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Quality and Global Satisfaction with Physicians' Dementia Care as Reported by Family Caregivers

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Quality and Global Satisfaction with Physicians’ Dementia Care

as Reported by Family Caregivers

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Quality and Global Satisfaction with Physicians' Dementia Care
as Reported by Family Caregivers

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References
1. Introduction/purpose of research

Dementia is a growing public health problem, as it is a major cause of disability and mortality. With dramatically increasing numbers of Americans aged 65 and over, dementia has become a problem of epidemic proportions. In 2000, there were 4.5 million estimated cases of Alzheimer’s disease, which is the most common type of dementia; this number is projected to grow to 14 million in the next 50 years (Hebert et al. 2003). The demands dementia places on the public health system and on medical and social services are enormous (Sloane, Zimmerman et al. 2002).

Family members and friends provide most of the care provided to older people with dementia. The cost of keeping patients with dementia at home is much less than the cost of institutionalization, but caregiving weighs heavily on family members and can frequently lead to deterioration in their physical health, higher levels of depression, and decreased social and occupational functioning (Schulz and Martire 2004). Numerous studies on dementia caregiving show the physical and emotional burdens of caregiving for a relative with dementia; all these studies conclude that support is key for caregivers.

Physicians, nurses, care managers, and other ancillary professionals all play a critical role in providing support to dementia patients and their caregivers. In most dementia cases, physicians are those who work closely with family caregivers to care for
the patient. Dementia is particularly challenging for physicians because their responsibilities entail management not only of the medical aspects of the disease; they also bear responsibility for the many social and behavioral aspects of dementia. Indeed, physician surveys show that they are still uncertain about their ability to provide the highest quality dementia care (Brodaty, et al. 1994; Fortinsky, et al. 1995; Connell and Gallant, 1996; Barrett, et al. 1997; Fortinsky, 1998). Furthermore, physicians are being challenged to care not only for the growing number of older adults with dementia but also to care and support their family caregivers who will themselves often become “hidden patients” (Fortinsky, 2001).

In recent years, greater recognition of Alzheimer's disease symptoms and the availability of new drugs have been critical for patients who now receive a diagnosis and treatment much earlier in the process of cognitive decline. One of the main advantages of an early diagnosis is that it allows physicians, caregivers, and patients to interact in the early stages of the disease and to plan for future health care needs, community resources, and available support.

Yet, little is known about how caregivers perceive and report their encounters with physicians. Although dementia caregiving has been extensively studied, research has maintained a focus on the hardship of dementia on caregiver. There is little literature that addresses how caregivers rate the quality of care and their global satisfaction with physician care and if and how these ratings are associated with certain patient and caregiver characteristics. Previous studies indicate that family caregivers are dissatisfied
with their interactions with physicians and other health care professionals (Haley, Clair et al. 1992; Fortinsky 2001). Because caregivers’ perceptions of, and global satisfaction with, physicians’ dementia care are important issues to consider, both in terms of improving the health and welfare of caregivers and in terms of minimizing the suffering of dementia patients, there is a strong rationale for measuring them.

Therefore, the purpose of this thesis is to explore physician-family caregiver encounters regarding dementia care. I will examine the quality of these medical encounters and global satisfaction with dementia care from the family caregivers’ point of view, and the extent to which patient and caregiver characteristics are associated with how caregivers rate physicians’ care.

The objectives of this study are:

- To develop a measurement tool for understanding family caregivers’ encounters with physicians regarding dementia care.
- To assess caregivers’ global satisfaction with physician care.
- To identify patient and caregiver characteristics associated with caregiver reports of physician encounters and their global satisfaction with physician care.

More specifically, this study aims to answer the following research questions:

- What are the psychometric properties of a new tool for measuring quality of physician care as reported by family caregivers of dementia patients?
• What is the relationship between quality of dementia care scores as rated by family caregivers and caregiver characteristics (age, gender, relationship to patient, level of education, and ethnicity)?

• What is the relationship between global satisfaction with dementia care scores as rated by family caregivers and caregiver characteristics (age, gender, relationship to patient, level of education, and ethnicity)?

• What is the relationship between quality of dementia care scores as rated by family caregivers and patient characteristics (cognitive status, problematic behavior, personal activities of daily living, instrumental activities of daily living)?

• What is the relationship between global satisfaction with dementia care scores as rated by family caregivers and patient characteristics (cognitive status, problematic behavior, personal activities of daily living, instrumental activities of daily living)?

• What is the relationship between quality of dementia care scores and caregivers’ global satisfaction with care, controlling for patient and caregiver characteristics?

To accomplish study aims a secondary analysis was conducted using data collected in two studies involving family caregivers of persons with dementia: the Help Line Callers Study and The Physician Referrals Study, both directed by Dr. Richard Fortinsky between 1996 and 1998 in the Cleveland, Ohio metropolitan area. The integrated conceptual framework proposed by Dr. Fortinsky regarding interactions among the participants in the health care triad - physicians, caregivers, and persons with dementia (Fortinsky, 2001) will serve as a foundation for this project.
Results of this study will contribute to scientific knowledge by probing more deeply than previous investigations into how family caregivers view the help they receive from physicians as they try to manage their relatives who are affected by Alzheimer’s disease and other types of dementia. Results will contribute important public health information related to the quality of support and care family caregivers receive and to factors within physicians’ purview that can influence caregiver global satisfaction with care. As the number of Americans with dementia is projected to grow dramatically in the next few decades, it is hoped that study findings will aid the development of new interventions to improve physicians’ effectiveness in providing medication and symptom management, social support linkage and emotional support for these patients and their families.

2. Dementia as a major public health problem

Various factors combine to make dementia a major and increasing concern in worldwide public health. The suffering it brings to patients and their families is tremendous. The challenges dementia presents to caregivers are extreme. Dementia is one of the major causes of dysfunction and disability as well as decreased quality of life among the elderly (Katzman 1976; Ewbank 1999). It has been associated with functional status limitations (Gauthier, Gelas et al. 1997), increased comorbidity (Thomas, Darvesh et al. 2001; Bridges-Webb 2002), and mortality (Hoyert and Rosenberg 1997; Fried, Kronmal et al. 1998; Morrison and Siu 2000). Its prevalence is alarmingly on the rise; currently Alzheimer’s disease affects 4.5 million Americans (Hebert, Scherr et al.
2003); this number is projected to grow to 14 million in the next 50 years. Societal and individual financial costs for dementia are high, even when compared to other chronic conditions for which prevalence rises with age (Bowler, Munoz et al. 1998) such as diabetes, lung disease, and stroke (Mokdad, Ford et al. 2000; Rice, Fillit et al. 2001; Hickenbottom, Fendrick et al. 2002; Langa, Fendrick et al. 2002).

2.1. Dementia in an aging world

Worldwide, the number of persons aged 60 years or over is expected almost to triple, increasing from 672 million in 2005 to nearly 1.9 billion by 2050 (New York: United Nations, 2005). The elderly make up an expanding segment of the population in the United States: in 2000, 12.4% of the U.S. population was over age 65; by 2030 that level will rise to 19.6%. The population of the oldest-old (those 85 years and older) is the fastest-growing segment of the population in the United States. Trends within this age group are especially important, as the oldest-old are the most vulnerable to dementia: 47% of them will develop Alzheimer's disease (National Center for Chronic Disease Prevention and Health Promotion 1999). Today this group makes up 3.2% of the U.S. population, while by 2030 that number will increase to 5.0%, and by 2050, to 7.2%. In 2050, when the "baby boomers" reach old age, it is expected that the oldest old will number 19 million.

The aging of the population is a direct consequence of both fertility decline and increased life expectancy. Infant and childhood mortality have steadily declined, in part
because of new and effective treatment for acute diseases and vaccines and other effective public health measures (Kinsella and Velkoff 2001). Better living conditions and better health care and accompanying changes in personal behavior have led to much lower levels of mortality in middle and late life. Life expectancy at birth among the more developed nations of the world now ranges from 76 to 80 years (Kinsella and Velkoff 2001). In parallel with fertility decline and increased life expectancy, an epidemiological transition in the leading causes of death, from infectious disease and acute illness to chronic disease and degenerative illness, is now under way. Chronic diseases diminish quality of life for elderly patients and their families, contribute to disability, and increase health- and long-term care costs. Managing the challenges presented by these diseases, most notably dementia, will be the overwhelming priority of public health during this century.

