiving affected you spiritually?	1 = Very negatively, 2 = Negatively, 3 = No affect, 4 = Positively 5 = Very positively	1 = Very positively, 2 = Positively, 3 = No affect, 4 = Negatively 5 = Very negatively	Lower # value = lower CG_B
Qe46 Are you psychologically/ spiritually unwell?	1 = Yes 2 = No	1 = No 2 = Yes	Lower # value = lower CG_B
Qj108 While providing care, have you ever felt angry?	1 = Exceedingly, 2 = Generally, 3 = Sometimes, 4 = Very Seldom 5 = Never	1 = Never, 2 = Very Seldom, 3 = Sometimes 4 = Generally 5 = Exceedingly	Lower # value = lower CG_B
Qg73 In your opinion, do CGs of seniors need psychological counseling?	1 = Yes 2 = No 3 = I don't know 4 = Perhaps	1 = No 2 = Yes 3 = I don't know	Lower # value = lower CG_B& Few "Perhaps" responses transposed to "Yes"
Qj112 How has undertaking caregiving affected your social relationships?	1 = Very negatively 2 = Negatively, 3 = No affect 4 = Positively 5 = Very positively	1 = Positively 2 = No affect 3 = Negatively 4 = Very negatively	Lower # value = lower CG_B & No "Very positively" responses recorded
Qj115 How has undertaking caregiving affected your family relationships?	1 = Very negatively 2 = Negatively, 3 = No affect 4 = Positively 5 = Very positively	1 = Very positively 2 = Positively, 3 = No affect 4 = Negatively 5 = Very negatively	Lower # value = lower CG_B
Qj116 How has undertaking caregiving affected your relationship to your relatives?	1 = Very negatively 2 = Negatively, 3 = No affect 4 = Positively 5 = Very positively	1 = Very positively 2 = Positively, 3 = No affect 4 = Negatively 5 = Very negatively	Lower # value = lower CG_B
Qc113 How has undertaking caregiving affected your physical health?	1 = Very negatively 2 = Negatively, 3 = No affect 4 = Positively 5 = Very positively	1 = Positively 2 = No affect 3 = Negatively 4 = Very negatively	Lower # value = lower CG_B & No "Very positively" responses recorded

Table 10

CG Burden Variables in Original and Recoded Form with Justification - Part 2

Variables	Categories (original)	Categories(RECODED)	Justification
Qc36 In general, during what portion of the day do you need to be at your senior's side?	1 = morning (*m*), 2 = afternoon (*a*), 3 = evening (*e*), 4 = all day, 5 = *m-a*, 6 = *m-e*, 7 = *m-a-e*, 8 = no set time, 9 = at meals, 10 = *a-e*	1 = 1 portion/day *or* no set time 2 = 2 portions/day 3 = 3 portions/day 4 = All day	Lower # value=lower CG_B& RECODE of ADLs helped decision to transpose "8 = no set time" & "9 = at meals" to appropriate category[60]
Qe45 Do you have any physical disabilities?	1 = Yes 2 = No	1 = No, 2 = Yes	Lower # value = lower CG_B

Because CG burden is comprised of latent variables, a factor analysis was performed to determine the capability of the aforementioned 11 variables to explain burden among caregivers. Results of the factor analysis are recorded in Table 11.

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[60] Using the Recoded version of Qc35 (<7 ADLs, 7 ADLs, and >7 ADLs) as a frame of reference, those respondents responding, "there is no set time" in Qc36 were evaluated as a group and were found to consistently require assistance in <7 ADLs. The decision was made to transpose these responses as "1 portion/day or no set time". All respondents/responses of "at meals" were also evaluated one-by-one and as a group and placed into the appropriate RECODED category as follows: <7 ADLs = "1 portion/day or no set time", 7 ADLs were assigned to "2 portions/day", and >7 ADLs were assigned to the category "3 portions/day".

Table 11

Component Matrix with Factor Loading

Variable (Caregiver Perspective)	Component		
	Psycho/Spiritual Burden	Social Burden	Physical Burden
Qb29 As a result of caregiving are you under spiritual/ psychological stress?	.763		
QRj114 How has undertaking caregiving affected you spiritually?	.652	.444	.221
QRe46 Are you psychologically/spiritually unwell?	.600		
QRj108 While providing care, have you ever felt angry?	.700		
QRg73 In your opinion, do CGs of seniors need psychological counseling?	.399		-.239
QRj112 How has undertaking caregiving affected your social relationships?	.343	.604	
QRj115 How has undertaking caregiving affected your family relationships?		.854	
QRj116 How has undertaking caregiving affected your relationship to your relatives?		.855	
QRj113 How has undertaking caregiving affected your physical health?	.490	.286	.516
QRc36 In general, during what portion of the day do you need to be at your seniors side?			.624
QRe45 Do you have any physical disabilities?			.701

The factor analysis produced three components into which each of the 11 variables naturally clustered and were identified as follows: Psychological/spiritual burden, social burden, and physical burden. The ability of these components to explain caregiver burden is described in the variance figures as listed in Table 12.

Table 12

Percentage of Variance of Caregiver Burden Components

Component	Variance %	Cumulative Variance %
Psychological/Spiritual	31.181	31.181
Social	11.867	43.048
Physical	10.773	53.821

In Table 12, we see that the primary component, psychological-spiritual burden, explains nearly one-third (~31.2%) of caregiving burden, while the social and physical components explain approximately 11.9% and 10.8% respectively. Combined, the three CG burden components explained 53.8% of the variance in caregiver burden.

The descriptive results of the factor analysis according to the three components– psychological/spiritual, social, and physical –are given in Table 13.

Burden was measured within a trajectory and not according to binary logic, because this kind of measurement would not provide sufficient evidence of the variance of the burden. Each burden component retains the specific value for the marginal side of its trajectory. These marginal points are the minimum and maximum values of the burden components and reflect lowest burden (minimum) and highest burden (maximum). So if a respondent registered, for example, a -1.6 on the trajectory, this means that the individual registered less burden than a respondent having a value of 1.2. It should be noted that these measurements refer to dynamic and not static measures for a given caregiver at any point in time, meaning they may move in any direction. So should the conditions that influence burden become better at any point during the care continuum, then theoretically, their location should move toward the lower point along the burden trajectory.

Table 13

Central Tendency of Caregiver Burden Components

N = 332	Psycho/Spir^{TL} Burden	Social Burden	Physical Burden
Mean	.000	.000	.000
Std. Deviation	1.000	1.000	1.000
Range	4.810	8.781	6.104
Minimum	-1.795	-3.670	-1.701
Maximum	3.015	5.111	4.403

Among the results of the analysis, which are recorded in Table 13, it can be seen that the distribution of the burden components have a normal distribution – which is essential for the assumption of basic parametric tests such as t-test and ANOVA. The minimum value of the psycho-spiritual burden component is –1.795 and the maximum value is 3.015. The minimum value of the social burden component is -3.670 and the maximum value is 5.111. Lastly, the minimum value of the physical burden component is -1.701 and the maximum value is 4.403.

Based on the results of the factor analysis, the theoretical model for the study was modified to include the three components of caregiver burden, as illustrated in the outer concentric circle below in *Figure 19.*

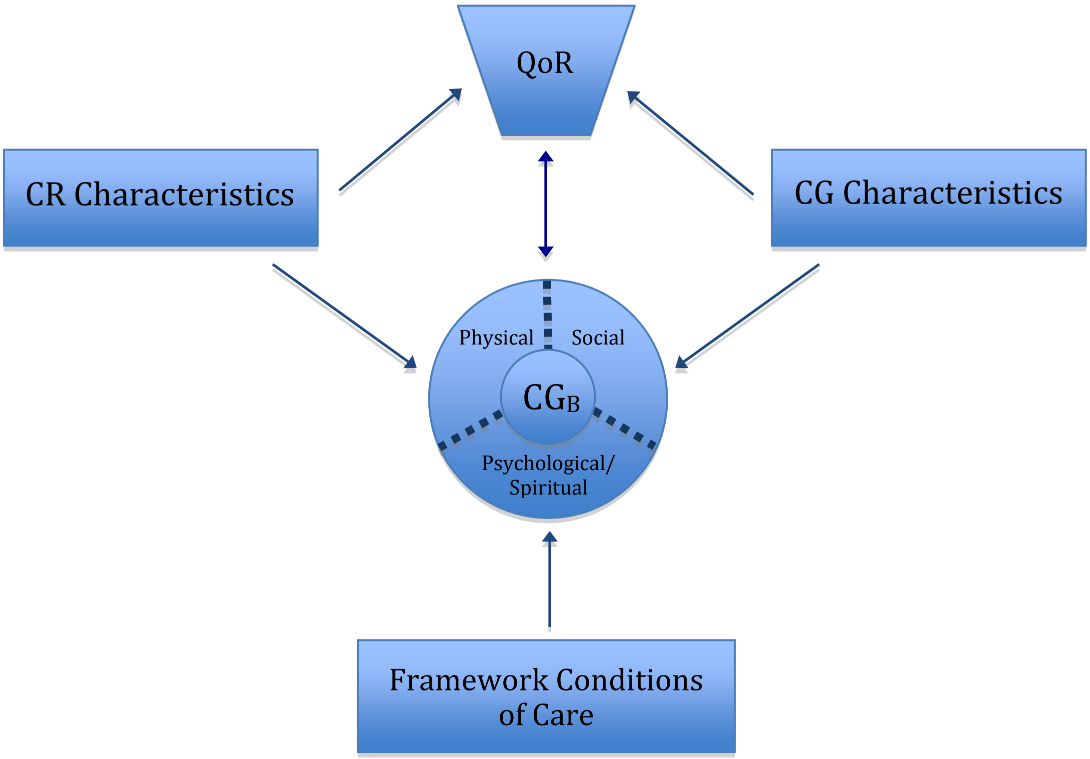

***Figure 19.* Theoretical research model with caregiver burden components**

In this study, a factor analysis (See Table 11) was performed to extract components of burden, while the Chi-Square test was employed to analyze whether a significant difference exists between economic burden and ten other caregiver characteristics with respect to environment type. Finally, the t-test and ANOVA were performed to test the hypotheses.

6.4 Caregiver Characteristics: Caregiver Burden and Environment Type

Due to its distinctly material nature, a variable measuring economic burden was not included in the caregiver burden factor analysis, but is addressed separately in a descriptive manner. *Though outside of the primary focus of this study, the economic implications of caregiving on caregivers is among the most important of issues requiring attention by researchers, governments, and policy makers at the national and international level.* This analysis provides us with a glimpse into the possible variations of economic impact on caregivers in different environments as a result of their informal caregiving role. Furthermore, this analysis represents a small but important evidence for an economy-CG burden relationship that may be used as a baseline for further study with a broader focus on the economy.

The statistical findings for caregiver responses to the question, "How has undertaking caregiving affected you economically?" [Very positively, Positively, No affect, Negatively, Very negatively], are incorporated into Table 14 below.

Table 14

Economic Burden on Caregivers by Environment

Affect	∑ (Total)	Urban	q-Rural	Rural
Very positively	0.3% (1)	0.8% (1)	0.0% (0)	0.0% (0)
Positively	1.2% (4)	2.3% (3)	0.0% (0)	0.9% (1)
No affect	69.0% (229)	61.1% (80)	80.9% (72)	68.8% (77)
Negatively	24.7% (82)	26.7% (35)	16.9% (15)	28.6% (32)
Very negatively	4.8% (16)	9.2% (12)	2.2% (2)	1.8% (2)
Total	100% (332)	100% (131)	100% (89)	100% (112)

$\chi^2 = 18.597$ $df = 8$ $p = .017$

According to the Chi-Square test, there is a significant difference (χ^2 = 18.597; df = 8; p = 0.017) between the three environments with regard to economic burden. Some 35.9% of urban-based caregivers reported negative economic burden (i.e. sum of “negatively” and “very negatively”), compared to 19.1% of quasi-rural, and 30.4% of rural caregivers, as a result of undertaking caregiving responsibilities. Of these, 9.2% of urban caregivers reported being very negatively affected with regard to economic burden while roughly 2% of quasi-rural and rural respondents reported the same. From the reverse perspective, four respondents (representing 3.1%) of urban caregivers reported caregiving to have had a positive (i.e. sum of “very positively” and “positively”) affect on their economic situation while just 1 respondent (or 0.9%) and no respondents (0.0%) from among rural and quasi-rural respondents, respectively, reported caregiving to have affected their economic position in a positive way. Further details related to the statistical analysis may be obtained from Table 14.

As an objective measure, *caregiver income* is of particular interest as a control variable to weigh against the subjective results of the previous measure of economic burden. For this reason, caregiver income is also analyzed and addressed below.

Chi-Square test results for caregiver responses to the question, “Approximately how much do you earn a month? (denote personal income – *Write exact number*)“ were recorded in exact numbers/amount but also entered as one of the following categories [None, < 200 TL, 200-400 TL, 401-600 TL, 601-800 TL, 801-1000 TL, > 1000 TL], and later calculated according to the Euro currency and as such incorporated into Table 15.

Table 15

Caregiver Income by Environment – Calculated in Euros/monthly

Income (monthly/Euros)[61]	∑ (Total)	Urban	q-Rural	Rural
None	62.5% (207)	38.2% (50)	77.5% (69)	79.8% (88)
<100	4.8% (16)	5.3% (7)	3.4% (3)	5.4% (6)
100-279	14.8% (49)	22.1% (29)	11.2% (10)	9.0% (10)
280-465	12.4% (41)	22.1% (29)	6.7% (6)	5.4% (6)
>465	5.4% (18)	12.2% (16)	1.1% (1)	0.9% (1)
Total	100% (331)	100% (131)	100% (89)	100% (111)

$\chi^2 = 64.22$ $df = 8$ $p = .0001$

A significant difference in physical environments was found relative to caregiver income ($\chi^2 = 64.22$; df = 8;$p = 0.0001$). Less than two in five caregivers in urban areas (38.2%) reported having no personal income compared to nearly four in five caregivers in rural (79.8%) and quasi-rural (77.5%) areas. Caregivers in urban settings were nearly five times more likely to earn 280 or more Euros per month than caregivers in rural settings and one in twelve urban caregivers earned in excess of 465 Euros monthly compared to just one in one hundred caregivers in rural settings. This may be primarily a result of higher education attainment among female urban caregivers compared to rural caregivers as well as more work opportunities available in urban compared to rural settings. Additionally, according to statistical analysis of caregivers reporting on

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[61] Original responses were in Turkish Lira (TL). These figures were converted into Euros (€) based on Turkey's Central Bank exchange figures (accessed June 11, 2012 on http://www.isyatirim.com.tr/p_exchange_avarege.aspx) calculated for the period April 2009 – March 2010 TL (data collection period) by taking the average exchange rate for each of the 12 months, adding them together and dividing by 12 to produce an overall average exchange rate of 1€ = 2.1424TL. Actual rates compared with the TL figures represented in Euros above are as follows: 100€ = 93.35€; 279€ = 280.06€; 280€ = 280.53€; 465€ = 466.80€.

availability of care assistance[62], more rural caregivers (59.8%) compared to urban caregivers (49.6%) reported that there was no one to help them in the provision of care. Thus, it is plausible that a lack of available assistance in sharing caregiving responsibilities in rural compared to urban environments may contribute to lower levels of gainful employment and thus to lower levels of income, including no reported income, among rural caregivers.

Understanding the association between a given environment (i.e. urban, quasi-rural and rural) and the affect on level of burden experienced by community-dwelling-caregivers is pertinent to the development of effective strategies and policies to moderate burden. Therefore, in addition to economic burden on caregivers, additional analyses for select caregiver characteristics were carried out using the Chi-Square test to see whether a significant association exists according to environment type. Caregiver characteristics analyzed include caregiver: (a) motivation to care, (b) self-rated health, (c) present dyadic QoR, (d) pre-care dependency QoR comparison to present QoR, (e) kin relationship to CR, (f) sufficiency of knowledge of government assistance, (g) sufficiency of knowledge of health institution-based assistance, (h) availability of community-based assistance to caregivers, (i) anxiety of future, and (j) monthly income.[63] Findings for the first four variables (i.e. motivation, self-rated health, and the two dyadic QoR variables) are directly related to a corresponding hypothesis, and as such, are displayed separately in Table 16, accompanied by a description

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[62] Results of this calculation/analysis are not represented beyond the verbal description offered here.

[63] Caregiver characteristics were analyzed in accordance to responses gathered from questions in the Caregiver Questionnaire (in Appendix F) corresponding to the following questions: Motivation – RB26; Self-rated health – RE43; QoR – RD41 & RD42; Kin Relationship – RB20; Knowledge/info about care – g70, g71, & g72; Anxiety of future – RJ110; Income – RB17.

Table 16

Caregiver Characteristics and Affect on Caregiver Burden by Environment: Research-Question-Related-Variables

Motivation (*affect*)	Σ (Total)	Urban	q-Rural	Rural
Self-imposed	92.2% (306)	89.3% (117)	95.5% (85)	92.9% (104)
Other-imposed	7.8% (26)	10.7% (14)	4.5% (4)	7.1% (8)
Total	100% (332)	100% (131)	100% (89)	100% (112)
χ^2 = 2.93	*df* = 2			*p* = .231

Self-rated health	Σ (Total)	Urban	q-Rural	Rural
*Good***	38.9% (129)	38.2% (50)	46.1% (41)	33.9% (38)
Neither good nor bad	23.8% (79)	18.3% (24)	20.2% (18)	33.0% (37)
*Bad****	37.3% (124)	43.5% (57)	33.7% (30)	33.0% (37)
Total	100% (332)	100% (131)	100% (89)	100% (112)
χ^2 = 10.26	*df* = 4			*p* = .036

Quality of Relationship (QoR): Present	Σ (Total)	Urban	q-Rural	Rural
*Good*****	84.0% (279)	85.5% (112)	83.1% (74)	83.0% (93)
Neither good nor bad	13.9% (46)	11.5% (15)	14.6% (13)	16.1% (18)
Bad	2.1% (7)	3.1% (4)	2.2% (2)	0.9% (1)
Total	100% (332)	100% (131)	100% (89)	100% (112)
χ^2 = 2.38	*df* = 4			*p* = .666

Quality of Relationship (QoR): Pre-dependency vs. present	Σ (Total)	Urban	q-Rural	Rural
*Better******	7.8% (26)	11.5% (15)	6.7% (6)	4.5% (5)
*Not changed*******	75.3% (250)	66.4% (87)	79.8% (71)	82.1% (92)
*Worse********	16.9% (56)	22.1% (29)	13.5% (12)	13.4% (15)
Total	100% (332)	100% (131)	100% (89)	100% (112)
χ^2 = 9.82	*df* = 4			*p* = .044

* ∝ = .05; ***Good = Sum of "Very good" and "Good"*; ****Bad = Sum of "Very Poor" and "Poor"*; *****Good = Sum of "Very good" and "Good"*; ******Better = Sum of "It's much better" and "Better"*; *******Not changed = Sum of "Not changed", "I did not know senior before" and "Both better and worse"*; ********Worse = Sum of "Much Worse" and "Worse"*

of the findings. Findings for the later six variables are displayed in Table 17, and likewise are accompanied by a description of the findings. Corresponding to the results shown in Table 16, a significant association was found between environment type and self-rated health and pre-care-dependency QoR compared to present dyadic QoR, while no significant association was found between environment type and caregiver burden for motivation and present dyadic QoR. Details of these findings are recorded in the proceeding text and in Table 16.