2.2. Dementia – types, treatment, and prognosis

Dementia is one of the most devastating illnesses common in the elderly (Hendrie 1998). But the term "dementia" refers not to a disease but rather to a variety of conditions. These conditions are caused by or associated with damage of brain tissue which results in memory impairment and impairment in at least one other cognitive domain. The impairments in memory and cognitive functioning are severe enough to interfere with the person’s ability to function independently and perform routine activities. Dementia may also result in behavioral and personality changes in the more advanced stages.
Dementia can be irreversible or reversible, but most cases are irreversible. Reversible decrease in cognitive ability may be caused by nutritional deficiencies, alcohol abuse, and some diseases. There are over 70 identified conditions that cause dementia; the most common one is Alzheimer’s disease (Schoenberg, Kokmen et al. 1987; Evans, Funkenstein et al. 1989). Alzheimer’s disease is irreversible and constitutes 50% to 70% of all dementia cases. Other causes include vascular dementia (10 to 20 %), Lewy body dementia (10 to 15 %), frontotemporal dementia, and dementia associated with Parkinson's disease and Huntington's disease.

To date there is no cure and no effective treatment for irreversible types of dementia. The established therapy of dementia consists of two classes of drugs: the cholinesterase inhibitors of which the following three are currently available -- donepezil, galantamine, and rivastigmine; and the glutamate modulators, of which there is one -- memantine (Knopman 2006). Pharmacologic therapies for cognitive impairment and nonpharmacologic and pharmacologic treatments for the behavioral problems associated with dementia can enhance patients’ quality of life (Small, Rabins et al. 1997). Newer psychotropic drugs, including atypical antipsychotics and serotonergic agents, may help reduce some of the symptoms associated with dementia, such as sleeping disorder, anxiety, depressed mood, agitation, and psychotic symptoms. New drugs that may influence the underlying mechanisms of the disease are currently in development.
We still know less about the prognosis of dementia than about the prognosis of other life-threatening illnesses (Wolfson, Wolfson et al. 2001). Dementia is a progressive disease with an onset gradually over time, starting usually with memory problems and advancing through stages of cognitive decline. The course of the disease can range from eight to as many as twenty years but recent data suggests even shorter life expectancy (Wolfson, Wolfson et al. 2001). As patients lose their ability to remember and learn, think and reason, communicate and respond they also lose their ability to take care of their personal needs and to live independently.

2.3. Prevalence, incidence and risk factors

The lifetime risk of developing Alzheimer’s disease in the general population is 10-15%. The greatest risk factor for dementing disorders is advanced age. Although dementia can occur at any age, it is rare below the age of 60 years. Certain dementias have well-defined genetic causes (Evans, Beckett et al. 1997; Farrer, Cupples et al. 1997). The search for non-genetic risk factors has been less conclusive. Untreated infectious and metabolic disease and substance abuse can lead to dementia. Other risk factors include a brain tumor, cardiovascular disease, head injury, and lower education level (Commenges, Joly et al. 2004). Some studies suggest that Alzheimer’s disease is more prevalent in African Americans than in Caucasians (Tang, Stern et al. 1998; Hendrie, Ogunniyi et al. 2001), and is least prevalent in Japanese Americans (Graves, Larson et al. 1996).
Even though the prevalence estimates vary, depending on the definition for dementia and on the methods used, it is clear that dementia is a disease with a high prevalence (Kukull and Bowen 2002). Dementia prevalence has increased over the past few decades. It is due to increased longevity for the overall population and increased longevity for dementia patients themselves. It is also due to a greater awareness among professional and lay people leading to an earlier and more accurate diagnosis.

Both the incidence and the prevalence of dementia rise steeply with increasing age and approximately double every five years of age (National Institute on Aging 1999). It is estimated that as many as 20% to 50% of people in their 80s suffer from dementia. When compared, the incidence of Alzheimer's disease among people older than 85 years is approximately 14 times higher than among people between 65 and 69 years of age (Hebert, Scherr et al. 1995).

Worldwide, the number of new cases of dementia in 2000 was estimated to be 4.6 million (Wimo, Winblad et al. 2003). In developed countries, dementia incidence is about 1% per year in people aged 65 and older (Ritchie and Lovestone 2002). An estimated 24.3 million people in the world now suffer from dementia (Ferri, Prince et al. 2005); which is about 6.1% of the population above 65 years of age or about 0.5% of the world population (Wimo, Winblad et al. 2003).

In the United States, the prevalence of Alzheimer’s disease alone is estimated to be 4.5 million (Hebert, Scherr et al. 2003) or approximately 6%-10% of the population
65 years and older (Hendrie 1998); if people suffering from vascular dementia and other common dementias were included, the numbers might double (DeKosky and Orgogozo 2001). The incidence is estimated to be 360,000 new cases per year (Brookmeyer, Gray et al. 1998).

The growth and aging of the U.S. population forecast a considerable increase in the size of the population with dementia. It is projected that the prevalence will nearly quadruple in 50 years, by 2050 there will be between 7.98 and 12.95 million people suffering from AD, or approximately 1 in 45 Americans (Brookmeyer, Gray et al. 1998).

2.4. Comorbidity and disability

Dementia is a major and growing cause of disability and decreased quality of life among the elderly (Katzman 1976; Ewbank 1999). The World Health Organization predicts that Alzheimer’s disease will most likely become one of the leading causes of disability in the elderly (Essink-Bot, Pereira et al. 2002). Cognitive impairment is a well-known risk factor for physical disability (Sauvaget, Yamada et al. 2002), which in turn is considered a significant marker of dementia severity (Noale, Maggi et al. 2003). From a population health perspective, disability represents an extremely serious problem, particularly in terms of medical care utilization and long-term care need (Guralnik, Fried et al. 1996).
People with dementia have more, and more severe, functional impairments than their counterparts without dementia; consequently, decline in functional abilities in people with dementia requires greater assistance with their personal activities of daily living (ADL). The elderly with dementia also incur a significantly larger proportion of long-term care services (Garber and MaCurdy 1990). A Canadian longitudinal study (Hebert, Dubois et al. 2001) identified severity of cognitive and functional disability due to dementia as one of the key predictors for institutionalization. Over half of elderly nursing home residents suffer from dementia (Sahyoun, Pratt et al. 2001); up to one-third of nursing home residents may have Alzheimer’s disease (Leon and Moyer 1999).

Disruptive behaviors are common among patients with dementing illness: agitation (50% of patients), aggression (20%), delusions (33%), and wandering (25%). Depression among dementia patients is also common and underrecognized. Memory loss complicates management of comorbid medical conditions (Brauner, Muir et al. 2000). There are also safety issues related to driving risks (Fitten, Perryman et al. 1995), wandering, and increased vulnerability to abuse.

2.5. Mortality

Dementia is associated with increased mortality (Fried, Kronmal et al. 1998; Morrison and Siu 2000; Doody, Stevens et al. 2001). Alzheimer’s disease could reduce life expectancy by 50% in males and 40% in females at age 70 (Dodge, Shen et al. 2003). Estimates suggest that 7.1% of all deaths in the United States in 1995 were attributable to
Alzheimer's disease, placing it on a par with cerebrovascular diseases as the third leading cause of death (Ewbank 1999). Dementia death rates are consistently increasing in the US (Ewbank 1999).

2. 6. Social and economic impacts of dementia

Dementia creates massive human suffering for patients and their families. It also presents an enormous social and economic burden to communities. Exponential recent and projected growth in the number of persons with dementia places high demands on the public health system and on medical and social services (Sloane, Zimmerman et al. 2002).

Spouses, children, and other relatives provide important care for dementia patients who are not institutionalized. As a consequence of the increased dementia prevalence, family caregiving for dementia patients has become the norm. The cost of keeping patients with dementia at home is much less than the cost of institutionalization, but caregiving weighs heavily on family members and can frequently lead to deterioration in their physical health, higher levels of depression, and decreased social and occupational functioning (Schulz and Martire 2004). Numerous studies on dementia caregiving show the physical and emotional burdens of caregiving for a relative with dementia; all these studies conclude that support is key for caregivers.
Alzheimer’s disease is the third most expensive illness in the United State after heart disease and cancer (Fillit and Hill 2005). The economic cost of dementia in the U.S. has been estimated to be between $67-100 billion annually (Ernst and Hay 1994; Ernst, Hay et al. 1997; Cummings and Cole 2002; Bloom, de Pouvourville et al. 2003). Average lifetime cost per Alzheimer’s disease patient has been estimated to be $174,000, the average annual cost - $50,000. A substantial portion of this cost is attributable to lost patient and caregiver productivity and to family out-of-pocket expenses (Schumock 1998). Public spending is largely for institutional care, often accounting for as much as 84% of the cost for people with severe disease (Welch, Walsh et al. 1992; Hux, O'Brien et al. 1998). Primary providers of institution-based care for dementia patients are the nursing homes. Most direct costs which increase with disease severity (Rice, Fox et al. 1993; Ernst, Hay et al. 1997; Hux, O'Brien et al. 1998) are absorbed by the expense of nursing home care, approximately $47,000 per patient per year (Welch, Walsh et al. 1992).