No significant difference was found in physical environments regarding motivation for care, whether self-imposed or other-imposed (χ^2 = 2.93; df = 2; p = 0.231).

There was a significant difference in physical environments regarding self-rated health (χ^2 = 10.26; df = 4; p = 0.036). Nearly one-in-two (46.1%) quasi-rural caregivers reported their health to be good, compared to roughly one-in-three (33.9%) in rural environments. This may be due, in part, to the comparatively more sedentary life style observed in many of the economically depressed non-farming rural areas compared to the more active quasi-rural areas where greenhouses, in particular, are widely used in the growing of produce.[64] Age may also be a factor as results from this study show the typical primary caregiver in quasi-rural areas to be younger [$\bar{x}$ = 47.1] compared to the rural primary caregiver [$\bar{x}$ = 49.6]. The percentage of primary caregivers rating their health as bad or poor was roughly 10% higher in urban versus rural environments. Perhaps higher levels of education and higher expectations, in general, lend to a higher percentage of poor self-assessments of health among urban caregivers. While no significant difference was found in physical environments related to caregivers' assessments of present quality of

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[64] As of 2008, some 59.3% of vegetables raised in Turkey's greenhouses were produced in the province of Antalya (Toksöz, 2011).

relationship (QoR) to care-recipients (χ^2 = 2.38; df = 4; p = 0.666), a significant environment-based difference was found in caregivers' assessment of QoR regarding pre-dependency versus present relationships with care-recipients (χ^2 = 9.82; df = 4; p = 0.044). Fewer urban caregivers, roughly two out of three compared to approximately four out of five rural caregivers, 'sat on the fence' on this issue. Urban caregivers were nearly two-times more likely to report that their present relationship to care-recipients had changed for the better (11.5%) or for the worse (22.1%).

Findings from other caregiver characteristics, as represented in Table 17, suggest a significant association between environment type and caregiver burden for kin relationship (between caregiver and care-recipient), anxiety regarding the future (as a caregiver), and caregiver income. On the other hand, no significant association was found between environment type and caregiver burden with respect to the remaining variables, namely, assessed sufficiency of civil agencies provision of adequate care information, assessed sufficiency of health institutions provision of adequate care information, and assessed availability of resources in providing care information in the immediate community. The details of findings for other caregiver characteristics related to relationships between environment type and caregiver burden may be found in Table 17 and in the proceeding text.

A significant difference between physical environments was found in kin relationships reported among caregivers and care-recipients (χ^2 = 48.60; df = 8; p = 0.0001). A far lesser percentage of caregivers reported caring for a spouse in quasi-rural areas (5.6%) compared to urban and rural areas (29.8% and 25.9% respectively). While adult children were the most prolific in urban

Table 17

Other Caregiver Characteristics and Affect on Caregiver Burden by Environment

Kin Relationship (*affect*)	Σ (Total)	Urban	q-Rural	Rural
Spouse	22.0% (73)	29.8% (39)	5.6% (5)	25.9% (29)
Parent	32.2% (107)	41.2% (54)	29.2% (26)	24.1% (27)
Parent-in-law	38.6% (128)	19.8% (26)	61.8% (55)	42.0% (47)
Other (relative/neighbor)	6.6%/0.6% (22)/(2)	8.4%/0.8% (11)/(1)	3.4%/- (3)/(-)	7.1%/0.9% (8)/(1)
Total	100% (332)	100% (131)	100% (89)	100% (112)
$\chi^2 = 48.60$	*df* = 8			*p* = .0001
Civil agencies provision of adequate care-giving information	Σ (Total)	Urban	q-Rural	Rural
Yes	5.8% (19)	8.5% (11)	3.4% (3)	4.5% (5)
No	94.2% (310)	91.5% (119)	96.6% (85)	95.5% (106)
Total	100% (329)	100% (130)	100% (88)	100% (111)
$\chi^2 = 2.96$	*df* = 2			*p* = .228
Health institutions provision of adequate caregiving information	Σ (Total)	Urban	q-Rural	Rural
Yes	10.0% (33)	10.7% (14)	9.0% (8)	9.9% (11)
No	90.0% (298)	89.3% (117)	91.0% (81)	90.1% (100)
Total	100% (331)	100% (131)	100% (89)	100% (111)
$\chi^2 = 0.17$	*df* = 2			*p* = .918
Availability of resources (caregiving information) in immediate community	Σ (Total)	Urban	q-Rural	Rural
Yes	6.6% (22)	7.6% (10)	7.9% (7)	4.5% (5)
No	93.4% (309)	92.4% (121)	92.1% (82)	95.5% (106)
Total	100% (331)	100% (131)	100% (89)	100% (111)
$\chi^2 = 1.24$	*df* = 2			*p* = .538
Anxiety of future as caregiver	Σ (Total)	Urban	q-Rural	Rural
*Yes ***	39.5% (131)	42.0% (55)	34.8% (31)	40.2% (45)
Never	60.5% (201)	58% (76)	65.2% (58)	59.8% (67)
Total	100% (332)	100% (131)	100% (89)	100% (112)
$\chi^2 = 17.81$	*df* = 8			*p* = .027

* ∝ = .05; ** *Yes* = Sum of “Very seldom”, “Sometimes”, “Generally”, or “Exceedingly”

environments (41.2%), daughters-in-law[65] clearly comprised the largest group of caregivers among quasi-rural and rural settings (61.8% and 42.0% respectively). No significant difference was found between physical environments regarding reported sufficiency of information about care among government agencies ($\chi^2 = 2.96$; df $= 2$; $p = 0.228$), health institutions ($\chi^2 = 0.17$;df $= 2$; $p = 0.918$), or the availability of care information in immediate communities ($\chi^2 = 1.24$; df $= 2$; $p = 0.538$). There was a significant difference in levels of anxiety of the future as a caregiver between physical environment types ($\chi^2 = 17.81$; df $= 8$; $p = 0.027$). Some 42.0% of urban caregivers reported worrying that at some point in the future they would not be able to care for their care-recipient, compared to a slightly lower percentage in rural (40.2%), and the lowest percentage in quasi-rural (34.8%) environments.

In the following section, sub-section 6.5, the research questions are addressed through the analysis of the additional hypotheses using t-test and ANOVA.

In summary, eleven variables among caregiver characteristics were tested to determine whether a significant association exists based on environment type. Of the variables analyzed, Chi-Square tests found six variables significantly related to environment type, namely, (a) economic burden, (b) caregiver income, (c) kin relationship, (d) anxiety of future, (e) self-rated health, and (f) past-present comparison of dyadic QoR. On the other hand, Chi-Square test results suggested no significant association to environment type for the following five variables: (*a*) motivation, (*b*) present dyadic QoR, (*c*) sufficiency of civil agencies provision of adequate care information, (*d*) sufficiency of health institutions provision of adequate care information, and (*e*) availability of resources (care information) in immediate community.

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[65] While one in ten CGs in this studies data set were male, only one male CG was caring for an in-law, and this particular CG was in an urban environment. Thus, all PCGs caring for a parent-in-law in q-rural and rural settings were female.

6.5 Results from Caregiver Samples Regarding Research Questions

6.5.1 Caregiver-Characteristics-Related Results

Note: The higher the Mean ($\bar{x}$) score the higher caregiver burden (CG_B) and the lower the $\bar{x}$ score the lower CG_B. Additionally, all references in sub-section 6.5 to *caregivers* are synonymous with *primary family caregivers*.

Hypothesis 1a: Older caregivers experience more CG_B *than younger caregivers.*

Table 18: *Level of burden according to age groups (t-Test)*

Burden Type		*N*	Mean	Std. Deviation	Analysis

Psycho/Spiritual	59 or less
	60 and above
		241
		90
			-.058
			.141
				.980
				1.039
					t = -1.618;
					df = 329;
					p = .107

Social	59 or less
	60 and above
		241
		90
			-.012
			.072
				.958
				1.044
					t = -.688;
					df = 329;
					p = .492

Physical	59 or less
	60 and above
		241
		90
			-.100
			.271
				.889
				1.220
					t = -2.633;
					df =125,902;
					p = .010

A significant difference was found between age groups of caregivers according to physical burden (t = -2.633; df = 125,902; p = 0.010) while no significant difference was found for psycho-spiritual burden (t = -1.618; df = 329; p = 0.107) or social burden (t = -.688; df = 329; p = 0.492). Therefore, t-test results indicate that caregivers 60 years of age and older experience more physical burden than younger caregivers.

Hypothesis 1b: Women experience more CG_B than men.

Table 19: *Level of burden according to gender (t-Test)*

Burden Type		*N*	Mean	Std. Deviation	Analysis

Psycho/Spiritual	Male
	Female
		35
		297
			-.383
			.045
				.912
				1.002
					t = -2.415;
					df = 330;
					p = .016

Social	Male
	Female
		35
		297
			-.117
			.014
				.828
				1.019
					t = -.730;
					df = 330;
					p = .466

Physical	Male
	Female
		35
		297
			-.040
			.005
				1.006
				1.001
					t = -.252;
					df = 330;
					p = .802

While there appears to be a general trend of greater burden experienced by female caregivers, only in regards to psycho-spiritual burden (t = -2.415; df = 330; p = 0.016) do female caregivers experience significantly more burden than their male counterparts. Therefore, t-test results indicate that female caregivers experience greater psycho-spiritual burden than male caregivers.

Hypothesis 1c: CGs with higher education experience lower care-induced burden.

Table 20: *Level of burden according to educational attainment (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho /Spiritual	No school/diploma	86	.156	1.053	F = 1.081; df = 331; p = .366
	Elementary (1-5)	197	-.063	.987	
	Middle school (6-8)	17	-.250	.848	
	High school (9-12)	16	.132	1.090	
	Tertiary educ. (12/13+)	16	.078	.902	
Social	No school/diploma	86	-.064	.983	F = 1.896; df = 331; p = .111
	Elementary (1-5)	197	-.004	.954	
	Middle school (6-8)	17	-.356	.469	
	High school (9-12)	16	.285	1.006	
	Tertiary educ. (12/13+)	16	.480	1.719	
Physical	No school/diploma	86	.284	1.170	F = 2.911; df = 331; p = .022
	Elementary (1-5)	197	-.102	.857	
	Middle school (6-8)	17	.127	1.260	
	High school (9-12)	16	-.360	.704	
	Tertiary educ. (12/13+)	16	-.055	1.328	

A significant difference was found related to the levels of educational attainment in terms of physical burden (F = 2.911; df = 331; p = 0.022) experienced by caregivers. In general, caregivers having completed high school or tertiary education (just under 1 in 10 caregivers) experienced less physical burden than those having completed less, and in particular, no education ($\bar{x}$ = 0.284). However, the largest group of caregivers, those completing an elementary education (nearly 3 in 5 caregivers), are a bit of an exception in that they showed comparatively less burden ($\bar{x}$ = -0.102) than the small group of caregivers (n = 16) having completed a tertiary education ($\bar{x}$ = -0.055). Though educational attainment indicates a significant difference in levels of physical burden for caregivers, overall ANOVA figures offer no clear confirmation to support the hypothesis that caregivers with higher education experience lower care-induced burden.

Hypothesis 2: Caregivers who provide care by their own free will experience lower CG_B.

Table 21: *Level of burden according to motivation (t-Test)*

Burden Type		*N*	Mean	Std. Deviation	Analysis

Psycho/ Spiritual	I wanted to
	Family (or someone else) wanted me to
		306
		26
			-.017
			.201
				1.005
				.941
					t = -1.065;
					df = 330;
					p = .288

Social	I wanted to
	Family (or someone else) wanted me to
		306
		26
			-.002
			.018
				.982
				1.216
					t = -.095;
					df = 330;
					p = .924

Physical	I wanted to
	Family (or someone else) wanted me to
		306
		26
			-.006
			.068
				1.010
				.892
					t = -.359;
					df = 330;
					p = .719

No significant difference was found for source of motivation and burden among any of the three types of caregiver burden namely, psycho-spiritual (t = -1.065; df = 330; p = 0.288), social (t = -.095; df = 330; p = 0.924), and physical burden (t = -.359; df = 330; p = 0.719). It will suffice for now to note that the concepts *source of motivation* and *free will* are very difficult to operationalize. This is addressed further in sub-chapter 7.3. In summary, t-test does not indicate that caregivers who provide care by their own free will experience lower caregiver burden than caregivers asked to provide care by their family (or some other individual).

Hypothesis 3: Caregivers who rate their health as poor experience more caregiver burden.

Table 22: *Level of burden according to caregivers' self-rated health (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Good	129	-.358	.764	F = 16,137;
	Neither good nor poor	79	.085	1.028	df = 329;
	Poor	124	.318	1.083	p = .0001
Social	Good	129	-.060	.770	F = .748;
	Neither good nor poor	79	-.037	.894	df = 329;
	Poor	124	.086	1.247	p = .474
Physical	Good	129	-.228	.755	F = 10,951;
	Neither good nor poor	79	-.128	.866	df = 329;
	Poor	124	.319	1.206	p = .0001

A significant difference was found for caregiver self-rated health and psycho-spiritual burden (F = 16,137; df = 329; p = 0.0001) and physical burden (F = 10,951; df = 329; p = 0.0001). On the other hand, no significant difference was identified for self-rated health and social burden (F = .748; df = 329; p = 0.474). Therefore ANOVA results indicate that caregivers who rate their health as poor experience significantly more psycho-spiritual and physical burden.

6.5.2 Dyadic Quality-of-Relationship-Related Results

Quality of relationship was measured with two variables in order to bring a time-dimension (i.e. present and past QoR) to bear on this measure. The first variable assessed the present QoR, while the second variable compared the dyadic relationship in pre-care-dependency days with the present.

Hypothesis 4a: The better the present quality of relationship (QoR) between CR-CG, the less CG_B experienced.

Table 23: *Level of burden according to present quality of relationship (QoR) between CR-CG (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Good Neither good nor bad Bad	279 46 7	-.172 .846 1.277	.907 1.016 .737	F = 31,040; df = 329; p = .0001
Social	Good Neither good nor bad Bad	279 46 7	-.071 .372 .374	.913 1.261 1.770	F = 4,453; df = 329; p = .012
Physical	Good Neither good nor bad Bad	279 46 7	.009 -.027 -.172	1.042 .750 .793	F = .130; df = 329; p = .878

A significant difference was found related to both psycho-spiritual burden (F = 31,040; df = 329; p = 0.0001) and social burden (F = 4,453; df = 329; p = 0.012) in terms of the present QoR between caregivers and care-recipients. On the other hand, no significant difference was found for physical burden (F = .130; df = 329; p = 0.878) in terms of the present QoR between caregivers and care-recipients. Therefore, ANOVA results indicate that where the CG-CR relationship is good, the extent of psycho-spiritual and social burden experienced by caregivers is lower.

Hypothesis 4b: Where the dyadic quality of relationship (QoR) has improved for the better (comparing present with pre-care-dependency relationship), less CG_B *is experienced.*

Table 24: *Level of burden according to quality of relationship (QoR) comparison of pre-care-dependency relationship and present relationship (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Better	26	.013	1.086	F = 20,049; df = 329; p = .0001
	Not changed	250	-.163	.900	
	Worse	56	.723	1.078	
Social	Better	26	.085	.759	F = 6,423; df = 329; p = .002
	Not changed	250	-.102	.893	
	Worse	56	.415	1.387	
Physical	Better	26	-.138	.680	F = .635; df = 329; p = .531
	Not changed	250	-.011	1.066	
	Worse	56	.115	.798	

A significant difference was found related to caregiver assessment of the present relationship between CG-CR compared to the past relationship and levels of psycho-spiritual burden (F = 20,049; df = 329; p= 0.0001) and social burden (F = 6,423; df = 329; p = 0.002). For measures of both psycho-spiritual and social burden, caregivers who said their relationship was better when compared to pre-care-dependency days experienced less burden than respondents who said their relationship had become worse. Therefore ANOVA results indicate that where caregivers reported improvement in the QoR between CG and CR, as assessed by caregivers comparing past (pre-care-dependency) and present relationships, the less psycho-spiritual burden and social burden experienced. However, caregivers who reported that their relationship with the care-recipient had "not changed" (n = 250), experienced less burden for psycho-spiritual ($\bar{x}$= -0.163) and social ($\bar{x}$= -0.102) components than those reporting their relationships had changed for the better ($\bar{x}$ = 0.013 and $\bar{x}$= 0.085, respectively). These results suggest that historical consistency in the tenor of the relationship between CG-CR (whether bad or good) lends to less psycho-spiritual and social burden for caregivers.

6.5.3 Framework Conditions of Care Related Results

In measuring assistance received by a caregivers' social network, two variables were assessed, namely: assistance received from family members and assistance received from neighbors.

Hypothesis 5a: The more assistance provided by caregivers' family members, the less caregiver burden experienced.

Table 25: *Level of burden according to assistance received from family members (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Generally Sometimes Never	176 89 67	-.172 .182 .210	.938 1.041 1.035	F = 5.690; df = 331; p = .004
Social	Generally Sometimes Never	176 89 67	-.065 .049 .105	1.000 1.012 .986	F = .838; df = 331; p = .433
Physical	Generally Sometimes Never	176 89 67	-.005 -.047 .077	1.015 .967 1.015	F = .300; df = 331; p = .741

A significant difference was found related to the extent of assistance received from family members and the level of psycho-spiritual burden (F = 5.690; df = 331; p = 0.004) experienced by the caregiver. No significant difference was found between the extent of assistance received from family members and the level of either social burden (F = .838; df = 331; p = 0.433) or physical burden (F = .300; df = 331; p = 0.741). Therefore, ANOVA results indicate that in social networks where family members generally provide care assistance, primary caregivers experience less psycho-spiritual burden.

Hypothesis 5b: The more assistance provided by caregiver's neighbors, the less caregiver burden experienced.

Table 26: *Level of burden according to assistance received from neighbors (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Generally	44	-.098	.948	F = .253;
	Sometimes	74	.030	.978	df = 331;
	Never	214	.010	1.021	p = .776
Social	Generally	44	-.235	.529	F = 1.880;
	Sometimes	74	-.061	1.264	df = 331;
	Never	214	.069	.966	p = .154
Physical	Generally	44	-.076	1.184	F = 1.352;
	Sometimes	74	-.144	.863	df = 331;
	Never	214	.065	1.002	p = .260

No significant difference was found related to the extent of assistance received from neighbors and the level of psycho-spiritual burden (F = .253; df = 331; p = 0.776), social burden (F = 1.880; df = 331; p = 0.154), or physical burden (F = 1.352; df = 331; p = 0.260) experienced by caregivers. Therefore, ANOVA results indicate that no significant difference exists related to the extent of assistance received from neighbors and the level of burden experienced by caregivers.