Alzheimer's disease undoubtedly has profound indirect costs the greatest components of which are unpaid caregiver time and use of community services. These costs increase as the disease progresses (Hux, O'Brien et al. 1998; Langa, Chernew et al. 2001). The additional yearly cost of informal care per case is $3,630 dollars for mild dementia, $7,420 dollars for moderate dementia, and $17,700 dollars for severe dementia. This represents a national annual cost of more than 18 billion dollars (Langa, Chernew et al. 2001). The value of the services family caregivers provide for "free" is estimated to be $257 billion a year.
Frequency, duration of hospitalization (Fillenbaum, Heyman et al. 2000), and expenditures (Martin, Ricci et al. 2000; Sloan and Taylor 2002) are greater in recipients with Alzheimer’s disease compared with other Medicare and Medicaid recipients. Institutionalization lowers quality of life and reduces independence for the Alzheimer sufferer. Although Medicare is the largest source of federal health insurance for older adults only 0.57 % of total Medicare expenditures are for mental health services, coverage for community-based services is limited. There is an alarming under-investment in knowledge dissemination, research, and service development to meet future need that could lead to a public health crisis (Bartels and Smyer 2002).

Epidemiological and economic data on dementia is important in that it shows the public health impact of dementia. Taken as a whole, the body of evidence demonstrates the seriousness of dementia as now widely recognized major public health problem (Haan and Wallace 2004). With the aging of the population, it becomes increasingly important to understand the effects of dementia and Alzheimer’s disease on individuals, families, caregivers, community health services, and long-term care facilities. The public health system in the U.S is the most important contributor to the creation of awareness and understanding of dementia, and informing and educating the public about the support available to people with dementia and their caregivers. The potential impact of public health interventions to help patients and caregivers manage the challenges of dementia is of an enormous dimension.
3. Background/literature review

3.1. Caregiver and patient characteristics

There has been a growing trend in the United States for social policies to place more responsibility on family members to provide care at home for their dependent relatives (Maletta and Hepburn 1986; Haug 1994; Spillman and Black 2005). Dementia patients typically live long after illness onset. Approximately 80% of them reside in the community and depend on family members for assistance (Haley 1997; Gonzalez-Salvador, Arango et al. 1999). The primary source of informal care and support dementia patients receive is the family, and in some cases, friends or neighbors. Family caregivers are responsible for ensuring adherence to treatment regimens and for facilitating optimal health care and well-being (Bass and Noelker 1987). They provide assistance with personal care, housekeeping, and financial transactions. Home care is the preferred choice families make as an alternative to institutionalization.

Caregivers are often viewed as primary and secondary caregivers. A primary caregiver is someone who has assumed the responsibility for providing the care and management of the patient on a daily basis. It is typically a family member, often the spouse or an adult child (Beisecker, Chrisman et al. 1997). A secondary caregiver, frequently a more distant relative or a friend, regularly assists with tasks such as shopping, providing transportation but the help is clearly less intense (Tennstedt, McKinlay et al. 1989). Although estimates vary, in a recently published study (Wolff and
Kasper 2006) providing a nationally representative profile of family caregivers, adult children comprised 41.3%, 38.4% were spouses, and 20.4% were other family members or friends.

On average, dementia caregivers are in their mid-50s; over one-third of them are elderly themselves (Stone, Cafferata et al. 1987). The large majority of caregivers are female relatives – wives and daughters (Atienza, Henderson et al. 2001); accounting for 70 to 80% of the primary caregivers (Stone, Cafferata et al. 1987; Malonebeach and Zarit 1991).

Dementia caregivers spend significantly more hours per week providing care than nondementia caregivers (Ory, Hoffman et al. 1999). They report performing between 40 and 60 hours of caregiving tasks per week, depending on the patient's disease stage (Schulz, O'Brien et al. 1995; Cavallo and Fattore 1997; Haley 1997; Ory, Hoffman et al. 1999; Schulz, Mendelsohn et al. 2003). About half of all caregivers live in the same residence as their care recipient (Malonebeach and Zarit 1991).

There has been considerable interest in ethnicity and family caregiving for persons with dementia. Although caregiving appears to have similar negative social consequences for families regardless of their ethnicity (Haley, West et al. 1995), African-American caregivers of persons with dementia demonstrate lower anxiety, lower levels of depression, stress and burden, and better well-being, than Caucasian caregivers (Haley, West et al. 1995; Janevic and Connell 2001; Haley, Gitlin et al. 2004; Toth-Cohen 2004).
Family caregiving can have both positive and negative outcomes (Walker, Pratt et al. 1995; Narayan, Lewis et al. 2001). Individual caregivers have reported benefits from caregiving such as a personal growth (Leipold, Schacke et al. 2006), shared purpose and focus, an opportunity to cooperate and communicate (Singer 1996). Other positive concepts found in the family caregiving literature include caregiver esteem, uplifts of caregiving, caregiver global satisfaction, finding or making meaning through caregiving, and gain in the caregiving experience (Hunt 2003). Feelings of gratification, love, and pride were also reported by caregiving families of mentally ill relatives (Veltman, Cameron et al. 2002). Positive outcomes are being more and more explored in the literature (Millet, Powell Lawton et al. 1997; Lopez, Lopez-Arrieta et al. 2005). Farran and colleagues have developed a measure designed to assess positive aspects and ways that caregivers find meaning through their experience of caring for a person with Alzheimer's disease (Farran, Miller et al. 1999). Positive feelings about caregiving were associated with lower burden and better self assessed health (Cohen, Colantonio et al. 2002). Understanding the close relationship between both the positive and negative aspects of caregiving may be used to design interventions to support caregivers (Narayan, Lewis et al. 2001).

Despite the positive aspects that caregiving may have, it is a difficult role for family members (Haug 1994; McKinlay, Crawford et al. 1995; Aupperle 2006). It requires investing a great deal of time, physical and emotional energy and overcoming many unique challenges including patient’s difficult behaviors, emotional responses, and
safety issues. Coping with dementia is much more difficult than dealing with a physical
disability (Gwyther 1998; Aupperle 2006). The cost of keeping patients with dementia at
home is much less than the cost of institutionalization, but caregiving weighs heavily on
family members and can frequently lead to deterioration in their physical health, higher
levels of depression, and decreased social and occupational functioning (Schulz and
Martire 2004).

Numerous studies on dementia caregiving show the physical and emotional
burdens of caregiving for a relative with dementia. Managing patient problem behaviors
and providing constant supervision have been proven as sources of great psychosocial
stress. Studies have found that dementia caregivers have more stress related symptoms
such as inertia, heart palpitations, insomnia, perspiration, headaches, and bad dreams than
the general population (George and Gwyther 1986; Pruchno and Potashnik 1989).

Consistently, caregivers have been found to suffer from depression (Drinka,
Smith et al. 1987; Cohen and Eisdorfer 1988; Gallagher, Rose et al. 1989; Moritz, Kasl et
al. 1989; Fortinsky, Kercher et al. 2002; Schulz and Martire 2004). As many as 30% to
55% of dementia caregivers report clinically significant depression on self-report
instruments; these rates are two to three times higher than those reported in population
norms and demographically comparable control groups (Haley, Levine et al. 1987; Haley,
West et al. 1995; Schulz, O'Brien et al. 1995). Depression appears to be significantly
more likely among caregivers of dementia patients than among other noncaregivers of the
same age, when assessed through structured diagnostic interviews (Schulz and Williamson 1991; Schulz, O'Brien et al. 1995). It was also found that even when caregivers' symptoms of depression do not meet strict criteria for a diagnosis of depression, they may still impair their ability to function (Schulz and Williamson 1991; Baumgarten, Battista et al. 1992).