Hypothesis 6: Caregivers who live in the same house with care-recipients experience greater caregiver burden.

Table 27: *Level of burden according to living arrangements (t-Test)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/Spiritual	No Yes	96 236	-.171 .070	.885 1.037	t = .-2.139 df =204,921; p = .034
Social	No Yes	96 236	-.158 .064	.653 1.105	t = -2.270 df =287,753; p = .024
Physical	No Yes	96 236	-.283 .115	.852 1.034	t = -3.341 df = 330; p = .001

A significant difference was found for caregivers living together with and separate from care-recipients in regards to level of caregiver burden for all three burden types, specifically: psycho-spiritual (t = -2.139; df = 204,921; p = 0.034), social (t = -2.270; df = 287,753; p = 0.024), and physical burden (t = -3.341; df = 330; p = 0.001). For all three-burden types, caregivers living together with care-recipients experienced (on average) greater levels of burden than caregivers living separate from care-recipients. Thus, t-test results indicate that caregivers who live in the same house with care-recipients experience significantly greater caregiver burden in regards to psycho-spiritual, social, and physical burden.

Hypothesis 7: Caregivers who live in rural areas experience more burden than those living in urban environments.

Table 28: *Level of burden according to environment type (ANOVA)*

Burden Type		*N*	Mean	Std. Deviation	Analysis
Psycho/ Spiritual	Urban	131	.159	1.092	F = 5,609;
	quasi-Rural	89	-.288	.838	df = 329;
	Rural	112	.043	.964	p = .004
Social	Urban	131	.126	1.161	F = 1,809;
	quasi-Rural	89	-.115	.762	df = 329;
	Rural	112	-.055	.955	p = .165
Physical	Urban	131	.125	1.063	F = 3,963;
	quasi-Rural	89	-.248	.948	df = 329;
	Rural	112	.050	.936	p = .020

A significant difference was found for environment type and the level of psycho-spiritual (F = 5,609; df = 329; p = .0004) and physical burden (F = 3,963; df = 329; p = 0.020) experienced by caregivers. Contrary to the hypothesis, on average, urban caregivers experienced significantly greater burden compared to rural caregivers in terms of psycho-spiritual ($\bar{x}_U$ = .159; $\bar{x}_R$ = .043) and physical burden ($\bar{x}_U$ = .125; $\bar{x}_R$ = .050). A more striking difference is observed in quasi-rural results, which show caregivers in this environment experienced less psycho-spiritual ($\bar{x}_{qR}$ = -.288) or physical burden ($\bar{x}_U$ = -.248) than caregivers in urban or rural environment types. No significant difference was found for environment type and the level of social burden (F = 1,809; df = 329; p = 0.165) experienced by caregivers. Thus, contrary to hypothesis number seven, ANOVA results indicate that urban (not rural) caregivers experience significantly greater levels of psycho-spiritual burden and physical burden than rural, and especially quasi-rural caregivers.

Hypothesis 8: CG_B is higher for those CGs who perform five or more ADL tasks for the CR.

Table 29: *Level of burden according to care-recipient limitations in performing activities of daily living (ADL) (t-Test)*

Burden Type		*N*	Mean	Std. Deviation	Analysis

Psycho/
Spiritual
	< 5 ADLs
	≥ 5 ADLs
		188
		108
			-.160
			.400
				.913
				1.062
					t = -4.591;
					df = 196,960;
					p = .0001

Social	< 5 ADLs
	≥ 5 ADLs
		188
		108
			-.062
			.116
				.891
				1.226
					t = -1.439;
					df = 294;
					p = .151

Physical	< 5 ADLs
	≥ 5 ADLs
		188
		108
			-.182
			.388
				.931
				1.074
					t = -4.610;
					df = 198,191;
					p = .0001

A significant difference was found for caregivers who perform less than five ADLs and five or more ADLs in regards to psycho-spiritual (t = -4.591; df = 196,960; p = 0.0001) and physical burden (t = -4.610; df = 198,191; p = 0.0001). On average, caregivers performing less than five ADLs ($\bar{x}$ = -.160) experienced less psycho-spiritual burden than those performing five or more ADLs ($\bar{x}$ = .400). In regards to physical burden, caregivers performing less than five ADLs ($\bar{x}$ = -.182) experienced less physical burden than those performing five or more ADLs ($\bar{x}$ = .388). On the other hand, no significant difference was found for caregivers in regards to ADL limitations of care-recipients and social burden (t = -1.439; df = 294; p = 0.151) experienced by caregivers. Therefore, t-test results indicate that levels of psycho-spiritual and physical burden are significantly higher for those caregivers who perform five or more ADL tasks for the care-recipient.

6.6 Summary of Hypotheses-Related Findings

All twelve of the additional hypotheses of this study were analyzed using t-test or ANOVA analyses. Each of the analyses was generated to show level of burden with relation to three caregiver burden components derived from factor analysis, namely, psycho-spiritual burden, social burden, and physical burden. Combined, psycho-spiritual, social, and physical burden accounted for more than half (53.8%) of the overall proportion of variance of caregiver burden. Of the three components, psycho-spiritual burden accounted for the largest percentage of variance at 31.2%, while social burden and physical burden each accounted for 11.9% and 10.8% of variance, respectively.

A summary of the hypotheses analyses findings is submitted below under the categories caregiver characteristics, dyadic quality of relationship, and framework conditions of care.

Caregiver characteristics used to test level of burden was composed of caregivers' age groups, gender, educational attainment, motivation, and self-rated health. Of these characteristics, self-rated health, age, and gender of caregivers were found to have significant association to one or more of the three caregiver burden components. Caregiver self-rated health was found to be significantly related to both the psycho-spiritual (p = .0001) and physical (p = .0001) components of caregiver burden such that caregivers assessing their health to be poor experience greater psycho-spiritual burden. A significant association between age of caregivers and physical burden (p = .010) was found suggesting that caregivers 60 years of age and older experience more physical burden than younger caregivers. While t-test results showed a general trend of greater burden among female caregivers, the difference was only significant in regards to psycho-spiritual burden (p = .016). Thus, female caregivers were found to experience significantly greater levels of psycho-spiritual burden than male caregivers. Of the two remaining caregiver characteristics, level of educational attainment was found significantly related to physical burden. However, upon closer inspection of ANOVA figures, no clear pattern was found to support the hypothesis that caregivers with higher education experience lower care-induced burden. Lastly, no significant difference was found relating motivation to care to any one of the three burden types.

Two variables, present quality of relationship (QoR) and a comparison of pre-care-dependency and present QoR, were analyzed to test whether a significant association exists between dyadic QoR and one or more of the three components of caregiver burden. Findings suggest a significant difference in psycho-spiritual ($p = .0001$) and social ($p = .012$) burden such that where the present CG-CR relationship is good, the level of psycho-spiritual burden and social burden experienced by caregivers is lower. Similarly, a comparison of pre-care-dependency (past) to present QoR and the relation to caregiver burden found significant differences with regard to psycho-spiritual ($p = .0001$) and social ($p = .002$) burden. Thus, results suggest that caregivers reporting improvement from past pre-care-dependency to present QoR experienced less psycho-spiritual and social burden. Interestingly, caregivers reporting no change ($n = 250$) in the past and present QoR experienced less psycho-spiritual and social burden than those reporting that their relationship with the care-recipient had changed for the better. Possible reasons for these results will be addressed in chapter seven.

Framework conditions of care tested in relation to affect on caregiver burden were caregiver assistance received from family members, assistance received from neighbors, living arrangements, environment type, and number of ADLs performed by caregivers. Four out of five of these variables showed a significant difference on one or more components of caregiver burden, namely, living arrangements, number of ADLs performed by caregiver, environment type, and assistance received from family members. Only with regard to assistance received from neighbors was no significant relationship found to caregiver burden.

Caregiver living arrangements was the only variable among those tested found to have a significant association to all three caregiver burden components. T-test results indicate that caregivers living together with care-recipients experienced greater levels of burden in regards to psycho-spiritual ($p = .034$), social ($p = .024$), and physical ($p = .001$) burden compared to caregivers living apart from care-recipients. A significant association was found in regards to psycho-spiritual ($p = .0001$) and physical ($p = .0001$) burden between caregivers who perform less than five ADLs and five or more ADLs. T-test results suggest that caregivers who performed five or more ADLs experienced significantly greater levels of psycho-spiritual and physical burden than caregivers performing less than five ADLs. Similar to ADL performance results, a significant association was found between environment type and psycho-spiritual ($p = .004$) and physical ($p = .020$) burden such that, contrary to hypothesis seven, urban caregivers experienced greater psycho-spiritual and physical burden than rural caregivers. Lastly, caregiver assistance received from family members was found significantly related to psycho-spiritual burden ($p = .004$). ANOVA results indicate that caregivers generally receiving assistance from family members experienced less psycho-spiritual burden than those caregivers receiving lesser or no assistance from family members.

In the next chapter, chapter seven, select findings will be addressed further in greater detail with respect to support of or additions to the literature as well as possible explanations for unexpected results

CHAPTER 7

SUMMARY AND DISCUSSION

7.1 Summary

7.1.1 Introduction

As population ageing is a present and advancing reality in most countries around the world, older adults aged 60 and over represent the fastest growing cohort in modern Turkey. In particular, between the years 1950 to 2000, the proportion of older adults aged 80 and over in Turkey increased by an unprecedented seven and one half fold, an upward trend that is expected to increase to more than eight and one half fold between 2000 to 2050 (UN, 2002 [66]). This is an indicator that the ratio of care-dependent older adults to non-dependent persons in Turkey will likewise continue to increase. With the extension of life expectancy and concomitant decrease in acute illnesses and prevalence of chronic long-term conditions especially among the oldest old, today's family caregiver– the principal provider of care to the elderly in Turkey –might expect to care for their dependent older relatives for an extended period, situating the issue of caregiver burden among informal family caregivers as one of the major challenges to be addressed by society and within the Turkish welfare system in the 21st century.

This research represents the first study in Turkey to assess the situation of both primary caregivers and their community-dwelling older adults with regard to caregiver burden. Furthermore, inclusion of subjects from urban, quasi-rural and rural settings has afforded opportunity to draw upon comparisons between care situations in different physical environments providing for a more holistic

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[66] Calculation performed by the principal investigator based on UN prediction figures.

perspective from which to interpret results and make environment-sensitive recommendations for future research and policy initiatives.

7.1.2 Research Questions

The purpose of this study, as informed by the main research question was to determine the nature and extent to which primary caregivers of community-dwelling older adults (aged 60 and over) in the Province of Antalya, Turkey experience caregiver burden. Additional research questions sought to determine which variables contribute to or moderate caregiver burden among primary family[67] caregivers. These questions inquired into the possible influence or impact on caregiver burden of several variables, namely (a) caregiver socio-demographic variables (i.e. gender, age, and educational attainment), (b) motivation to care, (c) caregiver self-rated health, (d) dyadic quality of relationship (QoR), (e) extent of social support, (f) living arrangements, (g) physical environment, and (h) extent of assistance with ADLs.

7.1.3 Data Chosen for Study

For comparative purposes, this cross-sectional study was devised to include primary caregivers and their care-recipients[68] situated in diverse physical settings, including urban, quasi-rural, and rural environments. Data from 332 households consisting of 664 interviews were collected in fifteen of Antalya's nineteen districts between April of 2009 and March of 2010.

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[67] Of the 332 CGs included in this study, just two were non-family members (they were neighbors).

[68] Physically frail and mentally competent care-recipients were sought in this study. Thus, inclusion in this study required the cognitive intactness of would be care-dependent older adults.

7.1.4 Collection and Analysis of the Data

All data represented in the Antalya Home Care Survey (AHCS) was collected via face-to-face interviews using distinctly different standardized surveys on parallel topics with caregivers and their respective care-recipients.[69] A random survey approach was used in urban neighborhoods to obtain one-on-one interviews while assistance from local elected headmen (*muhtar*) and their assistants (*aza*) were obtained using a convenience sampling approach in quasi-rural and rural settings.[70] Data storage and analysis were performed using SPSS version 20 for Mac.

7.1.5 Major Findings

Overall, three-quarters of the diverse variables analyzed were found to be significantly related to one or more components of caregiver burden, therefore supporting the Pearlin Stress Process Model which advocates that multiple factors, including socio-demographic characteristics of the caregiver and care needs (Iecovich, 2011), may contribute to caregiver burden.

Three burden components– psycho-spiritual , social, and physical burden –were derived from a factor analysis. These components combined explained 53.8% of the variance in caregiver burden. Of the three burden components, the psycho-spiritual component explained approximately 31.2% of caregiver burden while the social and physical burden components explained approximately 11.9% and 10.8% respectively. This finding suggests that psycho-spiritual burden had the most significant negative consequence on caregiver burden[71] and supports Raveis et al. (1990) and Stuart and Hansen

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[69] See Table 6 in sub-section 5.4.1 for details of topics covered in the AHCS.

[70] See sub-section 5.6 for further details.

[71] It should be noted that five variables were included in the measure of the psycho-spiritual burden component compared to just three variables each for measuring social and physical

(2006)'s premise that the emotional or psychological domain may represent the most significant negative and pervasive consequence of caregiver burden.

According to study findings, the profile of caregivers experiencing the greatest care-related burden are: (a) older (b) women who (c) report low self-rated health, (d) poor present QoR and (e) poorer present compared to pre-care-dependency QoR, (f) report little or no care-assistance from family members, (g) co-reside with the care-recipient, (h) care for the care-recipient in an urban environment, (i) and perform five or more ADL tasks for the care-recipient.

Select variables were analyzed using the Chi-Square test, to determine whether they were significantly related to environment type. Of the eleven variables analyzed, six variables were found significantly related to environment type, namely, economic burden, caregiver income, kin relationship, anxiety of future, self-rated health, and past-present comparison of dyadic QoR. The variables showing no significant relation between environment and caregiver burden were motivation, present dyadic QoR, sufficiency of civil agencies provision of adequate care information, sufficiency of health institutions provision of adequate care information, and availability of resources (care information) in the immediate community.

Results for analysis of the additional hypotheses using t-test and ANOVA found living arrangements, provision of ADL support, self-rated health, present QoR and past-present comparison of QoR, physical environment, family assistance, age and gender to be significantly related to caregiver burden. Among these variables, only living arrangements were found significantly related to all three components of burden, namely, psycho-spiritual, social, and physical burden. Of the remaining variables, provision of ADL support, self-rated health, and

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dimensions of burden. This disproportion in number of variables may account, in part, for the extent of the larger variance found for psycho-spiritual burden compared to social and physical burden.

physical environment each showed significant correlation to the psycho-spiritual and physical burden components, while present and past-present comparison of QoR both showed significant correlation to the psycho-spiritual and social components of burden. Caregiver age was found significantly related to physical burden while gender was found significantly related to the psycho-spiritual burden component.

Though educational attainment showed statistical significance with relation to physical burden, because no clear linear pattern was found to decidedly confirm or contradict the hypothesis[72] (that higher educational attainment lends to lower levels of burden), this result is not included in the above list. Of the hypotheses-related variables tested, *motivation to care* and *assistance received from neighbors* showed no significant relation to caregiver burden.

7.2 Comparison with the Literature

Independent variables in this study accounted for 53.8% of the variance in caregiver burden, and as indicated by Iecovich (2011, p. 585) suggests that other variables such as feeling of accomplishment, meaning attached to the daily caregiver role, self-efficacy (Carbonneau, Caron, & Desrosiers, 2010), and emotional support (Tolkacheva, Van Groenou, De Boer, & Van Tilburg,2010) may also affect caregiver burden.

The results of this study revealed both expected and unexpected findings. Findings related to the independent variables tested are presented according to the three categories, namely, caregiver characteristics, dyadic quality of relationship (QoR), and framework conditions of care. Support of previous research as well as additions to the literature are also addressed.

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[72] See t-test results for Hypothesis 1c in sub-section 6.5.1 for further details.

Among caregiver characteristics, self-rated health was found significantly related to caregiver burden as likewise reported in other studies, (NAC and AARP, 2004; Iecovich, 2011), with regards to both psycho-spiritual and physical burden. As hypothesized, caregiver age was also found significantly related to caregiver burden such that older caregivers (aged 60 or older) experienced greater physical burden than younger caregivers. This result is also consistent with the findings of studies by Kim et al. (2010) and Iecovich (2011) that found correlation between caregivers' increased age and greater care-related burden, in general. An increase in physical burden for older caregivers may be, in part, an outcome of the caregivers' experience of their own ageing which Hooyman and Kiyak (1999) have referred to as a "gradual accumulation of irreversible functional losses" (p. 55). In turn functional losses, and for some older caregivers an increase in chronic illness(es), when combined with additional care tasks may equate to increases in physical stress for older caregivers. While the hypothesis was not supported in regards to psycho-spiritual and social burden, overall psycho-spiritual and social burden figures for younger caregivers (age 59 and under) were lower than for older caregivers (60 and above), suggesting that while not statistically significant, there was a difference. Bringing attention to a counter perspective, Carretero et al. (2009), refers to a study by Navaie-Walliser et al. (2002) that found younger caregivers to experience greater burden than older caregivers. With regards to gender, study results found female caregivers experienced significantly greater caregiver burden, as also reported in a study by Kim et al. (2010), but only with regards to physical burden. A study by Knight et al. (2011), on the other hand, found male caregivers at greater risk of negative physical burden. Carretero et al. (2009), however, refers to Gaugler et al. (2000) who suggest that only a few researchers in a very general way have found correlations between young age and male gender of caregivers in relation to greater caregiver burden.

Results for educational attainment and caregiver motivation in this study were not as hypothesized. Though ANOVA test results suggest a significant relationship between educational attainment and physical burden, upon closer inspection, no clear confirmation is found to support the hypothesis that higher educational attainment lends to lower caregiver burden.[73] Other studies have found lower levels of caregiver educational attainment to be significantly associated with higher caregiver burden (Cameron et al., 2002; Hughes et al., 1999; Papastavrou et al., 2007; as cited in Byrd et al., 2011; Iecovich, 2011).

Regarding source of motivation to care, in line with other study results (NAC & AARP, 2005), it was hypothesized that motivation would be significantly related to caregiver burden such that caregivers providing care of their own free will would experience lower caregiver burden than caregivers asked by their family to provide care. Results, however, suggest that no significant correlation existed between source of motivation and level of caregiver burden. Possible reasons for this outcome are addressed in sub-section 7.3.

It should be noted that while several factors related to caregiver characteristics indicated significant correlation to physical and especially psycho-spiritual burden, none of the caregiver characteristics were found significantly related to social burden. This would suggest that social interactions are not significantly limited by caregiver characteristics so as to produce care-related burden, at least not for those characteristics analyzed. More specifically, caregivers of a particular age, gender, level of educational attainment, motivation in care, or level of self-rated health are not more or less likely, at a level of statistical significance, to experience social burden as a result of care.