Several studies showed that caring for a relative with dementia sometimes leads to more physician visits (Donaldson and Burns 1999) and to increased prescription medication use by the caregiver (George and Gwyther 1986; Haley, Levine et al. 1987; Pruchno and Potashnik 1989; Donaldson and Burns 1999). Providing care to a relative with dementia often has detrimental social effects on caregivers such as increased feelings of social isolation and confinement (Rodriguez, De Leo et al. 2003), reducing or giving-up the time spent on paid jobs and on social and leisure activities (Gottlieb, Kelloway et al. 1994; Mittelman, Epstein et al. 2003). Furthermore, caregiver's perceived stress or burden (Hebert, Dubois et al. 2001; Gaugler, Kane et al. 2003), caregiver depression (Arai, Sugiura et al. 2001), and health problems (Hebert, Dubois et al. 2001; Gaugler, Kane et al. 2003) have been found to be key predictors of institutionalization of the dementia patients. All studies conclude that support is key for caregivers.

3.2. Quality of physician-patient-caregiver interaction

To properly fulfill their role without compromising their own health, family caregivers need information (Fortinsky and Hathaway 1990; Brodaty and Green 2002),
quality services (Fortinsky, Unson et al. 2002; Chapman, Williams et al. 2006), advocacy, emotional support, and recognition of their health needs taken into account (Cohen 1994; Fortinsky 2001).

In most dementia cases, physicians are those who work closely with family caregivers to care for the patient. Physicians are in a key position to diagnose and provide an ongoing management of people with dementia, to consider and assess caregivers’ unique needs for care and support services and to develop a care partnership with the family caregiver (Brown, Potter et al. 1990; 1993; Brotman and Yaffe 1994; Dello Buono, Busato et al. 1999; Schulz and Beach 1999).

Dementia as a psycho-socio-biological disorder is particularly challenging for physicians because their responsibilities entail management not only of the medical aspects of the disease; they also bear responsibility for the many social and behavioral aspects of dementia. The presence of a third party in the physician-patient encounter – the patient’s caregiver – also adds to the difficulties in managing dementia patients (Fortinsky 2001; Glasser, Prohaska et al. 2001). Furthermore, physicians are being challenged to care not only for the growing number of older adults with dementia but also to care and support their family caregivers who will themselves often become “hidden patients” (Fortinsky, 2001).

In recent years, greater recognition of Alzheimer's disease symptoms and the availability of new drugs have been critical for patients who now receive a diagnosis and treatment much earlier in the process of cognitive decline. Early detection and new
treatments have led to slowing disease progression and improved quality of life for people suffering from dementia. One of the main advantages of an early diagnosis is that it allows physicians, caregivers, and patients to interact in the early stages of the disease and to plan for future health care needs, community resources, and available support.

Once diagnosis of dementia has been established, information and support become crucial to the management of the condition for the person with dementia and the family caregiver. Physicians should provide information and advice to caregivers about the illness of their relative (Zarit and Edwards 1999; Cohen 2000; Albinsson and Strang 2003). They should educate them regarding dementia symptoms and management of patient psychiatric and behavioral disturbances (Council on Scientific Affairs 1993; Silliman 2000). Caregivers' education should become a priority for physicians, especially since psychological distress and emotional burden appear to be related to caregiver level of knowledge about dementia (Werner 2001). Helpful information should not only include advice considered relevant by physicians but should also be addressed to the information needs of caregivers (Vernooij-Dassen, Van Hout et al. 2003). Providing adequate information about patient rights and planning for informed consent, health care surrogates, and/or durable power of attorney (Rosen, Chow et al. 2002) while addressing family concerns about patient safety and dignity is one of the important responsibilities of physicians.

Physicians are also asked to encourage families to use community-based support services and to provide caregivers with information on how to access relevant services.
Physicians’ referral to appropriate community resources is an effective means of reaching caregivers at the most appropriate point in their caregiving career. Timely access to support services often minimizes caregivers’ stress and burden, and assists in the maintenance of social and functional skills of the person with dementia. Research has indicated that confidence in problem solving (Levesque, Gendron et al. 2002), spiritual support (Haley, Gitlin et al. 2004; Spurlock 2005), seeking social support (Karlin, Bell et al. 2001; Levesque, Gendron et al. 2002), and utilizing local support groups (Aronson and Yatzkan 1984) are among the factors related to a caregiver’s enhanced well-being. Several studies have demonstrated that community support services can relieve stress for caregivers, reduce negative consequences of caregiving (Cohen 2000; Cohen, Pringle et al. 2001), and delay institutionalization for patients (Cohen, et al. 2001). Support groups, in particular, are effective resource for family members because they provide caregivers with information, education, emotional support, and respite from caregiving responsibilities (Gonyea 1989; Toseland and Rossiter 1989; Toseland, Rossiter et al. 1989). Day respite programs benefit both caregivers and the person with dementia (Zarit, Stephens et al. 1998; Gaugler, Jarrott et al. 2003; Gaugler, Jarrott et al. 2003); these programs have become increasingly available (Gottlieb and Johnson 2000). Dementia caregivers using adult day care services experience less caregiving related stress and better psychological well-being (Zarit, Stephens et al. 1998). It is therefore crucial that physicians are able to link caregivers to the resources available to help them with their care.
It is as yet unclear how well physicians are linking caregivers and dementia patients to community support services. Physicians play a central role in facilitating referrals to community support services (Bruce and Paterson 2000; Cohen 2000; Cohen, Pringle et al. 2001), yet few refer (Brodaty, Griffin et al. 1990; Cody, Beck et al. 2002). In an early survey, published in 1985, physicians rated service referral activity for dementia patients at a high level of difficulty compared to other dementia management (Glosser, Wexler et al. 1985). Organizing social support was regarded as the most difficult task by physicians yet in another, more recent survey (Olafsdottir, Foldevi et al. 2001). Results from a mail survey of spouse caregivers of dementia patients suggest that primary care physicians need to increase referrals to community based services (Connell and Gallant 1996). A clinical vignette study found that physicians more likely to make referrals were more recently trained and had more patients with dementia in their own practices (Fortinsky, Leighton et al. 1995).

One of the physicians’ responsibilities is to offer psychological and emotional support for dementia patients and their families (Downs 1996; Nankervis, Schofield et al. 1997; Zarit and Edwards 1999; Silliman 2000; van Hout, Vernooij-Dassen et al. 2000; Cohen, Pringle et al. 2001). Conveying emotional support is extremely important for reducing caregiver burden. Some studies have indicated that simply listening to family caregivers of dementia patients may have a therapeutic effect (Sheldon 1982; Arie 1986; Philp, McKee et al. 1995; Albinsson and Strang 2003). Physicians’ ongoing approval of the caregiver’s performance has much credibility with the caregiver and serves as an
important validation of the caregiver role, thus providing relief (Maletta and Hepburn 1986; 1993; Council on Scientific Affairs 1993).

Physicians need to support caregivers so that their caregiving role does not become detrimental to their health. But improving the quality of care for patients with dementia and their family caregivers is a continuing challenge to physicians. Indeed, physicians’ surveys show that they are still uncertain about their ability to provide the highest quality dementia care (Baumgarten 1989; Brodaty, Howarth et al. 1994; Fortinsky, Leighton et al. 1995; Barrett, Haley et al. 1997; Fortinsky 1998). Despite the availability of several screening tests suitable for use in primary care practice that detect undiagnosed dementia (Boustani, Peterson et al. 2003), dementia continues to be underrecognized (Fillit 2000). Only between 15% and 42% of dementia cases are being recognized by primary care physicians; with the more severe cases more easily recognized (Eefsting, Boersma et al. 1996 Valcour, 2000 #337 Ganguli, 2004 #338). Furthermore, dementia patients often do not receive treatment (Fillit 2000), only 7.6% of dementia cases were treated by primary care physicians in one study (Larrieu, Letenneur et al. 2004).

Physicians also acknowledge a disconnect between evidence-based knowledge and what they actually do when providing patient care in their offices. There are numerous clinical guidelines published regarding the management of dementia but few physicians follow them on a regular basis, fewer than 8% in one study (Rosen, Chow et al. 2002; Swearer, Drachman et al. 2002).
Several studies have revealed that the most important barriers reported by physicians to providing optimal dementia management (Fortinsky 1998; Boise, Camicioli et al. 1999; Olafsdottir, Foldevi et al. 2001) include unfamiliarity with available community support services or service referral procedures, limited time for the encounter, lack of reimbursement, and negative attitudes regarding the benefits of new antidementia drug treatments.

An important step to improving quality of physicians’ dementia care is to ask the caregivers themselves what their needs are and what they think about the quality of care they receive from physicians. By doing that, caregivers would be able to provide important feedback about their encounters with physicians. Yet, little is known about how caregivers perceive and report their encounters with physicians. Although dementia caregiving has been extensively studied, research has maintained a focus on the hardship of dementia on caregiver. There is little literature that addresses how caregivers rate the quality of care and their global satisfaction with quality of care and if and how these ratings are associated with certain patient and caregiver characteristics.

The common needs for caregivers identified throughout the literature are information and emotional support. Thomas and colleagues (Thomas, Chantoin-Merlet et al. 2002), in a study of the complaints, problems and requirements of family caregivers providing care for dementia patients, concluded that physicians do not completely answer to certain family questions or needs about the development and characteristics of the
disease and the availability of day care facilities. Family caregivers would like to receive more information and support from their physicians (Dello Buono, Busato et al. 1999; Bruce and Paterson 2000). Other caregivers were greatly interested in learning how to effectively manage their relatives at various points in the caregiving process. They expressed a need for information about patients’ symptoms and about available community services, such as paid in-home care, adult day care, and respite care (Fortinsky and Hathaway 1990; MaloneBeach, Zarit et al. 1992).

Family caregivers express need not only for information about the diagnosis and treatment options but also legal and financial information (Wackerbarth and Johnson 2002). Family caregivers identified issues related to care knowledge and skills and self-care as the most difficult aspects of caregiving (Habermann and Davis 2005). Other studies reported that most caregivers emphasized their high need for community services and the need for more information about service eligibility and availability (Fortinsky and Hathaway 1990; MaloneBeach, Zarit et al. 1992). Emotional support is the most common unmet need of family caregivers; the majority of family caregivers describe their experience as “one of constant searching for support and information” (Chambers, Ryan et al. 2001).

3.3. **Global satisfaction with physicians’ dementia care**

Caregiver satisfaction is an important outcome measure of physicians’ dementia care as it offers information on physicians’ success at meeting the expectations of most
relevance to family caregivers. Identifying factors that distinguish patients' specific
dissatisfactions may help physicians prevent dissatisfaction in the first place (Pichert,
Miller et al. 1998).

Even though physicians face many barriers in providing quality dementia care,
they have little systematic evidence to guide them in developing effective quality
improvements. The need for better scientific evidence to help physicians care for
dementia patients and their family caregivers is widely recognized.

No study was found in the literature that has been specifically devoted to
comprehensive factors that may affect level of satisfaction with physicians’ dementia
care among family caregivers. The majority of studies identifying predictors of
satisfaction with health care in the general patient population have determined that
demographic and socioeconomic factors, such as income, age, gender, education and
ethnicity significantly predict patient satisfaction (Locker and Dunt 1978; Nelson-
1992; Hall, Irish et al. 1994; Lee and Kasper 1998); the results from other studies
contradict these findings (Hsieh and Kagle 1991; Ross, Steward et al. 1993). Researchers
have found that patient satisfaction increases with age (Fox and Storms 1981; Hall and
Dornan 1990; Williams and Calnan 1991; Cleary, Edgman-Levitan et al. 1992); few,
however, have reported no significant relationship between age and satisfaction (Snider
1980; Linn, DiMatteo et al. 1984). Hall and Dornan (Hall and Dornan 1990) have
undertaken a meta-analysis of 221 quantitative patient satisfaction studies. They
concluded that sociodemographic characteristics were a minor predictor of satisfaction, and for some variables, go in opposite directions. Being older, being married, having less education, and having higher social status were the trends toward higher satisfaction found in their analysis. Women and men were equally satisfied.

In addition to sociodemographic characteristics, other individual differences may help to explain variation in satisfaction ratings. There is strong evidence for a positive association between patient satisfaction and health status with individuals in poorer health reporting lower ratings of satisfaction with their health care (Rubin 1990; Aharony and Strasser 1993; Hall, Milburn et al. 1993; Kane, Maciejewski et al. 1997; Lee and Kasper 1998; Smith 2000). Further, Hall and colleagues (Hall, Milburn et al. 1993) have found health status to be a causal determinant of satisfaction.

Various studies of satisfaction with medical care have demonstrated its positive link with better self-perceived overall health, better ability to perform activities of daily living, higher service utilization, greater compliance to treatment and physicians’ recommendations, fewer hospitalizations, higher chances to obtain positive results from care, better emotional health, and greater social activity (DiMatteo and DiNicola 1981; Pascoe 1983; Hall, Feldstein et al. 1990; Sherbourne, Hays et al. 1992; Wellwood, Dennis et al. 1995). In contrast, dissatisfaction with poor quality medical care may in turn adversely affect health outcomes.
The literature also suggests that physicians' interpersonal skills and communication style when interacting with patients and caregivers are particularly valued (Downs, Ariss et al. 2006) and are good predictors for patient satisfaction (Buller and Buller 1987). Satisfaction is increased when physicians provide more information, and include more psychosocial counseling (Hall, Roter et al. 1988; Haley, Clair et al. 1992). Patient satisfaction was positively correlated with physician questioning and supportiveness on patient-raised topics, patient information-giving on patient-raised topics in a study of an older patient population (Greene, Adelman et al. 1994).

Studies specifically focusing on caregiver perceived satisfaction with medical care, have demonstrated that caregivers' age, education, marital status, social status, health status are associated with caregiver satisfaction (Cleary and McNeil 1988; Hall and Dornan 1988; Hall, Roter et al. 1988; Hall and Dornan 1990; Hall, Feldstein et al. 1990). Lower caregiver satisfaction in these studies is often related to insufficient information they received on diagnosis, course of illness or community services (Haley, Clair et al. 1992; Venohr, Fine et al. 2001).

Existing studies of caregiver satisfaction are often limited to satisfaction with support services. In these studies, the characteristics of the frail seniors associated with lower caregiver satisfaction are being a female, being of a different cultural heritage than the majority, not living with the frail senior or thinking about placement for the frail senior (Wackerbarth and Johnson 2002), greater ADL impairment, greater number of health problems of frail individuals, dementia or at least one disruptive behavior (Durand, Krueger et al. 1995), increasing age and caregivers not working (Weissert, Elston et al.
Factors increasing satisfaction are caregiver being the spouse of the frail person, as well as greater caregiver perceived health, autonomy in instrumental activities of daily living, available social support, information, advice, or emotional support (Savard, Leduc et al. 2006).

No studies were found in the literature that examined associations between caregiver or patient sociodemographic characteristics and the quality and satisfaction with physicians' dementia care as perceived by family caregivers. Variables related to caregiving outcomes in dementia caregiver populations include age, gender, marital status and relationship to the care-recipient (Gold, Cohen et al. 1995; Almberg, Jansson et al. 1998; Silliman 2000). Family caregivers of people with dementia are less satisfied with the care provided by their physicians then family caregivers of non-demented elderly people (Haley, Clair et al. 1992; Dello Buono, Busato et al. 1999). Dissatisfaction with receiving insufficient information about dementia and insufficient referrals for supportive services is the most evident (Glosser, Wexler et al. 1985; Fortinsky and Hathaway 1990; Haley, Clair et al. 1992; Morgan and Zhao 1993). In a recent qualitative study of dementia caregivers' accounts of encounters with primary care physicians both caregiver-related and physician-related issues were cited as reasons for caregivers' ratings of service as being at least 'good' (Downs, Ariss et al. 2006). Researchers conclude that expressed satisfaction does not necessarily reflect a satisfactory service. The study confirms the association between perceived quality and interpersonal skills in professionals.
Given the widespread use of satisfaction studies (Cleary and McNeil 1988; Sitzia and Wood 1997), surprisingly little work has been done to analyze the relationship between objective measures of quality of care and subjective patient satisfaction with health care or mental health care.Ware and colleagues (Ware, Snyder et al. 1983) recognize the importance of care experienced in explaining satisfaction; Meredith et al. (Meredith, Orlando et al. 2001) have found significantly higher satisfaction among patients with depression receiving better quality care, especially for medication use. In their review of the theoretical and empirical work on patient satisfaction with care, the most consistent finding Cleary and McNeil (Cleary and McNeil 1988) note is that the characteristics of providers or organizations that result in more "personal" care are associated with higher levels of satisfaction. Cleary and McNeil (1988) also note that "there is no consensus within the medical profession on the role satisfaction should play in the assessment of quality of care." According to Fitzpatrick and Hopkins patient satisfaction is usually overestimated (Fitzpatrick and Hopkins 1983). Patients may be reluctant to criticize their healthcare providers, as they may not want to risk appearing ungrateful or unappreciative. That is why results derived from patient satisfaction research provide only partial and sometimes misleading insights into the perspectives of the patients studied (Fitzpatrick and Hopkins 1983). Forbes (1996) clarifies some of the constructs of satisfaction and dissatisfaction with care and reveals that satisfaction with care is influenced by patient characteristics (Forbes 1996). Further, results of satisfaction evaluations depend on the measurement method used. The unreliability of the measurement may be a significant problem in satisfaction measurement, especially for the oldest and most ill patients (Ross, Steward et al. 1995). There are only a few
measuring instruments explicitly developed for the assessment of quality of care from the patient's perspective (van Campen, Sixma et al. 1995).