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[73] While looking from a macro-perspective, the hypothesis seems partially confirmed. However, closer inspection of the non-linear results, particularly of those CGs attaining up to an elementary level of education (nearly 3 in 5 CGs), indicates less CG burden among elementary compared to middle school and university level graduates, bringing into question clear confirmation of the hypothesis stating CGs with higher education experience lower care-induced burden.

Quality of relationship (QoR) was found to have a significant correlation to caregiver burden. Two variables, present QoR and a comparison of pre-care-dependency and present QoR, were assessed. Both variables were found significantly related to caregiver burden, lending support to similar findings of several recent studies (Snyder, 2000; Steadman et al., 2007; Iecovich, 2011), but only with respect to psycho-spiritual and social burden. The later variable, however, produced an interesting result. Findings indicate that caregivers reporting "no change" in the past and present dyadic QoR experienced less psycho-spiritual and social burden than those reporting a change in their relationship for the better. Possible explanations of this finding are discussed in sub-section 7.3.

Among the framework conditions of care variables analyzed, four out of five were found significantly related to one or more caregiver burden components, namely, living arrangements, number of ADLs performed by caregiver, environment type, and assistance received from family members. Only assistance received from neighbors was not found to have a significant correlation to caregiver burden.

Caregiver living arrangements were found to be significantly related to all three burden components such that caregivers living together with the care-recipient experienced greater levels of psycho-spiritual, physical and social burden. This finding supports a study by Kim et al. (2010) that also found caregivers co-residing with care-recipients experienced greater burden.

Likewise, it came as no surprise that caregivers performing five or more ADLs were found to clearly experience greater levels of psycho-spiritual and physical burden, than caregivers performing less than five ADLs. These findings support previous studies by Savundranayagam and Montgomery (2010) and Iecovich (2011) that arrived upon similar results.

The surprise came in regard to results for the environment type variable. Contrary to hypothesis number seven and previous study findings (Jones et al., 2009; as cited in Byrd et al., 2011; Saldana, 1999), while environment type was found significantly related to caregiver burden, it was caregivers caring in urban and not rural environments that registered greater psycho-spiritual and physical burden. Possible reasons for this outcome are addressed in sub-section 7.3.

Data regarding the affect of social support from family members and neighbors was analyzed separately. Assistance received from family members was found significantly related to psycho-spiritual burden while no significant relation was found between assistance from neighbors and caregiver burden. These findings provide an addition to the literature, offering partial support to the hypothesis of Tolkacheva et al. (2010) and Iecovich (2011) who have suggested that social support may affect caregiver burden.

7.3 Reflections on Select Hypothesis Test Results

In chapter six, reference was made to the difficulty in operationalizing the concepts *free will* and *source of motivation.*[74] For example, there may be a very fine line between a daughter feeling she 'must' care for her mother out of obligation (reciprocity) as her mother once cared for her and a daughter reporting that she 'wanted' to care for her mother. The former may answer, "My family wanted me to" though she herself felt an internal obligation while the later may respond, "I wanted to" though the *want* may likewise be driven by obligation, which says, "I must". From another viewpoint, sense of obligation which says "I've no other choice" may weigh heaviest in the decision to care, especially in a familialistic society, but the respondent may perceive this, and from one perspective rightly so, as "I wanted to". Since one of the values of a familialistic society typical of Southern or Mediterranean type countries like

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[74] See results of the Hypothesis 2 analysis in sub-section 6.5.1

Turkey (as opposed to an individualistic society) is to put the needs of family above one's own needs or preferences, it reasons that in the mind of such a caregiver, reciprocity or obligation to family would prevail in the form of "I wanted to" even if that person, at the individual level, would prefer not to be the caregiver.

Reflecting on the fact that less than one in ten caregivers reported that the motivation to care was external– based on family and not personal preference – another possible explanation for motivation showing no significant relationship to caregiver burden is that some of the respondents may have lied. Because the pressure for family members, whether daughters-in-law, spouses, adult children, or other relatives, to care for older dependent relatives is a clear cultural and societal expectation in Turkey, for a family caregiver to acknowledge that they did not want or choose to care might bring shame. Because shame is an emotion and stigma to be avoided perhaps at all costs, in a shame-based society such as Turkey, to lie might be evaluated by some (caregivers) as the better option to a response that generates shame such as "family wanted me to".

Hypothesis 4b asserts that, "Where the dyadic QoR has improved for the better (comparing present with pre-care-dependency relationship), less CG burden is experienced." As mentioned in the previous sub-section, this hypothesis was partially confirmed in that respondents who reported their relationship to the care-recipient had improved for the *better* as opposed to for the *worse* experienced significantly less burden with respect to psycho-spiritual and social burden. However, caregivers reporting that their relationship to the care-recipient had *not changed* experienced lesser burden than respondents reporting change for the better or for the worse, with regards to both psycho-spiritual and social burden. Two possible and related explanations for these findings are offered. Firstly, it is suggested here that change, even for the better, may produce fear - fear of the unknown (e.g. unpredictability with regards to feelings or outcome). Change may leave a residual sense of instability and fear of future change, in this case, of change in the future state of the CG-CR relationship. Secondly, change for the better implies that the relationship (of the past) was not good or at least not as good as that of the present and the possibility exists of residual pain connected to the past. Pain from the past, if not dealt with properly, may produce relational rifts in the form of resentment that lingers in the present, if only below the surface, unseen but continuing to influence the present relationship to some extent. So while one might assume that change for the "better" might render the lowest overall burden scores, based on empirical results from this study, it is suggested that ongoing continuity or equilibrium in the CG-CR relationship (i.e. "not changed") may typically yield less reported caregiver burden than even relationships reported to have changed for the "better".

An additional unexpected finding was attained with reference to the relationship between environment type and caregiver burden. Hypothesis seven posited that greater caregiver burden would be reported in rural compared to urban environments. While significantly greater burden was found in relation to environment type, it was urban and not rural environments that registered greater burden for caregivers with respect to psycho-spiritual and social burden. Respondents in urban environments reported greater levels of both psycho-spiritual and physical burden than caregivers in rural and especially quasi-rural settings. There are several possible explanations for this outcome. One possible explanation is that together with higher levels of educational attainment among urban caregivers compared to both rural and quasi-rural caregivers, general expectations regarding quality of life may be higher for urban caregivers than their rural counterparts.[75] The observation

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[75] This is similar to perceived differences between older adults from the "Victorian" versus "Baby Boomer" eras in the US, where older adults from the Victorian era are familiar with adversity, having lived during the Great Depression and generally have learned contentment whatever their circumstances. Baby Boomers, on the other hand, having been brought up in and

was made regularly during the field work phase of this study that a comparison of objective qualities (e.g. harsh rural living conditions including substandard housing and lack of amenities/resources) and subjective assessments (e.g. general acceptance of, resignation to or even contentment with 'difficult' living conditions) by rural respondents suggested that rural caregivers had much lower expectations compared to their urban counterparts. Because burden is a subjective construct, subjective 'perceptions' and not objective 'facts' will prevail in caregiver burden results. From the perspective of perceived burden, it seems reasonable that urban caregivers might have higher expectations and thus perceive less than ideal situations to produce greater burden compared to their rural counterparts. A second possible explanation is related to living arrangements. As reported in sub-section 6.5.3, results for Hypothesis six revealed that all three components of caregiver burden– psycho-spiritual, social, and physical burden –were found significantly related to living arrangements such that caregivers living together with the care-recipient experienced greater burden than those living apart from the care-recipient. An analysis of living arrangements across environment types shows that the largest proportion of caregivers living together with care-recipients are in urban settings at 86.3%, compared to 73.2% of rural and just 46.1% of quasi-rural settings. This would suggest that urban caregivers as a whole are susceptible to greater caregiver burden than rural and especially quasi-rural caregivers with respect to living arrangements.

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having experienced the riches of the golden era, are generally well educated and informed, and are not likely to be content with anything less than the best in regard to retirement benefits and care services.

CHAPTER 8

CONCLUSIONS

8.1 Main Research Question Response

No one variable in this study provides a basis for addressing the main research question's inquiry into the nature and extent to which primary caregivers of community-dwelling older adults in the Province of Antalya experience caregiver burden. For this reason, additional research questions were constructed and tested in the form of hypotheses tests. The results of these tests, which are addressed in sub-section 6.5, highlight the statistical significance of relationship between the various independent variables and dependent caregiver burden components – psycho-spiritual, social, and physical burden. Field observations and empirical results from the AHCS suggest that, based on a range of influences, primary family caregivers of community-dwelling older adults experience a variety of negative care-related outcomes to an extent that predicates the need for further investigation at the provincial as well as national level in urban and rural environments.

8.2 Recommendations

Minimizing the negative and maximizing the positive outcomes of care-related burden may be facilitated through making adequate care resources available to caregivers. In the following sub-sections, recommendations for minimizing caregiver burden are presented (in *italics*) with regard to the micro and macro level, with specific focus on the caregiving family, the role of care and social services, policy initiatives, and further research.

8.2.1 Caregiving Families

In the context of this study, at the micro level, *caregiving families* refer to those families who directly provide home-based care for one or more older dependent family members. In such a scenario, roles are assumed by the primary caregiver and care-recipients, but also by other family members. It is the principal researchers view that, *where possible, prior to an older family member's requiring care, that family members should gather to talk openly about expectations with regard to caregiving*. Creating open lines of communication in advance of care-dependency should help to head off potential tensions or misgivings due to unmet or unrecognized expectations. *It would be advisable for care-recipients and potential caregivers to become as informed as possible of support resources available in advance of requiring assistance, as well as the availability of alternatives to family care.* Otherwise, should care needs increase to the point where neither care-recipient nor caregiver are able (with respect to ability or time) to pursue help, its then– during survival mode –that the caregiver may forego, by default, needed assistance.

While Hoff and Hamblin (2011) have identified the personal responsibility of the caregiver to ask for help as needed, it is the observation of the principal researcher that family caregivers in Turkey, as in many other countries, are reluctant to ask for help in general, but especially from institutions, organizations, or individuals outside of the family.[76] For this reason, *the need to empower caregivers to ask for help must be emphasized*. Possible policy-related interventions to help carers to learn to ask for help are addressed in sub-section 8.2.3.

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[76] In large part, this leaning may be attributed to Turkey's strong familialistic heritage accompanied by an intrinsic assumption that care should take place or be provided entirely within the family.

It is advisable for potential or present caregivers to take the time to consider why it is that they would choose to care; to understand what it is that serves as their motivation to provide care. Time taken to reflect on the question "Why care?" may very well affirm the good reasons for caring and give needed resolve to proceed forward, while those opting to care based primarily on the (external) expectations of others, for instance, may find further reflection helpful in adopting the role of primary caregiver founded on healthier reasoning.

Lastly, caregivers will do well to examine the framework conditions of care such as living conditions and employment. *If the family caregiver should co-reside with the care-recipient, reflection on the availability of personal space (to retreat to as needed) and time away (a break from care duties) may prove prudent.* If these resources are not presently available, perhaps space may be created and time away from caregiving duties attained through assistance from other family members or neighbors, ideally on a regular basis. *If the caregiver should be employed outside of the home, then access to care support should be given consideration*. Assistance provided by other family members, friends or neighbors would likely provide psychological/emotional and practical assistance that should help to mediate care-related burden for the working caregiver.

8.2.2 Care and Social Services

The concept of "social care" as a set of intersecting relations between the state, market, and family (Daly and Lewis, 2000) is a helpful frame of reference in locating the role of care and social services in helping to alleviate caregiver burden. Many developed countries presently experiencing the challenges associated with population ageing have oriented national welfare policies to facilitate dependent older adults in remaining in and receiving care in the home for as long as possible. From a societal and economic perspective, enabling older adults to remain at home (age in place) creates a win-win situation. From a societal perspective, the vast majority of older adults and their families around the globe prefer ageing in place to ageing in a care facility. From an economic perspective, elders cared for at home versus in care facilities create less economic strain on welfare resources such as long-term care insurance.

A noteworthy goal for Antalya and Turkey as a whole is the creation of care services that recognize "care" as a growing market. It is estimated that there are 1,750,000 care-dependent older adults in Turkey today. Of these, some 600,000 are thought to have Alzheimer's disease (Tufan, 2011b). In contrast, the number of trained caregivers of older adults is estimated to be 1,400 (Tufan, 2011b), compared to Germany's 761,000 trained caregivers of the elderly (Gesundheitsberichterstattung des Bundes, 2005; as cited in Tufan, 2011b). Despite the limited number of trained caregivers of older adults, many are unable to find employment in the field of care due to the virtual absence of elder care services in Turkey. So while the potential care workers (though yet few in number) are being trained and stand ready for work, it is time that governments at the provincial as well as national level take notice, invest in research and based upon scientific findings, take action to provide resources to support family caregivers of community-dwelling dependent older adults. Thus, the development of public and private care services to assist families in caring for dependent older adults, along with the procurement of trained caregivers[77] of older adults is critically needed. Furthermore, caregiver training should focus on the practical as well as psychological needs of informal family caregivers and community-dwelling dependent older adults. While practical or physical needs are perhaps easiest to identify and address, according to AHCS results and the literature, the most significant negative consequences of care-

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[77] As Tufan (2011b) has argued, training provided caregivers of dependent elders must go beyond the primarily medical training typically provided nurses to include gerontologically-based training as well.

related burden may be connected to emotional or psychological burden.[78] Therefore, *it is recommended that care services give particular attention to the psychological burden of care*.

8.2.3 Policy Initiatives

While the principal researcher strongly affirms the value of families caring for *their own* within the family, *further development of recognition in Turkey that care is not only an individual but also a societal task is recommended*. Just as an imam, a rabbi, a priest or pastor look after the spiritual needs of their assembly, so society– both its leaders and constituents –should recognize a level of responsibility to care for their own. With regards to the role of policy initiatives in addressing caregiver burden, several recommendations are addressed below.

Recognition of family caregivers is needed in Antalya and in the whole of Turkey. The media could play a significant role in disseminating recognition of the valuable role that informal family caregivers make on a daily basis, affirming their importance within the family and within society. The saying "out of sight, out of mind" is appropriate to the situation of family caregivers. Many are literally out of sight as they provide needed care within the confines of the home, often foregoing the meeting of their own needs– whether social, economic, emotional, or physical such as the need for rest or recreation –in preference to the needs of those to whom they provide care. Judging by its collective passivity, society at the macro level does not value those who provide service to family and country by caring for the oldest among its numbers. Words and actions of affirmation and appreciation for the *work* that family caregivers do are needed. Television and radio programs and commercials, local and national newspapers, blog postings on the Internet, and magazine

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[78] See Table 12 in sub-section 6.3 for AHCS-related findings and sub-section 3.7.1 for an overview of literature research details.

articles might prove useful means of giving to family caregivers the recognition they are due.

One of the questions posed to primary caregivers in the Antalya Home Care Survey (AHCS) was whether health institutions provide them with sufficient information on caregiving. Results indicated that no significant difference was found between environment types in support offered caregivers because, in general, very little support was reported in all of the environments including urban, quasi-rural or rural settings.[79]*It is therefore recommended that health care professions in Turkey be encouraged to train their respective members to build a knowledge base for understanding and supporting family caregivers of older adults.*

It is recommended that health care professions in Turkey be encouraged to undertake advocacy roles that promote the development and refinement of public policy at the local and national levels to support family caregivers of older adults. Given the nature and level of responsibility resting upon family caregivers, they themselves are not in a position to organize and collectively make their needs known. Therefore, the family caregiver needs advocates, such as health care professionals, to make sure that their cause is heard by local and national leaders and to see that their needs are addressed.

According to findings in this study, less than half of the caregivers in all three environments reported having a practical knowledge with regard to care tasks.[80] Thus, results would suggest that a clear need exists for a means of imparting practical knowledge to caregivers of older adults in all environmental

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[79] In response to question g71 (See Appendix F), just 10.7% of urban, 9.0% of quasi-rural, and 9.8% of rural caregivers reported that health institutions provided them with sufficient information on caregiving.

[80] Some 38.9% of urban, 39.3% of quasi-rural, and 43.8% or rural caregiver respondents reported having a practical knowledge of care tasks.

contexts. *Therefore, it is recommended that inquiry be made into the creation of a role within the tertiary educational and existing Turkish welfare system for educating and employing regional "gerontological social workers"* [81] *to help increase caregiver knowledge of caring tasks.* Gerontological social workers employed to address the needs of family caregivers might serve, among other purposes, as a means of empowering caregivers to learn to ask for help as needed,[82] or in facilitating *self-help groups*,[83] as a means of encouraging and empowering caregivers. Further interventions recommended in empowering informal family caregivers to ask for help are (a) media campaigns at the macro level, and (b) through counsel/advice offered by trained health personnel such as doctors and nurses.

As previously addressed, findings of this AHCS suggest that the psycho-spiritual domain may contribute most significantly to the care-related burden experienced by caregivers. Thus, *it is recommended that future health care initiatives developed and implemented primarily for the direct support of family caregivers of dependent older adults include care options specific to their mental health service needs*.

Household Internet access rates in Turkey increased from 19.7% in 2007 to 47.2% as of April 2012, while internet usage rates increased from 30.1% to 47.4% for the same time period (Turkstat, 2012). Because primary family caregivers of community-dwelling dependent older adults are often bound to the care environment, Internet usage may be their best means of accessing information regarding needed care resources. The production of written information, on the other hand, would serve those families and caregivers who do not have access to or do not choose to use the Internet. Pamphlets, brochures, and leaflets might be distributed or posted in health institutions such

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[81] The concept of "gerontological social worker" is based on work by Butler et al., 2005.

[82] See sub-section 8.2.1, paragraph 2.

[83] Self-help groups are a popular means of assistance or respite to caregivers in some countries.

as hospitals and health centers, or made available for distribution by elected headmen in urban and rural environments as well as by local imams or leaders of other religious traditions/assemblies of worship. However, sensitivity should be given to the level of educational attainment among caregivers in Turkey. Study results based on the AHCS found that more than 1 in 4 caregivers had no schooling or diploma (25.9%) while more than half (59.3%) had completed no more than an elementary (grades 1-5) education.[84] Information produced for caregivers, therefore, need be produced at a grade appropriate level to insure comprehension for as many caregivers as possible. Therefore, *it is recommended that Antalya Province develop, implement and continuously update, strengthen and promote electronic and written forms of information to ensure that a range of pathways relating to health and care services are available for family caregivers from diverse educational, cultural and ethnic backgrounds.*

Furthermore, *it is recommended that different kinds of support systems be introduced in Turkey to address the care needs of community-dwelling dependent older adults and their informal family caregivers.* Up until this time, care for community-dwelling dependent older adults has, for the vast majority of families, been assigned by default to the family. However, to the extent that family caregivers are left to carry out caregiving alone, apart from the assistance of publicly organized support, they themselves also run the risk of becoming care-dependent as a result of the care-related accruement of psycho-spiritual, physical, economic, and social burden. A viable example of such an initiative has been developed by Dr. Ismail Tufan, (2006) based on the German Long Term Care Insurance model, and was presented before the Turkish Parliament in2006. Dr. Tufan's Social Care Insurance Model, which was developed to help meet a portion of the care needs of dependent older adults in Turkey, should be given serious consideration by politicians and policy makers.