4. Methodology

4.1. Research questions and conceptual model

This study aims to answer the following research questions:

• What are the psychometric properties of a new measure of quality of physician care as reported by family caregivers of dementia patients?

• What is the relationship between quality of dementia care scores as rated by family caregivers and caregiver characteristics (age, gender, relationship to patient, level of education, and ethnicity)?

• What is the relationship between global satisfaction with dementia care scores as rated by family caregivers and caregiver characteristics (age, gender, relationship to patient, level of education, and ethnicity)?

• What is the relationship between quality of dementia care scores as rated by family caregivers and patient characteristics (cognitive status, problematic behavior, personal activities of daily living, instrumental activities of daily living)?

• What is the relationship between global satisfaction with dementia care scores as rated by family caregivers and patient characteristics (cognitive status, problematic behavior, personal activities of daily living, instrumental activities of daily living)?
What is the relationship between quality of dementia care scores and caregivers' global satisfaction with care, controlling for patient and caregiver characteristics?

Various issues related to the research problem area have been explored in the literature review section and have been synthesized as a conceptual framework. To further advance our understanding of how patient and caregiver characteristics are associated with ratings with quality of physicians' care and global satisfaction as a health care outcome, a theoretical framework of the determinants of health care triadic interaction would be useful.

Bridging the existing gap between theory and research, Fortinsky (Fortinsky 2001) examined the current state of knowledge and thinking from several different fields to explain the complexity of the health care triads relations in dementia care. Fortinsky constructed a theoretical framework that incorporates and expands on published models of older patient-doctor relationships to include the caregiver as a third party in the encounter. The integrated theoretical framework proposed by Fortinsky regarding interactions among the participants in the health care triad – physicians, caregivers, and persons with dementia (Fortinsky 2001) is the first theoretical framework to examine dementia care in health care triads. Fortinsky defined five domains of dementia care interaction most important to family caregivers when interacting with physicians: symptom diagnosis, symptom management, medication management, support service linkage, and emotional support. The Fortinsky framework is centered on the idea that the quality of encounters in different domains of dementia care is affected by specific characteristics of members of the health care triad. The quality of these encounters is also
linked to health–related outcomes relevant to each member of the health care triad such as stability of medical comorbidities and behavior problems in the person with dementia, caregiver's health and well-being, and knowledge of and referral to community support services by physicians.

The health care triad framework is the most suitable and appropriate framework containing elements and concepts helpful in the organization of variables in this study. It is the only framework that has been specifically developed to capture dementia care in the health care triad—primary care physicians, family caregivers, and persons with dementia; the study hypotheses refer mainly to the assumptions underlying this conceptual theory.

Figure 1 illustrates the hypothesized sequence of the variables in a conceptual model for the current study. The conceptual model of this thesis predicts relationships between patient and caregiver characteristics and quality of care, and global satisfaction. The model comprises three elements. First, the patient and caregiver characteristics that are most directly involved in the caregiving process and that are taken into account for analyzing the relationships between quality of dementia care scores and caregivers' global satisfaction with care are illustrated in the conceptual model. Second, the model includes four of the original five conceptual domains of triadic encounters, which are most important to family caregivers when interacting with physicians. These are symptom management, medication management, support service linkage, and emotional support (Fortinsky 2001). The third element of the conceptual framework addressed in
this thesis pertains to the two health-related outcomes considered in the proposed model: caregivers' global satisfaction with physician's help to the patient and caregivers' global satisfaction with the help he or she received from the physician to take care of his or her relative.

The basic idea of the model is that patient and caregiver characteristics are associated with the quality of physician-family caregiver encounters and interaction regarding dementia care and caregivers' global satisfaction with dementia care. The model also suggests that the quality of physician-family caregiver encounters and interaction is related to caregivers' global satisfaction with care. Since the current research efforts are directed at empirically testing the health care triad framework proposed by Fortinsky, the arrows in the model indicate theoretically based relationships between the variables chosen for this study and congruent with his framework. The conceptual model only considers patient and caregiver characteristics, and not physicians' characteristics; thus representing a conservative test of the health care triads theoretical framework.
Figure 1—Conceptual Model for the Study *

* Based on Fortinsky, 2001
4. 2. Study Hypotheses

Thus, based on Fortinsky’s (2001) Health Care Triad Theoretical Framework and previous research, the following hypotheses were raised:

**H1:** Among caregiver characteristics, having higher education will be associated with/lead to lower quality of dementia care scores, and lower global satisfaction with care.

**H2:** Among caregiver characteristics, being older will be associated with/lead to higher quality of dementia care scores, and higher global satisfaction with care.

**H3:** Among caregiver characteristics, gender and ethnicity will not be associated with quality of dementia care scores and global satisfaction with care.

**H4:** Greater severity of patient symptoms will be associated with/lead to lower quality of dementia care scores, and lower global satisfaction with care.

**H5:** Higher patient ADL and IADL scores (higher levels of patient disability) will be associated with/lead to higher quality of dementia care scores, and higher global satisfaction with care.
**H6**: Higher scores on quality of dementia care will be associated with/lead to higher levels of global satisfaction with care, controlling for other variables in the models.

4.3. Sample eligibility criteria and data collection procedures

This study used pooled data from two studies involving family caregivers of persons with dementia: the Help Line Callers Study and The Physician Referral Study. Both of these studies were directed by Dr. Richard Fortinsky between 1996 and 1998, and were carried out in the Cleveland, Ohio metropolitan area. For both of these parent studies, the subject eligibility criteria were identical. Eligible participants were family caregivers of individuals who were: (1) diagnosed with Alzheimer’s disease or another type of irreversible dementia; (2) living at home; and (3) ambulatory without constant human assistance. Both parent studies restricted eligibility to family caregivers who were primarily responsible for patient’s daily care and attended physician visits with their relatives with dementia.

Although both parent studies gathered data at two points in time, data for the present investigation were taken from baseline interviews completed by caregivers enrolled in both studies. Caregivers completed interviewer-administered questionnaires via telephone that collected information on quality and global satisfaction with physicians’ dementia care as well as on sociodemographic and health status characteristics for both patients and caregivers. The questions used in the present study
were asked in an identical manner in both parent studies. Details of these studies have been published elsewhere (Fortinsky, Kercher et al. 2002; Fortinsky, Unson et al. 2002). The methods of the two studies are summarized below.

**Help Line Callers Study**

As part of a larger study on dementia care experiences with physicians, family caregivers were prospectively recruited from July 1996-June 1997 from the population of callers to the telephone Help Line of the Cleveland Area Alzheimer's Association (the Association). Help Line staff at the Association incorporated three study eligibility criteria into their telephone conversations with all callers throughout the 12-month enrollment period. First, callers were required to be family caregivers, defined as individuals with primary or secondary responsibility for daily care of a relative with dementia. Second, callers' relatives with dementia were required to be living in a home setting at the time of the Help Line call. Third, callers' relatives were required to have a physician's diagnosis of either Alzheimer's disease or another type of irreversible dementia. This study relied on verbal confirmation by callers that a physician gave their relatives a formal diagnosis. As further verification of physician involvement in the diagnostic process, only callers who reported a personal or telephone contact with a physician since the dementia diagnosis were eligible for this study.

Eligible family caregivers received a letter from the Association that described the larger study and encouraged their participation. Contact information about eligible family caregivers was forwarded from the Help Line staff to the study team. A member of the
study team verified eligibility, and assigned verified caregivers to study interviewers. Interviewers were instructed to wait at least one week after the Association’s letter was mailed before initiating telephone contact with eligible caregivers. When interviewers contacted eligible caregivers, they referred to the Help Line call and the letter from the Association, described participation via verbal consent. Eligible caregivers were considered enrolled in the study when they provided verbal consent. These consent procedures were approved by the human subjects review boards at University Hospitals of Cleveland and the Association. Two experienced interviewers conducted all telephone interviews. Pre-testing and initial interviewer training took place in March 1996, and a refresher training session was held in June 1996 to coincide with the beginning of sample enrollment. All interview data were entered and managed via SAS software on a mainframe platform, and were converted to SPSS system files for analyses on the PC platform.

Physician Referral Study

Primary care physicians in the metropolitan Cleveland area who responded to a survey about their practices in dementia care (survey described in Fortinsky, 1998) and who returned a postcard stating interest in participation, were sent written materials describing eligibility criteria for patients and family caregivers. Physicians also received a supply of study referral forms and instructions for their use. All participating physicians received reminder postcards quarterly throughout the recruitment period (July 1996-January 1998) to maximize the visibility of the study amid their busy practices.
Physicians were responsible for explaining the purpose of the study to eligible family caregivers during office visits. If caregivers agreed to participate based on this explanation, physicians completed a referral form and sent it to a member of the study’s research staff, who then contacted the family caregiver by telephone to conduct a pre-intervention structured interview. At this time, caregivers had the option to withdraw from the study, but none did so.

4. Variable Definition and Measurement

The measures considered in the study were patient and caregiver characteristics, a newly created measure of overall quality of physicians’ dementia care, and the two outcome variables - global satisfaction with physicians’ care for patient, and with physicians’ help for the caregivers.

Sociodemographic Characteristics of Caregivers

Age and gender. The age of the caregivers was measured continuously, asking for the exact age in number of years. Gender was measured categorically. Ethnicity was ascertained by asking caregivers to classify themselves into an ethnic or racial group (White or African American in this sample). Caregiver marital status was classified into four groups: single, married, divorced, and widowed. Education was classified into three levels: completed high school or lower, some college, and college graduate. The employment status was determined by asking caregivers if they worked outside of the
home for pay and if so, if they worked for 40 or more hours per week. Household income was categorized into three levels: less than $30,000; $30,000 - $49,999; and $50,000 and more. Relationship to patient was categorized as spouse, adult child, and other relative (the single non-relative caregiver in this sample was grouped with other relatives). Type of family caregiver was categorized as either primary (solo or main) or secondary (equal or supplemental) responsibility for care. Living arrangements were determined by asking caregivers if they lived with the patient and if not, if they lived within half an hour drive from patient’s residence.

_Caregivers’ mental and physical health symptoms_

Depressive symptoms were measured using the 10-item short form of the Center for Epidemiological Studies-Depression inventory (Kohout, Berkman et al. 1993). Caregivers were asked if they felt any item much of the time in the previous week (e.g., I felt depressed; I could not get going). Each item was presented in a yes/no format. Responses to each ‘yes’ item were scored as ‘1’; higher scores on the 0-10 scale represented more depressive symptoms.

Physical health symptoms were measured using the 12-item physical signs and symptoms subscale from the Hopkins Symptoms Checklist (Derogatis, Lipman et al. 1974). Caregivers were asked if they were bothered by each symptom during the previous week (e.g., headaches, faintness or dizziness; pains in the heart or chest). Higher scores on the 0-12 scale represented a greater number of symptoms.
Severity of relatives’ dementia symptoms

Four domains of dementia symptom severity were measured: cognitive status, behavioral problems, ability to conduct personal activities of daily living (ADL), and instrumental ADLs.

Cognitive status was measured using the Cognitive Status Scale developed and tested by Pearlin and colleagues (Pearlin, Mullan et al. 1990). This scale contains eight items such as remembering recent events, understanding simple instructions, and recognizing familiar people. Caregivers are asked to rate their relative on a four-point scale ranging from ‘can’t do at all’ to ‘not at all difficult’. Summed scale scores range from 0 (least impaired) to 32 (most impaired).

Behavioral problems were measured using the Problematic Behavior Scale, also developed by Pearlin and colleagues (Pearlin, Mullan et al. 1990). This scale contains 14 items such as suspiciousness, agitation, night wandering, and anger; responses are in terms of the number of days in the previous week the caregiver had to deal with these behaviors. Scale scores range from 14 (no problems in previous week) to 56 (five or more days in past week for all problems).

Independence in personal and instrumental activities of daily living (IADLs) was measured according to the caregiver’s report about the patient’s ability to perform personal care and instrumental ADLs. Activities of daily living were based on a modified scoring of the Katz measure (Katz, Ford et al. 1963); IADLs were based on a modified
version of the Duke Older Americans Resources and Services (OARS) measure (Duke University Center for the Study of Aging and Human Development 1978). The ADL scale contained five items: bathing, dressing, eating, transferring from bed to chair, and toileting. Caregivers were asked whether or not their relative could perform activities without help; responses were in a yes/no format (score range: 0-5). The IADL scale contained seven items ranging from telephone use to handling finances; responses were unable, some help, or no help (score range: 0-14). Both scales were scored such that lower values indicated more activities performed independently.

Quality of Physician Advice and Guidance about Dementia

A variable of major interest in this study refers to the advice and guidance that physicians provided to family caregivers about dementia symptom management, medication management, support service linkage, and emotional support. No standardized measures of this variable have been published to date.

To measure this variable, family caregivers were asked to give their appraisals of physician advice and guidance. Caregivers who reported contact with a single physician were asked to appraise that physician, while caregivers who reported contact with more than one physician were asked to appraise all such physicians in the aggregate.

Based on Fortinsky’s theoretical framework about health care triads and dementia care (Fortinsky 2001), a series of 12 items covering four conceptual domains of
physicians’ advice and guidance were included in this study for psychometric testing and used in the hypothesis testing analyses. Each item was presented in a yes/no format. Responses to each ‘yes’ item were scored as ‘1’ and to each ‘no’ – as ‘0’. Overall quality of physicians’ dementia care score was obtained by adding up the scores of each item. Conceptual domains were defined as: (1) dementia symptom management advice; (2) advice about medication management; (3) advice and guidance about support service linkage; (4) emotional support.

All 12 items are listed below according to the conceptual domains as proposed prior to any data analyses.

*Quality of dementia symptom management advice.* Three items inquired about physician advice and guidance related to managing dementia symptoms. These were:

- Has the doctor given you advice about handling any problems?
- Has the doctor given you advice about what problems to expect in future?
- Has the doctor given you ideas how to keep your relative as independent as possible?

*Quality of medication management advice.* Three items inquired about physician advice and guidance caregivers received about managing their relatives’ prescribed medications.

- Has the doctor provided you with information about possible side effects?
- Has the doctor made sure you know the number of medications your relative is taking?
Has the doctor given you instructions on how your relative should take his/her medications?

**Quality of support service advice and guidance.** Three items inquired about physician advice and guidance related to services available in the community to help caregivers. These items were:

- Has the doctor provided you with information about available services?
- Has the doctor provided you with information about how to arrange for services?
- Has the doctor provided you with information about ways to pay for services?

**Quality of emotional support.** Three items inquired about the more qualitative aspect of physician-caregiver interaction. Caregivers were asked questions about whether physicians helped them feel comfortable with their role as caregivers.

- Has the doctor given you a chance to talk about fears or anxieties?
- Has the doctor reassured you about doing the right things?
- Has the doctor asked you how you are doing?

**Global satisfaction with physicians’ care for patient, and global satisfaction with physicians’ help for the caregivers.** Caregivers were asked two questions about their satisfaction with physicians’ dementia care:

- Overall, how satisfied are you with the doctor’s care for your (RELATIONSHIP)?
- Overall, how satisfied are you with the help the doctor has given you to care for your (RELATIONSHIP)?
Both global satisfaction variables were measured using a four point ordinal scale (very dissatisfied, dissatisfied, satisfied, very satisfied).

4.5. Statistical Analyses

All analyses were cross-sectional. Data were analyzed on three levels, using descriptive and inferential statistics. On the univariate level, descriptive statistics were computed for each of the variables. Frequencies, percentages, means, standard deviations, and ranges were examined. All continuous variables were tested for normality using Kolmogorov-Smirnov test and non-parametric methods were adopted where data violated the assumptions of normality.