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[84] See sub-section 5.1.2.2 and Table 4 for further details.

Lastly, *it is recommended that local and national government leaders create a strategy and budget for implementing/offering housing subsidies or grants toward upgrading the home environment.* Such a policy would have as its goal enabling dependent older adults in continuing to age in place by facilitating adaptation through modification of the home environment in such a way that promotes accessibility and safety. This would, in turn, allow the care-recipient increased levels of independence within the home, which should decrease demand and subsequent care-related burden on the caregiver.

In line with Turkey's natural fit in the ideal Southern care regime, *a good long-term goal is the development of a comprehensive and family/person-centered national approach to assisting family units with the care needs of care-recipients and caregivers alike.* A family approach recognizes and supports not only care for the care-recipient, but also their care providers who often have real unmet needs as a result of taking on the care of a loved one. In the meantime, it behooves the provincial and especially the central government to take immediate steps to assist families in the care of the elderly, rather than leaving families to continue to shoulder the care of their elderly alone.

8.2.4 Further Research

While caregiver burden has been a field of study for roughly three decades in other countries, it is a topic that has received little to no exposure in Turkish society. This research represents the first study to focus on influences and outcomes of care-related burden in Turkey to date. A number of recommendations for further research birthed from this project are offered below with the hope that many other researchers will respond to advance the empirical knowledge base of understanding upon which meaningful and effective policies and programs may be derived and implemented on behalf of family caregivers and community-dwelling dependent older adults.

It may be argued that the availability of programs and the extent of care offered to family caregivers will have a direct impact, either negatively or positively, upon caregivers. Investigation of the programs and resources actually available to caregivers and the impact these resources/services might have on them would serve as a reference point and help gauge levels of effectiveness, thus providing direction for future interventions. Therefore, *it is recommended that a comprehensive investigation be initiated that examines the relationship between the current health care system in Turkey and the processes and outcomes of informal family caregiving for dependent older adults.*

Politicians and policy makers today are aware of the value of gleaning from the policies, programs and experiences of other localities or countries in addressing societal challenges. Turkey's researchers would do well to take a look at what other countries are doing, especially those further along on the population-ageing continuum. In particular, attention given to Southern or Mediterranean model countries (those embracing familialistic values) such as Italy, Spain, Greece, or Portugal might offer examples of health care systems that have close affinity and promise of adaptability within the Turkish context. It is also recommended that attention be given to Germany's Long Term Care Insurance, as a possible model to be replicated in some form in Turkey. Thus, *it is recommended that an investigation of other health care systems be carried out, especially of other Southern/Mediterranean model countries related to the process and outcomes of informal family caregiving for dependent older adults.*

Just as the conductor of a train must survey upcoming tracks (to the extent visible) in the event evasive actions are required, so it is important for researchers to understand the future ageing trends of Turkey projected against the current Turkish welfare system to ascertain potential challenges so as to avoid derailment. *It is recommended that future issues surrounding the nature of informal caregiving of older adults in Turkey be identified and ultimately resolved* *within the scope of the current operating principles and organizational framework of the Turkish welfare system.*

Old age is often accompanied by increased risk of loss with regards to social relationships, health, and mobility. As a result, transition into dependency in old age is often demarcated by major life transitions and crises for dependent older adults and their caregivers alike. Informal family caregivers of dependent older adults are particularly likely to experience loss and grief during the course of transitioning into the caring role and during the latter stages of caregiving. Therefore, *it is recommended that issues of loss and grief for family caregivers of older family members be explored that takes into account transitions into and out of the caregiving role including experiences of loss and grief during the early and later caregiving stages.*

Based on the inclusion of the care-recipient perspective, this study required that dependent older adults be dependent only with respect to physical status, requiring that their mental health be intact. Yet, because the literature suggests that caregivers of persons with dementia may experience greater caregiver burden than non-dementia caregivers, *it is recommended that research be carried out to assess the extent and nature of caregiver burden among informal caregivers of older persons with dementia in Turkey using a standardized instrument for measuring burden.* Use of a standardized instrument for measuring burden is recommended for comparability purposes with other studies.

Study results suggest that at most 1 in 10 caregivers (of physically frail but mentally intact dependent older adults) reported health institutions to provide sufficient information on caregiving, while 1 in 15 and 1 in 17 caregivers reported their immediate community and civil institutions to provide sufficient information on caregiving, respectively. Asked to evaluate their knowledge of three different aspects of care-dependency,[85] more than 1 in 4 (26.8 %) reported having no knowledge at all while the majority of respondents (65.4%) reported having knowledge of only one of the three types of knowledge. Given the high proportion of caregivers reporting no knowledge of care-dependency and the reported lack of available caregiving information in general, the following recommendation for further research is offered: *That a research focus be undertaken which targets the extent of primary family caregiver knowledge about (a) the caregiving role associated with the care of both mentally frail older family members (e.g. dementia) as well as physically frail but mentally intact older family members (e.g. chronic illness) and (b) their level of awareness and utilization of social support systems including relevant health care services.*

As documented in the literature review section of this study,[86] respite services for family caregivers of dependent older adults are generally seen as providing a valuable service by affording family caregivers a break away from caregiver duties. Therefore, *it is recommended that investigations be conducted within urban and rural settings throughout Turkey to ascertain the level of availability and access to informal and formal respite support services for family caregivers of dependent older persons.* In addition, among the handful of dementia day care services in Turkey, such as the one connected to the TIYAM [87] project in Nazilli, Aydın, *research could be conducted measuring the usage of elderly day care services and the corresponding outcome with respect to mediation of burden for family caregivers*.

Any number of factors, including reciprocity, interdependency, altruism, family or societal pressure or expectations of reward (as the result of religious belief)

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[85] The three different aspects of care-dependency referred to are *causes for care-dependency, general knowledge of care-dependency,* and *practical knowledge of care-dependency.*

[86] See sub-section 3.8.5.3.2 for details.

[87] TIYAM is a Turkish Acronym (Türkiye İleri Yaş Araştırma Merkezi) that stands for "Turkish Longevity Research Center".

may contribute to the reasons behind why a carer chooses to provide care for an older dependent family member. What are the reasons that informal family caregivers in Turkey tend to care for dependent older family members? In pursuit of an answer to this question, *it is recommended that investigation be made into the motivation of caregivers to do their job.*

While not directly related to caregiver burden, the principal investigator recognized in the course of carrying out fieldwork that a large number of care-dependent older women, especially in rural settings, lacked any form of assistance or care support. Though care-dependent, because these older women were without caregivers, they were not included in the AHCS. Therefore, *it is recommended that an investigation be made into the plight of care-dependent older women in primarily rural environments who either receive (a) no form of care support, or (b) no form of regular or dependable care support.*

Based on the ANOVA test results for Hypothesis 4b in sub-section 6.5.2 and as a means of testing suggested explanations, *it is recommended that further studies be carried out assessing dyadic quality of relationship (QoR) with respect to present QoR and a comparison of past-present QoR*. Results of further research may help to support or reject one or both of two psychology-oriented theories suggested by the principal investigator (See sub-section 7.3, paragraph 3) for explaining unexpected Hypothesis 4b results.

As noted in sub-section 8.3, results of the Antalya Home Care Survey suggest that psycho-spiritual burden accounts for the greatest variance in care-induced burden among caregiver respondents. However, *further research is needed in the other provinces of Turkey to confirm whether caregiver burden of the psycho-spiritual domain also accounts for the greatest proportion of variance at the national level.*

Additionally, *it is recommended that future research in Turkey include cross-sectional and longitudinal studies, as well as qualitative and quantitative studies.* Furthermore, *studies in Turkey that investigate gender differences; younger vs. older caregivers; spouse/partner vs. care for older parents vs. parents-in-law with respect to caregiver burden are recommended.*

8.3 Limitations

Several limitations of the study are acknowledged, including a non-representative sample size, exclusion of caregivers caring for individuals with Alzheimer's and advanced dementia, the omission of a regression analysis, and assessment of burden using a non-standardized instrument. These limitations are addressed below.

Data collected in this study was limited to the Province of Antalya[88] and the results therefore, may not be generalized for Turkey as a whole. Furthermore, the overall sampling size (N = 664) and that of caregivers (n = 332), while helpful in uncovering general trends, is not statistically sufficient for making generalizations for the Province of Antalya.

The mandate of the study, which required mental intactness of respondents in order to secure the collection of reliable information, precluded inclusion of care-recipients with Alzheimer's or severe dementia and their caregivers. This is of particular importance based on studies that report that compared to other care providers, caregivers caring for persons with dementia experience higher levels of burden (Chappell & Reid, 2002; Brodaty et al., 2009), especially with regards to their mental health (Knight and Losada, 2011). Given this study's requirement of cognitive cohesiveness, the care-recipients participating in this study were physically but not mentally frail older adults. Based on the literature, the inclusion of Alzheimer's and dementia caregivers– those

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[88] Antalya is just one of eighty-one provinces represented in the country of Turkey.

caregivers at greatest risk of caregiver burden –would likely have rendered increased levels of especially psycho-spiritual as well as social burden. On the other hand, inclusion of only physically frail older adults in this study may have led to higher levels of reported physical burden among caregivers than might have been expected had the study also included caregivers of mentally frail older adults.

A regression analysis, which was not performed in this study, would offer details as to the extent that variables related to caregiver characteristics, dyadic quality of relationship, and framework conditions of care have on caregiver burden. Such information would serve as verification of the theoretical model – that actual relationships exist between the dependent and independent variables.[89]

Lastly, in this study a non-standardized burden measurement was constructed from the data collected in the Antalya Home Care Survey. From the perspective of the author, the burden instrument made a helpful contribution to the literature, especially with regard to inclusion of the distinctive burden components namely, psycho-spiritual, social, and physical burden. Yet, because the burden measure used is not a standardized measure, comparability with previous studies is limited.

8.4 Concluding Remarks

Though presently a young country, Turkey's population may be described as being on the *fast track* with regard to ageing. As its population continues to age, an increasingly larger proportion of Turkey's population will become care-dependent with comparatively fewer family members available to provide care. Turkey's present position has been described as a "demographic gift period" (Arun, Forthcoming in 2013) and as a "window of opportunity" (Behar, 2006).

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[89] As represented by the theoretical research models found in *Figures 12 and 19*.

Turkey can no longer afford to leave the family– its greatest asset in the provision of welfare (Nolan, 1996) –on its own. In addition to the existing public health system, a support system is needed to address the issues related to supporting the real needs of family caregivers of older persons. It is therefore necessary that provincial and national leaders in Turkey take action to establish programs and services during the present *demographic gift period* to assist family caregivers in providing care for community-dwelling dependent older adults. Subsequent services and programs would help ensure that: (a) family caregivers do not become dependent as a result of providing care, (b) dependent older adults they care for will not be institutionalized or left vulnerable to mistreatment, and (c) informal caregivers of the future will be securable, supported, and feel appreciated in their role as caregivers.

APPENDIX A

FACTORS INFLUENCING AND/OR IMPACTING CAREGIVER BURDEN

SUMMARY OF REPORTED FINDINGS IN THE REVIEW OF LITERATURE

Who	**Outcomes/ Influences**	**What (negative)**	**(Original) Source**
CG	Influence	Correlation b/w CG responsibilities & dyadic QoR, CG health, & decision to institutionalize	Pinquart &Sörensen, 2007; Schulz & Martire, 2004; as cited in Savundranayagam et al., 2011
CGs of chronically ill	Outcome	Psy^{CL} & phy^{CL} burden (especially among caregivers of chronically ill family members)	Butler et al., 2005; Chang et al. 2010 (Pinquart &Sörensen, 2003; Shulz et al., 1995; as cited in Roth et al., 2009; Chang et al., 2010)
CG (in general)	Influence	Exposure to stress associated with various physical & psychological problems	Chiriboga et al., 1990
CGs, especially male & of persons w/ dementia	Outcome	Increased risk of neg. phy^{CL} burden	Knight et al., 2011
CG	Outcome	Decreases in preventative health & immunity; slower wound healing; Greater cardiovascular reactivity, greater risk of (serious) illness, & increased risk of mortality	Schulz & Beach, 1999;as cited in Butler et al., 2005
CG	Influence	Mental health influences physical health	Chang et al., 2010; Savundranayagam et al., 2011; Knight & Losada, 2011
CG	Outcome	Increase neg. phy^{CL} burden (lower antibody counts, higher stress hormones, possible mortality)	Knight et al., 2011
CG	Outcome	Increased levels: depression, anxiety, helplessness, hopelessness, emotional exhaustion, low morale, distress, feeling isolated, guilt, & anger	Raveis et al., 1990
CGs w/ competing demands	Influence	Potential sources of stress: competing demands, childrearing & employment	Stone, C. et al., 1987; as cited in Stuart, et al., 2006
CGs social relationships	Influence	Stressors evoked in social relationships related to psy^{CL} well-being	Chiriboga et al, 1990
CG especially of persons w/ dementia	Outcome	Effects of caregiving (especially of care-recipients with dementia) on caregivers mental health	Knight et al., 2011
CG	Influence	High correlation b/w depression and isolation, knowledge of CG tasks, CG task difficulty, & family support	Butler et al., 2005
CG	Influence	Correlation b/w care-specific & general stressors (especially hassles type & work & social relationships) and well-being	Chiriboga et al.,1990

CG	Influence	Demographic characteristics of CG & CR, level of care-related stress, & quality of CG coping resources	Dilworth-Anderson et al., 2004; as cited in Byrd, J. et al., 2011
CG	Influence	CG tasks + stress may lead to compromised health for caregivers	Shulz & Beach, 1999; as cited in Butler et al., 2005
CG isolation and availability of support - related stress	Outcome	Poorer psy^{CL} and [phy^{CL}] health due to stress from isolation and decreased available supports	Saldaña et al., 1999
CG	Outcome	Depressed immune systems & interferon production - may precipitate increased risk of multiple health problems including cancer	Stein & Schleifer, 1985; as cited in Chiriboga et al., 1990
CG	Influence	Correlation b/w CR behavioral problems with CG well-being, including: psy^{CL} & emotional distress; & increases in CG$_B$, risk of illness, and general phy^{CL} health problems	Casado et al., 2011
CGs education level	Influence	Correlation b/w educ^{TN} level of CG & CG$_B$: Lower educ^{TN} = higher burden & Higher educ^{TN} = lower burden	Cameron et al., 2002; Hughes et al., 1999; Papastavrou et al., 2007; as cited in Byrd et al., 2011; Iecovich, 2011
CG involvement in ADL assistance	Influence	Correlation b/w CG assistance w/ ADLs & CG$_B$: Increase in ADL assistance = increase in obj^{TV} burden	Savundranayagam & Montgomery, 2010; as cited in Savundranayagam et al., 2011
CG involvement in IADL assistance	Influence	Correlation b/w CG assistance w/ IADLs & CG$_B$: Increase in IADL assistance = increase in obj^{TV} burden	Byrd et al., 2011
CG	Influence	Correlation b/w CR characteristics (marital status, *educ^{TN}*, living arrangements, *self-rated health*, morbidity, functional status, *monthly income*, & perceived economic status) & CG$_B$	Iecovich, 2011
CG	Influence	Correlation b/w CG characteristics (age, *educ^{TN}*, *self-rated health*, co morbidity, employment status, & perceived economic status) & CG$_B$	Iecovich, 2011 (also NAC & AARP, 2004, for self-rated health)
CG	Influence	Correlation b/w caregiving characteristics (hrs. wkly. providing care, # ADL/*IADL* tasks performed by CG, & frequency of visits) & CG$_B$	Iecovich, 2011
CG – relation to CR: QoR	Influence	Correlation b/w dyadic *QoR*& CG$_B$ especially high	Iecovich, 2011
CG employment	Influence	Carers also employed in the work force experience less burden	Stoller & Pugliesi, 1989; as cited in Edwards et al., 2002; Jaffe & Blakely, 2000
CG employment	Influence	Employment (especially full-time) among CGs leads to greater levels of burden	Scharlach & Boyd, 1989; as cited in Edwards et al., 2002; Wang et al., 2011
CG employment	Influence	No significant differences b/w strain in employed and non-employed family CGs	Edwards et al., 2002

CG	Influence	Greater burden found among CGs who were older, female, a spouse, or residing together with the CR	Kim, Chang, & Rose, 2010
CG age	Influence	Younger CGs found to experience greater burden than older CGs	Navaie-Waliser et al., 2002; as cited in Carretero et al., 2009
CG of nonmetropolitan residence	Influence	Nonmetropolitan CGs found to be at a health disadvantage (reporting more medical conditions) when compared to metropolitan CGs	Jones, Parker, Ahearn, Mishra, & Variyam, 2009; as cited in Byrd et al., 2011
CG (financial hardship)	Influence	Greater financial hardship found among CGs reporting higher levels of burden & no choice in whether to take on caregiving responsibilities	NAC & AARP, 2005
CG (financial hardship)	Influence	Greater financial hardship found for CGs who were older, assessed health as poor, living with CR, & having a lower income	NAC & AARP, 2005
CG (financial hardship)	Influence	Financial hardship may increase over prolonged period of care, increased seriousness of CR illness, & if CG is a female & of advanced age.	Mears, 1998; as cited in Carretero, 2009

Key:

psy^{CL} - psychological	CG – caregiver	ADL – activities of daily living
phy^{CL} – physical	CR – care-recipient	IADL – instrumental activities of daily living
obj^{TV} – objective	educ^{TN} - education	QoR – quality of relationship

Note: Independent variables (IVs) in *italics*, in addition to having statistical significance in bivariate analyses, were found in subsequent regression analyses to have significant correlation to CG$_{B.}$

APPENDIX B

LISTING OF SAMPLES ACCORDING TO ENVIRONMENT TYPE

NUMBER OF CORRESPONDING HOUSEHOLDS AND INDIVIDUAL INTERVIEWS

Urban	**q**uasi-**R**ural	**R**ural
01 Ahatlı Nbhd *02*-6/12	41 Aydınlık Nbhd *01*-3/6 qR1	66 Cağlarca Vlg *01*-6/13 K1
02 Altınkum Nbhd *01*-1/2	42 Bahtılı Vlg 6/13 qR1	67 Geyikbayırı Vlg 2/5 K1
03 Atatürk Nbhd *02*-4/9	43 Çakırlar Nbhd 4/10 qR1	68 Hısarçandır Vlg 5/11 K3
04 Bahçelievler Nbhd *03*-13/26	44 Akdamlar Vlg 2/4 qR2	69 Kızıllı Vlg *02*-5/10 K1
05 Balbey Nbhd *03*-5/10	45 Hacısekililer Vlg 3/7 qR2	70 Hocaköy Vlg *04*-6/12 K3
06 Baraj Nbhd *02*-7/14	46 Karatepe Nbhd 4/9 qR2	71 Kepez Vlg 4/10 K3
07 Çaybaşı Nbhd *03*-1/2	47 Zümrüt Nbhd 1/3 qR1	72 Kepezbeleni Vlg 1/2 K3
08 Düdenbağı Nbhd *02*-1/2	48 Duacı Vlg *02*-4/8 qR3	73 Süleymanlar Vlg *06*-6/14 K3
09 Fatih Nbhd *02*-3/6	49 Gaziler Vlg 4/8 qR1	74 Kömürcüler Vlg *08*-4/8 K1
~~10 Fener Nbhd~~ -	50 Kirişçiler Vlg 4/9 qR2	75 Yağca Vlg 6/12 K1
11 Gürsü Nbhd *01*-6/12	51 Altınova Nbhd *05*-6/12 qR1	76 Ovacık Vlg *09*-11/22 K3
12 Güvenlik Nbhd *03*-5/10	52 Barbaros Nbhd 4/8 qR2	77 Çamlıbel Vlg *10*-2/4 K3
13 Hüsnü Karakaş Nbhd *02*-1/2	53 Boztepe Nbhd 4/8 qR2	78 Dağbağ Vlg 4/8 K3
14 Kanal Nbhd *02*-5/10	54 Cihadiye Nbhd 6/12 qR1	79 Günçalı Vlg 2/4 K3
15 Karşıyaka Nbhd *02*-1/2	55 Dumanlar Nbhd 3/6 qR3	80 Beden Vlg *12*-7/16 K3
16 Kepez Nbhd *02*-1/2	56 Karaçalı Nbhd 2/4 qR1	81 Beycik Vlg *15*-7/16 K1
17 Kışla Nbhd *03*-6/12	57 Kemerağzı Nbhd 5/10 qR1	82 Ulupınar Vlg 5/11 K1
18 Konuk Sever Nbhd *03*-6/12	58 Kurşunlu Vlg 6/13 qR3	83 Çaykenarı Vlg *16*-8/17 K2
19 Kültür Nbhd *02*-5/10	59 Solak Nbhd 5/10 qR2	84 Köseler Vlg 2/4 K2
20 Kütükçü Nbhd *02*-5/11	60 Yeni Nbhd 2/4 qR2	85 Büyükalan Vlg *17*-3/6 K3
21 Liman Nbhd *01*-1/2	61 Çıplaklı Vlg *08*-3/6 qR2	86 Dereköy Vlg 4/8 K3
22 Meltem Nbhd *03*-11/23	62 Karaman Nbhd 2/4 qR2	87 Beydiğin Vlg *18*-1/3 K2
23 Özgürlük Nbhd *02*-4/8	63 Nebiler Nbhd 3/7 qR1	88 Karabucak Vlg 1/2 K3
~~24 Pınarbaşı Nbhd~~ -	64 Ören Nbhd 1/2 qR2	89 Hasdümen Vlg *19*-10/21 K3
25 Santral Nbhd *02*-1/2	65 Odabaşı Vlg 3/7 qR2	
26 Sinan Nbhd *03*-1/2		Total: *01*-13/29 (Konyaaltı)
27 Siteler Nbhd *01*-3/6	Total: *01*-23/52 (dstr-hhs/intv)	(R) *02*-5/10 (Kepez)
28 Tahılpazar Nbhd *03*-2/4	(qR) *02*-12/25	*04*-11/24 (Akseki)
29 Teomanpaşa Nbhd *02*-5/10	*05*-43/87 (Aksu)	*06*-6/14 (Alanya)
30 Uluç Nbhd *01*-1/2	*08*-12/26	*08*-10/20 (Döşemealtı)
31 Üçgen Nbhd *03*-9/20		*09*-11/22 (Elmalı)
32 Yavuz Selim Nbhd *02*-2/4		*10*-8/16 (Finike)
33 Yeni Nbhd *02*-3/6	**U,qR,R Totals**: U: 38 Nbhd; 150 hhs/306 intv qR: 25 Nbhd/Vlg; 90 hhs/190 intv R: 24 Vlg; 112 hhs/239 intv Total – 87 Nbhd/Vlg 352 hhs/735 intv	*12*-7/16 (Gündoğmuş)
34 Yeşilbahçe Nbhd *03*-5/10		*15*-12/27 (Kemer)
35 Yeşilova Nbhd *03*-7/15		*16*-10/21 (Korkuteli)
36 Yeşiltepe Nbhd *02*-1/2		*17*-7/14 (Kumluca)
37 Yıldız Nbhd *03*-8/16		*18*-2/5 (Manavgat)
38 Yükseliş Nbhd *02*-2/4		*19*-10/21 (Serik)
39 Zerdalilik Nbhd *03*-1/2	**Key:** Nbhd = Neighborhood Vlg = Village dstr = district hhs = household intv = interview e.g. *01* (dstr)–13 (# hhs)/29 (# intv)	
40 Karşıyaka Nbhd(Varsak) *02*-1/2		
Total: *01*-12/24 (dstr-hhs/intv)		
(U) *02*-58/118		
03-80/164 (Muratpaşa)		

APPENDIX C

SECONDARY FACTORS ASSESSMENT FORM

EVALUATION OF ENVIRONMENT TYPE

SECONDARY FACTORS ASSESSMENT FORM ________________
Neighborhood/Village

Health (in immediate vicinity & active)	hospital ☐ 5	health center/ village clinic ☐ 3	health station ☐ 1	no health facility ☐ 0

Evaluation Factor: ....
Health Total: ☐

Education (in immediate vicinity & active)

High School ǀ 5	up to 8th grade ☐ 4	up to 5th grade ☐ 3	up to 3rd grade ☐ 2	no school but service to nearest school ☐ 1	no school ☐ 0

Evaluation Factor: ....
Education Total: ☐

Environmental Factors	A.Road	(road directly connecting community)		pavement ☐ 2	stabilized gravel ☐ 1	dirt/ rough ☐ 0
	B.Bus/ Shared taxi			daily ☐ 2	once/several times weekly ☐ 1	none ☐ 0
	C. Public utility			drinking water and sewage ☐ 2	only drinking water or sewage ☐ 1	neither ☐ 0
	D. Population/ Migration		Minimum of 1,000 population all year long ☐ 3	500 people ☐ 2	150 people ☐ 1	Less than 150 people ☐ 0
	E. Housing density			not scattered (homes adjacent) ☐ 2	medium degree scattered (closest neighbor 2 min. walking distance) ☐ 1	high degree scattered (most neighbors more than 15 min. walking distance) ☐ 0
	F. Communications			land line tel. connection & easy cell phone (gsm) receptivity ☐ 2	land line tel. but generally no gsm connectivity or just gsm connectivity ☐ 1	neither land line connection or gsm connectivity ☐ 0
	G. Electricity			vast majority or all homes have electricity ☐ 2	electricity available but most homes not connected ☐ 1	no electricity available ☐ 0

Evaluation Factor: ....
Environmental Factors Total: ☐

Secondary Factors/Total Pts.: ☐

Primary Factor (based on distance): ☐

.... *Neighborhood/Village* *Assessed Community Classification*: ☐

APPENDIX D

INDEPENDENT CAREGIVER AND CARE-RECIPIENT VARIABLES

ORIGINAL AND RECODED CATEGORIES WITH JUSTIFICATION

Primary Caregiver (PCG) Perspective

Variables	**Categories (original)**	**Categories(RECODED)**	**Justification**
Qj101 In your family (senior's family) are you the only person who can provide your senior with care?	1 = Yes 2 = No	1 = No 2 = Yes	Lower # value = lower CG_B; Higher # value = higher CG_B
ADL As a caregiver, with what tasks do you assist your senior? If assistance provided, recoded as "1". The ADL variable consists of 0-11 items. [Note: In the original data base, each category item was listed as a separate variable – e.g. c35a = comb hair (labeled "a" in ajoining column); c35b = lay down & raise from bed (labeled "b" in ajoining column), etc.].	a = Comb hair b = Lay down & raise from bed c = Undress & dress d = Assist sitting in & standing from chair e = Feed food f = Take to/from toilet g = Bathe h = (If male) Shave i = Assist going up/down steps j = Bowel incontinence cleaning k = Take outside/bring inside l = Other	Comb hair (1) Lay down & raise from bed (1) Undress & dress (1) Assist sitting in & standing from chair (1) Feed food (1) Take to/from toilet (1) Bathe (1) (If male) Shave (1) Assist going up/down steps(1) Bowel incontinence cleaning (1) Take outside/bring inside (1)	Deemed prudent to separate ADLs from IADLs. (Note: Original category item 17 was not included in the recoded version as none of the six items were deemed relevant to the topic.)
IADL As a caregiver, with what tasks do you assist your senior? If assistance provided, recoded as "1". The IADL variable consists of 0-5 items.	a = Cook food b = House cleaning c = Dishes & Laundry d = Shopping e = Assist in financial duties	Cook food (1) House cleaning (1) Dishes & Laundry (1) Shopping (1) Assist in financial duties (1)	Deemed prudent to separate IADLs from ADLs.
Qb23 Since when do you care for your senior?	b23a Days b23b Weeks b23c Months b23d Years	RB23 Years	It was necessary to recode all responses into one common denominator – "Years". All data was recoded via SPSS formula into years.
Qj110 Do you ever worry that you will come to the point where you can no longer continue providing care for your senior?	1 = Exceedingly 2 = Generally 3 = Sometimes 4 = Very Seldom 5 = Never	1 = Never 2 = Very Seldom 3 = Sometimes 4 = Generally 5 = Exceedingly	Lower # value = lower CG_B; Higher # value = higher CG_B

Qb13 Aside from caring for your senior, do you work for a wage at another job?	1 = Yes 2 = No	1 = No 2 = Yes	Lower # value = lower CG_B; Higher # value = higher CG_B
Qb14 (If yes) Do you need to work another job?	1 = Yes 2 = No	1 = No 2 = Yes	Lower # value = lower CG_B; Higher # value = higher CG_B
Qb16 Is this (other) job physically tiring?	1 = Yes 2 = No	1 = No 2 = Yes	Lower # value = lower CG_B; Higher # value = higher CG_B
Qa6 What is your education level? That is, what is the last school from which you graduated?	1 = I didn't go to school 2 = Reading/writing course 3 = Quit school (no diploma) 4 = Night school 5 = Elementary School 6 = Middle School 7 = High School 8 = Tertiary education/Univ	1 = No schooling/diploma 2 = Elementary school (1-5) 3 = Middle school (6-8) 4 = High school (9-11/12) 5 = Tertiary/Univ. (12/13+)	Deemed prudent to narrow top three original categories into one concise category (No schooling/ diploma). (Note: The last yr. of high school was once 11 yrs., now 12 years, thus 11/12 & 12/13+ categories required.)
Qa3 What is your present marital status?	1 = Married 2 = Single 3 = Separated 4 = Divorced 5 = Widowed	1 = Married 2 = Single 3 = Separated/Divorced 4 = Widowed	The total percentage of category items "separated" (n=2) and "divorced" (n=3) were so low (accounting for only 1.5% of respondents combined) that the two were combined into the category "Separated/Divorced"
Qa2 How old are you?	____ Years old	1 = 59 or less 2 = 60 and above	Putting raw age data into the categories "59 or less" and "60 or above" allowed for the testing of additional hypothesis number 1.
Care-Recipient (CR) Perspective			
Variables	**Categories (original)**	**Categories(RECODED)**	**Justification**
Qa2 How old are you?	____ Years old	1 = 74 & under 2 = 75-84 3 = 85 & over	Putting raw age data into the internationally recognized categories *young old* (74 & under), *old old* (75-84), and *oldest old* (85 & over) allows for wider comparisons [how to word?]

Qa3 What is your present marital status?	1 = Married 2 = Single 3 = Separated 4 = Divorced 5 = Widowed	1 = Married 2 = Single 3 = Separated/Divorced 4 = Widowed	The total percentage of category items "Separated" (n=2) and "Divorced" (n=2) were so low (accounting for only 1.2% of respondents combined) that the two were combined into the category "Separated/ Divorced".
Qa10 What level of education did you attain?	1 = I didn't go to school 2 = I know how to read/write 3 = Reading/writing course 4 = Learned reading/writing in military 5 = Quit school (no diploma) 7 = Elementary School 8 = Middle School 9 = High School 10 = Tertiary education/ Univ.	1 = No school/diploma 2 = Elementary (1-5) 3 = Middle school (6-8) 4 = High school (9-11/12) 5 = Tertiary/Univ. (12/13+)	Deemed prudent to narrow top five original categories into one concise category ("No schooling/ diploma"). (Note: The last yr. of high school was once 11 yrs., now 12 years, thus 11/12 & 12/13+ categories required.)

APPENDIX E

PURPOSE STATEMENT

AS FOUND ON COVER PAGE OF BOTH QUESTIONNAIRE TYPES

Project Topic: “Differences in In-Home Care for the Aged in Urban, Quasi-Rural, and Rural Contexts in Turkey”

Brief Purpose Statement: To look for answers to the question: “How can efforts to provide in-home care be best supported and encouraged?”

We want you to know that all of the information you provide will be used solely for scientific research pertaining to this project, namely, seeking to attain the necessary information to assist in improving living conditions for care-dependent seniors. You are not required to answer our questions and are free to terminate this interview at any time. Thank you for your time and assistance.

Prof. Dr. Ismail Tufan
Akdeniz University
Faculty of Science & Literature
Chair, Gerontology Department

Jason Holdsworth
Technical Univ. of Dortmund, Germany
PhD Student

APPENDIX F

CAREGIVER QUESTIONNAIRE

Topic: CAREGIVER PERSPECTIVE Respondent: CAREGIVER *In-Home Care for the Aged: Urban and Rural Contexts*

A) GENERAL INFORMATION

No.			
a1	Gender	Male ☐1 Female ☐2	
a2	How old are you?	☐ Years old	
a3	What is your present marital status?	Married ☐1 Single ☐2 Separated ☐3 Divorced ☐4 Widowed ☐5 Other ☐6	 ____________
a4	How many children do you have?	☐ Children	If no children: from 6 cont.
a5	Starting with the oldest, state the ages of your children.	☐ 1. Child ☐ 2. Child ☐ 3. Child ☐ 4. Child ☐ 5. Child ☐ Others	
a6	What is your education level? That is, what is the last school from which you graduated?	I didn't go to school ☐1 Reading/writing course ☐2 Quit school (no diploma) ☐3 Night school ☐4 Elementary school ☐5 Middle School ☐6 High school ☐7 Tertiary education/Univ. ☐8 Other ☐9	 from 8 cont. from 8 cont. from 8 cont. from 8 cont. ____________
a7	Do you know how to read and write?	Yes ☐1 Partial ☐2 I can only read ☐3 I know another language(s) ☐4 No ☐5	 ____________

B) CAREGIVERS EDUCATION, EXPERIENCE & INCOME ASSESSMENT

b8	Have you received education in caring for the aged?	Yes ☐1 No ☐2	 from 11 cont.
b9	(*If yes*) What was the duration of your education?	< 1month ☐1 1-3 months ☐2 4-6 months ☐3 Other ☐4	 ____________
b10	Where did you receive your education?	Public health center ☐1 Junior College ☐2 Private course ☐3 Other ☐4	 ____________
b11	Have you previous experience caring for another care-dependent senior? *(*If yes: who, how long, for pay?)* +	Evet ☐1 * Hayır ☐2	

Topic: CAREGIVER PERSPECTIVE Respondent: CAREGIVER *In-Home Care for the Aged: Urban and Rural Contexts*

b12	Do you receive a wage as compensation for caregiving?	Yes ☐ 1 No ☐ 2	
b13	Aside from caring for your senior, do you work for a wage at another job?	Yes ☐ 1 No ☐ 2	 from 17 cont.
b14	(*If yes*) Do you need to work another job?	Yes ☐ 1 No ☐ 2	
b15	At this other job, how many hours do you work per day? (*Write exact number*)	☐ Hours	
b16	Is this (other) job physically tiring?	Yes ☐ 1 No ☐ 2	
b17	Approximately how much do you earn a month? (denote personal income - *Write exact number*)	__________ None ☐ 1 < 200 TL ☐ 2 200-400 TL ☐ 3 401-600 TL ☐ 4 601-800 TL ☐ 5 801-1000 TL ☐ 6 > 1000 TL ☐ 7	
b18	Do you live in the same home with your senior?	Yes ☐ 1 No ☐ 2	from 20 cont.
b19	(*If no*) Coming from your home to your seniors, do you need to take some form of transport?	Yes ☐ 1 No ☐ 2	
b20	What is the relation between you and the senior you care for?	Spouse ☐ 1 Parent ☐ 2 Parent-in-law ☐ 3 Grandparent ☐ 4 Spouse's grandparent ☐ 5 Other ☐ 6	 ____________
b21	Do *you* provide all of the care needs for your senior?	Yes ☐ 1 No ☐ 2	
b22	How many seniors do you provide care for?	☐ Senior	
b23	Since when do you care for your senior?	☐ Year(s) ☐ Month(s)	
b24	Was there someone else, before you, who provided care for your senior?	Yes ☐ 1 No ☐ 2	 from 26 cont.
b25	(*If yes*) Who was the caregiver before you? (Denote the caregivers kin/family relation to the senior)	☐	
b26	Who suggested that you should look after your senior?	I wanted to ☐ 1 My family wanted me to ☐ 2 Other ☐ 3	 ____________

b27	Is it tiring to look after your senior?	Not at all	☐ 1	
		It's not	☐ 2	
		Normal	☐ 3	
		Tiring	☐ 4	
		Very tiring	☐ 5	
b28	(*If caregiver is relative*) Does caring for your senior bring *economic* burden?	Brings a heavy burden	☐ 1	
		Brings a burden	☐ 2	
		No change (regarding burden)	☐ 3	
		Doesn't bring burden	☐ 4	
		Brings no burden at all	☐ 5	
b29	As a result of caregiving are you under spiritual/psychological stress?	None at all	☐ 1	
		No	☐ 2	
		Normal	☐ 3	
		Yes	☐ 4	
		Very much	☐ 5	

C) ENVIRONMENTAL PERCEPTION & WORK BURDEN OF CAREGIVER

c30	Since taking on the role of caregiver, how have your social relationships changed?	They've become much better	☐ 1	
		Better	☐ 2	
		No change	☐ 3	from 32 cont.
		Gotten worse	☐ 4	
		Gotten much worse	☐ 5	
c31	(*If there's been change*) Who does this effect? + (*More than one answer may be marked*)	Family members	☐ 1	
		Relatives	☐ 2	
		Neighbors	☐ 3	
		Other	☐ 4	__________
c32	How do the people in your community percieve the work you do [as caregiver]?	Very well	☐ 1	
		Well	☐ 2	
		Normal	☐ 3	
		Poorly	☐ 4	
		Very poorly	☐ 5	
c33	How does this perception effect you?	Very well	☐ 1	
		Well	☐ 2	
		Normal	☐ 3	
		Poorly	☐ 4	
		Very poorly	☐ 5	
c34	Generally, in what environment do you provide care?	Only at home	☐ 1	
		Only outside the home	☐ 2	
		Both in & outside the home	☐ 3	
c35	As a caregiver, with what tasks do you assist your senior? (*More than one answer may be marked*)	Comb hair	☐ 1	
		Lay down & raise from bed	☐ 2	
		Undress & dress	☐ 3	
		Assist sitting in & standing from chair	☐ 4	
		Feed food	☐ 5	
		Take to/from toilet	☐ 6	
		Bathe	☐ 7	
		Cook food	☐ 8	
		(If male) Shave	☐ 9	

		House cleaning ☐10 Dishes & laundry ☐11 Assist going up/down steps ☐12 Shopping ☐13 Assist in financial duties ☐14 Bowel incontinence-based cleaning ☐15 Take outside/bring inside ☐16 Other ☐17 __________
c36	In general, during what portion of the day do you need to be at your seniors side?	Morning ☐1 Afternoon ☐2 Evening ☐3 All day/night ☐4
c37	For caregiving purposes only, how many hours do you need to set aside?	☐ Hours
c38	In the area of caregiving, is there anyone who helps you?	Yes ☐1 Who? _________ No ☐2

D) <u>ASSESSMENT OF CAREGIVER-SENIOR RELATIONSHIP</u>

d39	(If caregiver is relative) Would you prefer to have a trained caregiver come in to do your job?	Yes ☐1 No ☐2 from 41 cont.
d40	Up until this time, why have you not tried this path?	Couldn't find trained caregiver ☐1 Conscience would not permit ☐2 Economic reasons ☐3 Concerned what neighbors think ☐4 My family would not want this ☐5 Other reasons ☐6 __________
d41	Assess your relationship to your senior.	Very good ☐1 Good ☐2 Neither good nor bad ☐3 Bad ☐4 Very bad ☐5
d42	How has your relationship with your senior changed when compared to their pre-care-dependency days?	It's much better ☐1 Better ☐2 Not changed ☐3 Worse ☐4 Much worse ☐5

E) <u>CAREGIVERS GENERAL HEALTH</u>

e43	How is your general health?	Very good ☐1 Good ☐2 Normal ☐3 Poor ☐4 Very poor ☐5
e44	Do you have any chronic illnesses? +	Yes ☐1 No ☐2

e45	Do you have any physical disabilities?	Yes	☐ 1
		No	☐ 2
e46	Are you psychologically/spiritually unwell?	Yes	☐ 1
		No	☐ 2

F) <u>CAREGIVERS ATTITUDE & BEHAVIOR TOWARDS SENIOR</u>

f47	In your opinion, does your senior need professional care?	Most definitely	☐ 1
		Yes	☐ 2
		No	☐ 3
		Not at all	☐ 4
		I don't know	☐ 5
f48	In your opinion, are seniors better cared for in nursing/rest homes?	Most definitely	☐ 1
		Yes	☐ 2
		No	☐ 3
		Definitely not	☐ 4
		I don't know	☐ 5
f49	In your opinion, would your senior prefer to move into a nursing home?	S/he most certainly would	☐ 1
		S/he probably would	☐ 2
		S/he probably would not	☐ 3
		S/he most certainly would not	☐ 4
		I don't know	☐ 5
f50	Do you think that your senior is being well cared for in every respect?	Most definitely	☐ 1
		Yes	☐ 2
		No	☐ 3
		Definitely not	☐ 4
		I don't know	☐ 5
f51	Up until this time, has the word "*of*" [expressing frustration, complaint] ever come from your mouth?	Most certainly I've said it	☐ 1
		I've probably said it	☐ 2
		I don't think I've said it	☐ 3
		I definitely have not said it	☐ 4
		I don't know	☐ 5
f52	Do you make every effort to always give your senior his/her medication right on time?	I never give it late	☐ 1
		I generally do not give it late	☐ 2
		Generally given late	☐ 3
		I'm never able to give this issue my attention	☐ 4
		I don't know	☐ 5
f53	Do you make every effort to serve your senior food on time?	I never give it late	☐ 1
		I generally do not give it late	☐ 2
		Generally given late	☐ 3
		I'm never able to give this issue my attention	☐ 4
		I don't know	☐ 5
f54	From time-to-time every person may be unable to control their anger. While providing care, do you ever experience such moments?	Certainly happens	☐ 1
		Generally happens	☐ 2
		Generally does not happen	☐ 3
		Certainly does not happen	☐ 4
		I don't know	☐ 5

f55	Should a care-dependent person be grateful for the asistance received from those in their family/community?	Certainly should be [grateful] ☐ 1 Should be ☐ 2 No need to be ☐ 3 Definitely no need to be ☐ 4 I don't know ☐ 5
f56	In your opinion, at what level is your senior held in esteem/honor by his/her family?	Very high ☐ 1 High ☐ 2 Not very high ☐ 3 Not high at all ☐ 4 I don't know ☐ 5
f57	Are you careful not to *break* [upset] your seniors heart?	I'm very careful ☐ 1 I'm generally careful ☐ 2 I'm not able to be all that careful ☐ 3 I'm not able to be careful at all ☐ 4 I don't know ☐ 5
f58	(If caregiver is relative) If you had the means, would you hire a trained caregiver?	I'd hire one right away ☐ 1 I probably would ☐ 2 I probably would not ☐ 3 I definitely would not ☐ 4 I don't know ☐ 5
f59	Despite the pressures associated with caregiving, are you able to show your senior a smiling face?	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f60	A person can do things that they later come to regret. All of us do this from time-to-time. Do you do some things to your senior that you later come to regret.	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f61	Can your seniors behavior make you angry?	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f62	A person may be different one day from the next. In an angry moment, have you ever rebuked your senior?	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f63	In anger have you ever raised your hand at your senior?	Very often ☐ 1 More times than necessary ☐ 2 On rare occasion ☐ 3 Never ☐ 4 I don't know ☐ 5

f64	On holidays, do you maintain the tradition of kissing your seniors hand?	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f65	Are you able to change your seniors clothes on a regular basis?	All the time ☐ 1 Generally ☐ 2 Rarely ☐ 3 Never ☐ 4 I don't know ☐ 5
f66	Is it good, even in the event of care-dependency, for a person to live together with their aged family member?	Very good ☐ 1 Good ☐ 2 On rare occasions good ☐ 3 Not at all good ☐ 4 I don't know ☐ 5
f67	To what extent do you think your senior trusts you?	Very trusting ☐ 1 Trusting ☐ 2 Not very trusting ☐ 3 Not at all trusting ☐ 4 I don't know ☐ 5

G) SATISFACTION WITH INSTITUTIONAL SUPPORT FOR SENIOR CARE

g68	Evaluate your *knowledge* of care-dependency? *(More than one answer may be marked)*	I've general knowledge ☐ 1 I know causes (for c.-d.) ☐ 2 I've practical knowledge ☐ 3
g69	In your opinion, are senior care providers in need of a caregiver training course?	Yes ☐ 1 No ☐ 2
g70	Do civil institutions (govt. agencies) provide you with sufficient information on caregiving?	Yes ☐ 1 No ☐ 2
g71	Do health institutions provide you with sufficient information on caregiving?	Yes ☐ 1 No ☐ 2
g72	In your immediate community, are there resources from which you can obtain information on caregiving?	Yes ☐ 1 No ☐ 2
g73	In your opinion, do caregivers of seniors need psychological counseling?	Yes ☐ 1 No ☐ 2
g74	In your opinion, do caregivers of seniors need social counseling?	Yes ☐ 1 No ☐ 2

H) PHYSICAL PROFICIENCY IN CARE ENVIRONMENT

h75	Does your senior own a home?	Yes ☐ 1 No ☐ 2
h76	Is your senior cared for in his/her own home? (*If no, note the reason*) +	Yes ☐ 1 No ☐ 2

h77	How many rooms are in the home where your senior is cared for?	☐ Rooms
h78	How many people live in the home where your senior is cared for?	☐ People
h79	Is there a private room for the caregiver?	Yes ☐ 1 No ☐ 2
h80	Is there a private room for your senior?	Yes ☐ 1 No ☐ 2
h81	On what floor is the home?	Ground floor ☐ ☐ Floor
h82	Is there an elevator in the building?	Yes ☐ 1 No ☐ 2
h83	By what means is the house heated?	Coal stove ☐ 1 Electric heater ☐ 2 Central heating unit ☐ 3 Air conditioner ☐ 4 Other ☐ 5 __________
h84	Does the home have a bathroom?	Yes ☐ 1 No ☐ 2
h85	Is there a bathtub in the bathroom?	Yes ☐ 1 No ☐ 2
h86	Is there a hot water system in the home?	Yes ☐ 1 No ☐ 2
h87	Is there a heater in the bathroom?	Yes ☐ 1 No ☐ 2
h88	Is the bathroom wide enough for two people to comfortably enter?	Yes ☐ 1 No ☐ 2
h89	Where does your senior take a bath?	Bathroom ☐ 1 Bedroom ☐ 2 Kitchen ☐ 3 Sitting room ☐ 4 Other ☐ 5 __________
h90	Is the toilet in the house?	Yes ☐ 1 No ☐ 2
h91	Is the toilet wide enough for two people to comfortably enter?	Yes ☐ 1 No ☐ 2
h92	What style is your toilet?	Turkish style ☐ 1 European style ☐ 2
h93	Is there hot water available in the toilet?	Yes ☐ 1 No ☐ 2

i) FALLS & HOME ACCIDENTS

i94	Has your senior ever fallen while in your care?	Yes ☐ 1 No ☐ 2 from 97 cont.	
i95	(*If yes*) Where and how did s/he fall? +	Sitting room ☐ 1 Bathroom ☐ 2 Toilet ☐ 3 Bedroom ☐ 4 Kitchen ☐ 5 Other ☐ 6 __________	
i96	After falling, was any precaution taken to prevent it from happening again? +	Yes ☐ 1 No ☐ 2	
i97	Apart from falling, has your senior had an accident in the home?	Yes ☐ 1 No ☐ 2 from 101 cont.	
i98	What accident(s)?	1. ________________ 2. ________________ 3. ________________	
i99	At the time of the accident, were you beside/with your senior?	Yes ☐ 1 1 -2 - 3 No ☐ 2 1 -2 - 3	Circl appr numl
i100	After the accident, was any precaution taken to prevent it from happening again? +	Yes ☐ 1 No ☐ 2	

J) MATERIAL & SPIRITUAL INFLUENCES BEARING UPON CAREGIVER

No.		
j101	In your family (senior's family) are you the only person who can provide your senior with care?	Yes ☐ 1 No ☐ 2

No.		Exceedingly	Generally	Sometimes	Very seldom	Never
j102	Do your family members assist you in providing care?	1	2	3	4	5
j103	Do your neighbors assist you in providing care?	1	2	3	4	5
j104	In general (for whatever reason), while providing care have you experienced disillusionment?	1	2	3	4	5
j105	Does your senior have a part in this disillusionment?	1	2	3	4	5
j106	Do your family members have a part in this disillusionment?	1	2	3	4	5
j107	Do your neighbors have a part in this disillusionment?	1	2	3	4	5
j108	While providing care, have you ever felt angry?	1	2	3	4	5
j109	As much as possible, does your senior try and make your job as easy as possible?	1	2	3	4	5
j110	Do you ever worry that you will come to the point where you can no longer continue providing care for your senior?	1	2	3	4	5

If *never*: from 108 cont.

No.		Very negatively	Negatively	No affect	Positively	Very positively
j111	How has undertaking caregiving affected you **economically**?	1	2	3	4	5
j112	How has undertaking caregiving affected your **social relationships**?	1	2	3	4	5
j113	How has undertaking caregiving affected your **physical** health?	1	2	3	4	5
j114	How has undertaking caregiving affected you **spiritually**?	1	2	3	4	5
j115	How has undertaking caregiving affected your **family relationships**?	1	2	3	4	5
j116	How has undertaking caregiving affected your **relationship to your relatives**?	1	2	3	4	5

K) AVAILABILITY OF COMMUNITY RESOURCES IN MEETING SENIORS MEDICAL & SOCIAL NEEDS

No.

k117 Are you able to meet your seniors medical needs with the resources available in your local community?

Yes ☐ 1
Partially ☐ 2
No ☐ 3

k118 Is there a pharmacy in your local vicinity?

Yes ☐ 1
No ☐ 2

k119 Is there a public health center in your local vicinity?

Yes ☐ 1
No ☐ 2

k120 Is there a hospital in your local vicinity?

Yes ☐ 1
No ☐ 2

k121 Is there a doctor in your local vicinity?

Yes ☐ 1
No ☐ 2

k122 How often does the task of visiting a pharmacy on behalf of your senior fall upon you?

≥ 1 per week	1-3 per month	< 1 per month	1 time per 3 months	1 per year	Never
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

k123 How often does the task of visiting a public health center on behalf of your senior fall upon you?

≥ 1 per week	1-3 per month	< 1 per month	1 time per 3 months	1 per year	Never
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

k124 How often does the task of visiting a doctor on behalf of your senior fall upon you?

≥ 1 per week	1-3 per month	< 1 per month	1 time per 3 months	1 per year	Never
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

k125 Which of these require a vehicle?

Pharmacy ☐ 1
Public health center ☐ 2
Hospital ☐ 3

k126 Is it possible for your senior to board public transportation?

Yes	1
Can board with difficulty	2
Only with assistance	3
No	4

k127 When taking your senior to a medical facility such as a public health clinic or hospital, what form of transport do you benefit from?

Bus	1	
Shared taxi	2	
Train	3	
Private vehicle	4	
Horse drawn cart	5	
Pack animal	6	
Other	7	________

k128 How does available transportation, when employed in taking your senior to a medical facility such as a public health clinic or hospital, affect your senior?

Very positively	Positively	Neither positively nor negatively	Negatively	Very negatively
1	2	3	4	5

k129 If we think in general, is it possible for your senior to go out on the street with the assistance of an escort?

Yes	1	
With difficulty	2	
No	3	
Other	4	________

k130 Is your senior fit enough to go outside on his/her own?

There's no doubt, yes	Yes	Can't say for sure	No	Definitely not
1	2	3	4	5

k131 Does it do your senior good to get outside? (*How does it affect their general state?*)

Very positively	Positively	Neither positively nor negatively	Negatively	Very negatively
1	2	3	4	5

k132	If your senior should go outside, for what general reason does s/he do so? (*More than one answer may be marked*)	To be seen by a doctor	1
		Go to hospital	2
		Go public health center	3
		Go to pharmacy	4
		Go to visit neighbor	5
		Go for a stroll	6
		Other	7 _______

No.		Every day	Few times a week	Once a week	Few times a week	Few times a year	Never
k133	How often does your senior go outside?	1	2	3	4	5	6
k134	How often is your senior taken/go to a doctor?	1	2	3	4	5	6
k135	How often is your senior taken/go to a hospital?	1	2	3	4	5	6
k136	How often is your senior taken/go to a public health center?	1	2	3	4	5	6
k137	How often is your senior taken/go to a pharmacy?	1	2	3	4	5	6
k138	How often is your senior taken/go to visit a neighbor?	1	2	3	4	5	6
k139	How often is your senior taken out/go on an outing?	1	2	3	4	5	6

L) ENVIRONMETAL NOISE & AFFECTS ON SENIOR

		Very noisy	Noisy	Neither noisy nor quiet	Very quiet	No noise at all
L140	How do you evaluate environmental nosie levels?	1	2	3	4	5

... If *No noise*: from 146 cont

L141	What are the primary forms of noise pollution? *(More than one answer may be marked)*	Vehicles (car, *plane, motorcycle, bus, etc.*)	1
		Celebrations (*Sending off of soldier, wedding, soccer match, etc.*)	2
		Children	3
		Neighbors	4
		Loud speakers (*mosque, school, traveling salesperson*)	5
		Other	6 ______________________

L142 How does noise affect your senior?

Very positively	Positively	Neither positively nor negatively	Negatively	Very negatively
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

L143 During which period of the day is it most noisy?

Mornings ☐ 1
Afternoon ☐ 2
Evenings ☐ 3
All day long ☐ 4

L144 Have you taken any precautions to protect your senior from noise [pollution]?

Yes ☐ 1
No ☐ 2 from146 cont.

L145 (If yes) What precautions have you taken?

I don't open window(s) ☐ 1
I give sleeping medicine ☐ 2
I lower television volume ☐ 3
I request of neighbors to keep noise down ☐ 4
I request of children to keep noise down ☐ 5
Other ☐ 6

M) AIR POLLUTION & AFFECTS ON SENIOR

m146 Is there air pollution [in your vicinity]?

Yes ☐ 1
No ☐ 2 from 150 cont.

m147 During which season do pollution levels rise to an uncomfortable level?

During the winter ☐ 1
During the summer ☐ 2
In the spring ☐ 3
In the fall ☐ 4
All year long ☐ 5

m148 What are the general affects that air pollution have on your senior?

No affect	Minor negative affect	Negative affect	Very negative affect
☐ 1	☐ 2	☐ 3	☐ 4

m149 Does your senior suffer any resperatory illness?

Yes ☐ 1
No ☐ 2

N) GOVERNMENT AGENCIES APPROACH TO CARE DEPENDENCY

n150 Does the task of visiting a government agency (*Ex. Old age pension, land registry, public health center, social services, etc.)* on behalf of your senior fall upon you?

Very often	Often	Neither often nor seldom	Seldom	Never
1	2	3	4	5

If *never*: from 152 cont.

n151 When seeking care for your senior at a government agency, do they give you priority?

Very often	Often	Neither often nor seldom	Seldom	Never
1	2	3	4	5

n152 If your senior were offered priority at a government agency, would this affect care?

Would be very beneficial	Would be beneficial	Would not matter either way	Would not provide benefit	Would provide absolutely no benefit
1	2	3	4	5

n153 If at government agencies caregivers of seniors were offered priority, would this be of benefit to the caregiver?

Would be very beneficial	Would be beneficial	Would not matter either way	Would not provide benefit	Would provide absolutely no benefit
1	2	3	4	5

O) VIEWS ON DEATH AND DYING

No.

o154 I have some questions regarding death.
Do you mind my asking these questions?

Yes	☐ 1	..from 165 cont.
No	☐ 2	

o155 At the thought of losing your senior some day, does this prompt you to begin thinking about death?

Very often	Often	Neither often nor seldom	Seldom	Never
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o156 Does the thought that your senior could/will die frighten you?

Very much frightens me	Frightens me	I don't know	Doesn't frighten me	Doesn't frighten me at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o157 Has care-dependency changed your views concerning death and dying?

Totally changed	Changed	I don't know	Not changed	Not changed at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o158 Do your religious beliefs bring you relief on this topic?

Very much so	Yes	I don't know	No	Not at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o159 Do you believe that death can be beautiful?

I fully believe this	I believe	I don't know	I don't believe	I do not believe this at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o160 If the present situation could be preserved as is, would you like to continue living together with your senior?

Most definitely I would	I would	I don't know	I would not want to	Most definitely I would not
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

o161 Some people want to die. Can you understand those who would chose this road?

I definitely understand	I undersatnd	I don't know	I don't understand	I don't undersatnd at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

		Most certainly	Yes	I don't know	No	Certainly not
o162	If your senior were to experience unbearable pain, would s/he want to die?	1	2	3	4	5

		I'd give full support	I would	I don't know	I would not	Certainly not
o163	If your senior were to pursue **euthanasia** by his/her own will, would you support them?	1	2	3	4	5

		I would certainly show forbearance	I would	I don't know	I would not	I certainly would not
o164	Though the decision to take ones own life is not sanctioned by our religious beliefs, if your senior were to experience unbearable pain and pursue euthanasia, would you still show forbearance?	1	2	3	4	5

P) SEXUALITY

No.				
p165	I have some questions related to sexuality and old age. Do you mind my asking these?	Yes	1	from 173 cont.
		No	2	

No.		Without a doubt	Yes	I don't know	No	Certainly not
p166	Do you think that sexuality is a topic of interest among the aged?	1	2	3	4	5
p167	Do you think that sexuality is a topic of interest for your senior?	1	2	3	4	5
p168	Do you think that the aged should also participate in sexual relations?	1	2	3	4	5
p169	Do you feel uncomfortable when your senior undresses in your presence?	1	2	3	4	5
p170	Do you think that your senior is made uncomfortable by this?	1	2	3	4	5
p171	Can you share your thoughts regarding sexuality with your senior?	1	2	3	4	5

R) BURDEN OF CAREGIVING UPON CAREGIVER & IMPACT ON FAMILY

No. NOTE: *THIS SECTION PERTAINS ONLY TO CAREGIVERS OF FAMILY RELATION TO SENIOR*

r172	Does your seniors care-dependency have an effect on your family?	Yes	1	
		No	2	**Thank respondent and end interview!**

No.		Very negative	Negative	Neither negative nor positive	Positive	Very positive
r173	How do you appraise the general effect?	1	2	3	4	5
r174	What is the effect on your relationship to your senior? +	1	2	3	4	5
r175	(*If spouse is living*) What is the effect on your relationship to your spouse? +	1	2	3	4	5
r176	(*If have children*) What is the effect on your relationship to your children? +	1	2	3	4	5

Thank respondent and end interview!

APPENDIX G

CARE-RECIPIENT QUESTIONNAIRE

A) GENERAL INFORMATION

No.			
a1	Gender	Male ☐ 1 Female ☐ 2	
a2	How old are you?	☐ Years Old 19 ___ 9*	
a3	What is your present martital status?	Married ☐ 1 Single ☐ 2 Separated ☐ 3 Divorced ☐ 4 Widowed ☐ 5 Other ☐ 6	
a4	How many times have you married?	None ☐ 1 One time ☐ 2 More than once ☐ 3	...from 9 cont. ...from 8 cont.
a5	Do you have children from your previous marriages?	Yes ☐ 1 No ☐ 2	...from 6 cont. ...from 7 cont.
a6	How many children do you have still alive, including children from previous marriages? (enter whole number)	☐ Children	If 0: from 7 cont. ≥1: from 9 cont.
a7	How many living children do you have from your present marriage? (enter whole number)	☐ Children	If 0: from 9 cont.
a8	At present how many children do you have still living?	☐ Children	
a9	May I learn your date of birth?	19 _____ I don't know ☐ 2	
a10	What level of education did you attain?	I didn't go to school ☐ 1 I know how to read/write ☐ 2 Reading/writing course ☐ 3 Learned reading/writing in military ☐ 4 Quit school (no diploma) ☐ 5 Night school ☐ 6 Elementary school ☐ 7 Middle school ☐ 8 High school ☐ 9 Tertiary education/University ☐ 10 Other ☐ 11	 from 12 cont. from 12 cont. from 12 cont. from 12 cont. __________
a11	Do you know how to read and write?	I can read/write ☐ 1 With some difficulty ☐ 2 I can only read ☐ 3 I know another language(s) ☐ 4 No ☐ 5	 __________

B) ABILITY TO MEET PERSONAL NEEDS MEASUREMENT

NOTE: If *necessary*, would you be able to perform these tasks?

No.		I certainly can/could	I can	I can't say for sure	I can not	I certainly can not
b12	Comb hair	1	2	3	4	5
b13	Lay down & rise from bed	1	2	3	4	5
b14	Get dressed & undressed	1	2	3	4	5
b15	Sit down & stand up	1	2	3	4	5
b16	Eat & drink	1	2	3	4	5
b17	Go to the bathroom	1	2	3	4	5
b18	Bathe	1	2	3	4	5
b19	Cook food	1	2	3	4	5
b20	(*If male*) Shave	1	2	3	4	5
b21	Clean home	1	2	3	4	5
b22	Clean dishes & laundry (*Given no caregiver, dishwasher or washing machine*)	1	2	3	4	5
b23	Walk up & down stairs	1	2	3	4	5
b24	Shopping	1	2	3	4	5
b25	Purchase items from visiting street vendors	1	2	3	4	5
b26	Financial duties (*withdraw money & make payments*)	1	2	3	4	5
b27	Find your way walking around outside	1	2	3	4	5

C) LIFE VIEWS MEASUREMENT

No.		Very important	Important	Not important
c28	How important is mobility (ability to move about or engage in activity) to you?	1	2	3
c29	How important is friendship to you?	1	2	3
c30	*(If have children)* How important are your children to you?	1	2	3
c31	How important is your home to you?	1	2	3
c32	How important is peace of mind to you?	1	2	3
c33	How important is money to you?	1	2	3
c34	How important is it to you not to be dependent on others for care?	1	2	3
c35	How important is [your] health to you?	1	2	3
c36	How important is happiness to you?	1	2	3
c37	How important is security to you?	1	2	3
c38	How important is [day-to-day] life outside of your home to you?	1	2	3
c39	How important is your body to you?	1	2	3

No.		Yes	No
c40	Can you say that you are sufficienly active?	1	2
c41	Can you say that you have a sufficient number of friends?	1	2
c42	*(If have children)* Can you say that you are pleased with your relationship(s) with your children?	1	2
c43	Can you say that you are pleased with your home?	1	2
c44	Can you say that regarding peace of mind you have no problems?	1	2
c45	Can you say that you are pleased with your health?	1	2
c46	Can you say that you are a happy person?	1	2
c47	Can you say that you haven't any problems regarding community participation?	1	2
c48	Can you say that you are pleased with the condition of your body?	1	2

No.		Very often	Sometimes	Never
c49	Do you make plans regarding your life?	1	2	3
c50	Are you able to see your friends?	1	2	3
c51	Do you think about your children?	1	2	3
c52	Do you have financial problems?	1	2	3
c53	Do you desire to be independent & without need of care?	1	2	3
c54	Do you look for ways to protect your health?	1	2	3
c55	Are there times when you are fearful? +	1	2	3
c56	Do you miss getting together with friends?	1	2	3

D) <u>ASSESSMENT OF CAREGIVER, FAMILY & INSTITUTION(S)</u>

d57 Do you think about moving into a nursing home?

Very often	1
Sometimes	2
Only if necessary	3
Never	4
I don't know	5

d58 Do you have need of professional care?

Without a doubt	1
Yes	2
No	3
Definetly not	4
I don't know	5

d59 What do you think of the quality of care offered at nursing/rest homes?

Very high	1
High	2
Low	3
Very low	4
I don't know	5

d60 Would you like to live in a nursing/rest home?

Most certainly	1
I would	2
Not particularly	3
Definitely not	4
Only as necessary	5
I don't know	6

d61	At this time are you being well cared for?	Very well	☐ 1
		Pretty well	☐ 2
		Could be better	☐ 3
		Not at all	☐ 4
		I don't know	☐ 5
d62	Has the term "*of*" [expressing frustration/complaint] been spoken to you even once?	Very often	☐ 1
		Yes	☐ 2
		No	☐ 3
		Never	☐ 4
		I don't know	☐ 5
d63	Do you take your medications right on time?	Always on time	☐ 1
		Generally	☐ 2
		Rarely	☐ 3
		No	☐ 4
		I don't know	☐ 5
d64	Are you served food on a regular time schedule?	Always on time	☐ 1
		Generally	☐ 2
		Rarely	☐ 3
		No	☐ 4
		I don't know	☐ 5
d65	Is it normal for caregivers of seniors to get angry?	Very normal	☐ 1
		Normal	☐ 2
		Not normal	☐ 3
		Not normal at all	☐ 4
		I don't know	☐ 5
d66	Do you feel gratitude towards your caregiver for the care you're given?	I'm very grateful	☐ 1
		I feel grateful	☐ 2
		Not particularly grateful	☐ 3
		Not at all grateful	☐ 4
		I don't know	☐ 5
d67	Are you esteemed/honored within your family?	Most definitely	☐ 1
		You could say so	☐ 2
		Not particularly	☐ 3
		Not at all	☐ 4
		I don't know	☐ 5
d68	Does your caregiver ever raise his/her voice at you?	All the timer	☐ 1
		Frequently	☐ 2
		Sometimes	☐ 3
		Never	☐ 4
		I don't know	☐ 5
d69	If you had the means, would you hire a [professional] caregiver?	Right away	☐ 1
		Yes	☐ 2
		Perhaps	☐ 3
		No I would not	☐ 4
		Only as needed in the future	☐ 5

d70	Do you prefer to be cared for by your family?	Most certainly	☐ 1
		Yes	☐ 2
		No	☐ 3
		Definitely not	☐ 4
		I don't know	☐ 5
d71	Does your caregiver cast a 'sour face' towards you?	Most certainly	☐ 1
		Yes	☐ 2
		No	☐ 3
		Definitely not	☐ 4
		I don't know	☐ 5
d72	(Assuming a sour face) Is this normal?	Very normal	☐ 1
		Normal	☐ 2
		Not normal	☐ 3
		Not at all normal	☐ 4
		I don't know	☐ 5
d73	Since becoming care-dependent, have you been subjected to physical violence (hitting, beating, or being pushed)?	All the time	☐ 1
		Frequently	☐ 2
		Very infrequently	☐ 3
		Never	☐ 4
		I don't know	☐ 5
d74	Do you spend the holidays together with your children?	All the time	☐ 1
		Frequently	☐ 2
		Very infrequently	☐ 3
		Never	☐ 4
		I don't know	☐ 5
d75	Are your clothes changed on a regular basis?	All the time	☐ 1
		Frequently	☐ 2
		Very infrequently	☐ 3
		Never	☐ 4
		I don't know	☐ 5
d76	Is it good for a person to live together with his/her family?	Most certainly	☐ 1
		Yes	☐ 2
		No	☐ 3
		Definitely not	☐ 4
		I don't know	☐ 5

E) FINANCIAL/SOCIAL SECURITY

e77	Have you ever worked and received a salary?	Yes	☐ 1	
		No	☐ 2	
e78	Were you insured?	Yes	☐ 1	
		No	☐ 2	
e79	Were you able to retire?	Yes	☐ 1	from 81 cont.
		No	☐ 2	

e80	(*Assuming no retirement pension*) Do you receive an old age [non-contributory] pension?	Yes ☐ 1 from 82 cont. No ☐ 2 from 82 cont.
e81	What is the amount of your retirement pension?	☐ TL/Month
e82	What source(s) of income do you have? (More than one box may be marked)	Retirement ☐ 1 Rent ☐ 2 From family ☐ 3 Other ☐ 4 ____________ I have no income ☐ 5
e83	Does your income cover your care costs?	Yes ☐ 1 Just get by ☐ 2 No ☐ 3
e84	From a social standpoint do you feel safeguarded/secure?	Most certainly ☐ 1 Yes ☐ 2 No ☐ 3 Definitely not ☐ 4 I don't know ☐ 5
e85	Is your disability [state of care-dependence] a result of your job/vocation? +	Yes ☐ 1 No ☐ 2
e86	Since when have you had need of care?	☐ Year ☐ Month

F) HEALTH CONDITION & HOSPITAL EVALUATION

f87	Do you have any chronic illness(es)? +	Yes ☐ 1 ____________ No ☐ 2
f88	How many chronic illnesses do you have?	☐ Illness(es)
f89	How often do you go to the doctor?	Every week ☐ 1 Once every two weeks ☐ 2 Once a month ☐ 3 More seldom ☐ 4 Never ☐ 5
f90	Do you have a trusted doctor to whom you always go?	Yes ☐ 1 No ☐ 2
f91	Have you been admitted into a hospital during the past year?	Yes ☐ 1 No ☐ 2 from 99 cont.
f92	Was the cause pertaining to your care-dependency/disability?	Yes ☐ 1 No ☐ 2

f93	Did you find benefit [from the hospital stay]?	Yes	☐ 1	
		No	☐ 2	
f94	While at the hospital, who provided for your care?	Health care personel	☐ 1	
		A member of my family	☐ 2	
		My present caregiver	☐ 3	
		Professional caregiver	☐ 4	
		Other	☐ 5	
f95	Were you pleased with the care you received?	Yes	☐ 1	
		No	☐ 2	
f96	What made you most uncomfortable (*More than one answer may be marked*)?	Poor quality care	☐ 1	
		Nurses conduct	☐ 2	
		Unorganization	☐ 3	
		Poor sanitary conditions	☐ 4	
		Noise	☐ 5	
		Lack of medical services	☐ 6	
		Crowded room	☐ 7	
		Bed	☐ 8	
		Food	☐ 9	
		Doctors conduct	☐ 10	
		Patients conduct	☐ 11	
		Other	☐ 12	___________
f97	What were you most pleased with (*More than one answer may be marked*)?	Quality care	☐ 1	
		Nurses conduct	☐ 2	
		Organization	☐ 3	
		Sanitary conditions	☐ 4	
		Quiteness	☐ 5	
		Medical services	☐ 6	
		Uncrowded room	☐ 7	
		Bed	☐ 8	
		Food	☐ 9	
		Doctors conduct	☐ 10	
		Patients conduct	☐ 11	
		Other	☐ 12	___________
f98	(*Assuming caregiver's not hospital staff*) Where did your caregiver stay?	In my room	☐ 1	
		On the edge of my bed	☐ 2	
		In assigned hospital room	☐ 3	
		Hotel	☐ 4	
		In hospital garden	☐ 5	
		In hospital corridor	☐ 6	
		Own home	☐ 7	
		Home of an acquaintance	☐ 8	
		Other	☐ 9	___________

G) FALLS & HOME ACCIDENTS

g99	Have you ever fallen (*while care-dependent*)?	Yes	☐ 1	
		No	☐ 2	from 106 cont.
g100	How many times have you fallen?	☐	times	

g101	Did you suffer any bodily injury as a result of falling?	Yes ☐1 No ☐2
g102	*(If yes)* Is the damage permanent?	Yes ☐1 No ☐2
g103	When did you last fall?	☐ day ☐ week ☐ month
g104	Where did you last fall?	At home ☐1 Outside home ☐2
g105	How did you fall? Describe in a few words!	________________ ________________
g106	Have you had any home accidents?	Yes ☐1 No ☐2 from 109 cont.
g107	Identify the home accidents you've had?	1. ___________ _____________ 2. ___________ _____________ 3. ___________ _____________ 4. ___________ _____________ 5. ___________ _____________
g108	In the instant of the accident, was your caregiver at your side?	1. Yes ☐1 No ☐2 2. Yes ☐1 No ☐2 3. Yes ☐1 No ☐2 4. Yes ☐1 No ☐2 5. Yes ☐1 No ☐2
g109	Since when do you live in this house? + ________	Less than 1 year ☐1 More than 1 year ☐2 More than 5 years ☐3 More than 10 years ☐4
g110	During the last year have you continually resided in this home?	Yes ☐1 from 112 cont. No ☐2
g111	Why do you go to a different house?	Vacation ☐1 Escape heat - cold ☐2 Escape noise ☐3 To receive care ☐4 Other ☐5 __________
g112	How does noise affect you?	No affect ☐1 Minor negative affect ☐2 Negative affect ☐3 Very negative affect ☐4

H) VIEWS ON DEATH & DYING

h113 I have some questions regarding death. Would you like to answer these questions?
Yes ☐ 1
No ☐ 2 from 125 cont.

h114 Are death and nearing death topics that pertain to you?
Yes ☐ 1
No ☐ 2
I don't know ☐ 3

h115 Do you think about death and dying?
Very often ☐ 1
Rarely ☐ 2
Never ☐ 3

No.		Very often	Sometimes	Never
h116	Does the topic of death cause you anxiety?	1	2	3
h117	Since becoming care-dependent, how have your thoughts regarding death changed?	1	2	3
h118	Do your religious beliefs bring you relief on this topic?	1	2	3

No.		Yes	No	I don't know
h119	Do you believe that death can be beautiful?	1	2	3
h120	If you could preserve your present situation [health], would you desire to continue living?	1	2	3
h121	Some people want to die. Can you understand those who would chose this road?	1	2	3

h122 If you were to experience unbearable pain, would you want to die?
Most certainly ☐ 1
Probably ☐ 2
I would not want to die ☐ 3 from125 cont.

h123 (*If you'd want to die*) Would you pursue **euthanasia** (*voluntary decision to take ones own life*)?
Most certainly ☐ 1
Perhaps ☐ 2
Definitely not ☐ 3

h124 Though the decision to take ones own life is not sanctioned by our religious beliefs, if you experienced unbearable pain, would you still pursue euthanasia?
Most certainly ☐ 1
Perhaps ☐ 2
Definitely not ☐ 3

I) VIEWS ON SEXUALITY IN OLD AGE

i125 I have some questions about sexuality in old age. Do you mind my asking these questions?
Yes ☐ 1 from 131 cont.
No ☐ 2

No.		Very much so	A little	Not at all
i126	Is sexuality a topic of interest among the aged?	1	2	3
i127	Is sexuality a topic of interest for you?	1	2	3
i128	Does getting undressed in the presence of your caregiver make you uncomfortable?	1	2	3

i129 Do you think that your caregiver is made uncomfortable by this?

Very much so ☐ 1
A little ☐ 2
Not at all ☐ 3

i130 Can you share your thoughts regarding sexuality with your caregiver?

Most certainly ☐ 1
Perhaps ☐ 2
Definitely not ☐ 3

J) CARE-DEPENDENCY & IMPACT ON FAMILY

j131 Does your being care-dependent have an effect on your family relationships

Yes ☐ 1
No ☐ 2 **Thank the respondent & end the interview!**

No.		Very Negative	Negative	Neither negative nor positive	Positve	Very positive
j132	How do you appraise the general effect?	1	2	3	4	5
j133	What is the effect on your relationship to your caregiver? +	1	2	3	4	5
j134	! (*If spouse is living*) What is the effect on your relationship to your spouse? +	1	2	3	4	5
j135	What is the effect on your relationship to your children? +	1	2	3	4	5

Thank the respondent & end the interview!

APPENDIX H

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