Factor analysis was used to determine whether and how the 12 quality items measured the four conceptual domains of dementia management, which are most important to family caregivers when interacting with physicians. Factor analysis is usually based on Pearson correlations. However, there may be problems with using the Pearson correlations if the variables are dichotomous. Several advanced methods are available for factor analysis of dichotomous data; the method used in this study is factor analysis of the tetrachoric correlations between all item pairs (Knol and Berger 1991). First, because of the dichotomous nature of the variables, a matrix of tetrachoric correlations among the twelve items was calculated using TETCORR and then used as a correlation matrix input to SPSS’s factor analysis procedure. TETCORR is a software
program, which combines an algorithm developed by (Brown 1977) with starting values obtained from (Divgi 1979) for more efficient computation. TETCORR addresses several concerns: (1) efficient processing of a large number of variables and computing of a matrix of coefficients; (2) a matrix-smoothing capability; (3) an accurate, reliable computing algorithm; and (4) the ability to handle missing data (Fleming 2005). Next, with regard to the extraction, the principal components method was used. The eigenvalues obtained from the initial extraction were examined, which provided a preliminary indication of the number of factors represented by the data. Consequently, these initial extractions together with the theoretical design of the overall quality measure were used to determine the ultimate number of underlying factors to be extracted. The extractions were rotated to an orthogonal solution using a varimax rotation.

The internal consistency reliability of the overall quality of physician dementia care scale was assessed using Cronbach’s alpha.

Next, bivariate associations were examined between the overall quality of care scale, the four quality of care subscales, the two global satisfaction with dementia care variables, and the patient and caregiver characteristics. The bivariate associations among variables were examined using either eta or Spearman rank correlations depending upon the level of the variable.

Each dependent variable had more than two categories and the categories were ordinal (ratings of “very dissatisfied”, “dissatisfied”, “satisfied”, “very satisfied”).
Therefore, ordinal logistic regression models using the proportional odds assumption were constructed (Hosmer and Lemeshow 2000). The ordinal logistic regression models estimate the effects of exploratory variables on the log odds of having lower rather than higher scores on the dependent variable. Caregivers’ ratings of global satisfaction with physicians’ help to the patient and caregivers’ ratings of global satisfaction with the help he or she received from the physician to take care of his or her relative were treated as ordinal dependent variables in the constructed ordinal regression models. The quality of physicians’ dementia care variables, patient and caregiver characteristics were used as explanatory variables. All relevant variables were included in the models, regardless of their statistical significance, because there is a possibility that a collection of variables, each of which is weakly associated with the outcome, may become an important predictor of outcome when taken together (Hosmer and Lemeshow 2000). Some of the continuous explanatory variables were categorized to facilitate interpretation of results. To build the models the logit link function was used, thus obtaining not only the direction of the relationship between each explanatory and outcome variable but also the magnitude of the association between them, expressed in the form of odds ratios. Since SPSS does not report the odds ratio estimates, they were derived from the coefficients by taking the exponent of each coefficient. Similar to logistic regression, statistical significance occurs when the odds ratio (OR) differs statistically from 1.00. Pearson chi-square and deviance residuals statistics were used to assess the quality of the models. The ordinal regression model adequacy was verified by the test of parallel lines.
All analyses were performed with SPSS 12.0 with the exception of the tetrachoric correlations matrix which was performed in TETCORR and the odds ratios from the ordinal logistic regressions which were calculated using Excel 2000. For all analyses statistical significance was assumed if \( p < 0.05 \).

5. Results

5.1. Sample accrual and response rate

A total of 257 family caregivers in the Help Line Callers Study met study eligibility criteria and were contacted by study interviewers. Of these, a total of 197 family caregivers completed telephone interviews, for a 77% response rate. A total of 62 eligible family caregivers were enrolled in the Physician Referral Study. Of these 59 family caregivers completed telephone interviews, for a 95% response rate. Data for the present study were taken from baseline interviews completed by 256 caregivers enrolled in both studies. Because the focus of the current study was on caregivers of dementia patients taking prescribed medications, this criterion was used to further restrict eligibility. The final pooled data study included data from 204 caregivers, or 80% of those initially enrolled in both studies.
5. 2. Characteristics of family caregivers

Socio-demographic characteristics and health status characteristics of the 204 caregivers are summarized in Table 1. Caregivers in the study sample ranged in age from 26-81 years old (mean = 56 years old). More than 80% were female, 21% identified themselves as African-American or Black, and 76% were married.

Adult children and children-in-law made up 58% of the sample members, while spouses accounted for 29% of the sample. More than 40% of the caregivers had a high school education or less; 25% were college graduates. Nearly a half of the sample was gainfully employed, including almost one-quarter who worked full time in addition to their caregiving responsibilities. More than 30% of caregivers reported a total household income of less than $30,000 per year. More than one-half of caregivers (56%) lived in the same household as their relatives with diagnosed dementia, while an additional 30% lived within a 30 minute drive. Most caregivers reported that they were primary caregivers – the sole informal source of help (30%) or the main caregiver (39%).

Caregivers reported mild to moderate degrees of depressive symptoms, with a mean of nearly four symptoms (of a possible 10) reported in the week prior to their interview. They also reported mild degrees of physical symptoms, with a mean of more than two symptoms (of a possible 12) during the previous week.
### Table 1. Sociodemographic and health status characteristics of caregivers

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total (N=204)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) or N (%)</td>
</tr>
<tr>
<td><strong>Age (mean)</strong></td>
<td>56.1 (13.4)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37 (18.1%)</td>
</tr>
<tr>
<td>Female</td>
<td>166 (81.4%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>43 (21.1%)</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>158 (77.5%)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>18 (8.8%)</td>
</tr>
<tr>
<td>Married</td>
<td>156 (76.5%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>22 (10.8%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>8 (3.9%)</td>
</tr>
<tr>
<td><strong>Relationship to dementia patient</strong></td>
<td></td>
</tr>
<tr>
<td>Adult child</td>
<td>118 (57.8%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>59 (28.9%)</td>
</tr>
<tr>
<td>Other</td>
<td>27 (13.2%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>87 (42.6%)</td>
</tr>
<tr>
<td>Some college</td>
<td>66 (32.4%)</td>
</tr>
<tr>
<td>Graduated college</td>
<td>51 (25.0%)</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Working for pay</td>
<td>91 (44.6%)</td>
</tr>
<tr>
<td>Working 40 hrs/wk or more</td>
<td>50 (24.5%)</td>
</tr>
<tr>
<td><strong>Total household income</strong></td>
<td></td>
</tr>
<tr>
<td>Under - $29,999</td>
<td>65 (31.9%)</td>
</tr>
<tr>
<td>$30,000 - $49,999</td>
<td>53 (26.0%)</td>
</tr>
<tr>
<td>$50,000 - Above</td>
<td>62 (30.4%)</td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
<td></td>
</tr>
<tr>
<td>Lives with patient</td>
<td>114 (55.9%)</td>
</tr>
<tr>
<td>Lives within ½ hour drive</td>
<td>61 (29.9%)</td>
</tr>
<tr>
<td>Lives more than ½ hour drive</td>
<td>29 (14.2%)</td>
</tr>
<tr>
<td><strong>Caregiver involvement</strong></td>
<td></td>
</tr>
<tr>
<td>Solo caregiver</td>
<td>61 (29.9%)</td>
</tr>
<tr>
<td>Main caregiver</td>
<td>80 (39.2%)</td>
</tr>
<tr>
<td>Equal caregiver</td>
<td>41 (20.1%)</td>
</tr>
<tr>
<td>Supplemental</td>
<td>22 (10.8%)</td>
</tr>
<tr>
<td><strong>Health status</strong></td>
<td></td>
</tr>
<tr>
<td>Depression symptoms (range=0-10)</td>
<td>3.8 (1.7)</td>
</tr>
<tr>
<td>Physical Symptoms (range=0-12)</td>
<td>2.5 (2.6)</td>
</tr>
</tbody>
</table>

Notes: Percentages may not add to 100 because of missing data or rounding.
5.3. Characteristics of patients with dementia

Dementia patients are described as to socio-demographic and health status characteristics in Table 2. Patients ranged in age from 56-96 years old (mean = 78 years old), 62% were female and 22% were reported as African-American or Black. Mean scores on cognitive status and behavioral problem measures were in the midrange of possible values (14.2 of a possible 32 for cognitive status, and 28.8 of a possible 56 for behavioral problems). The mean number of instrumental activities of daily living (IADLs) limitations was 10.1 on a scale where 14 indicated maximum dependence. The mean number of personal ADLs limitations was 1.8 of five activities (5 indicated maximum dependence).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mean (SD) or percentage (N=204)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>78.3 (7.4)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37.7%</td>
</tr>
<tr>
<td>Female</td>
<td>62.3%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>22.1%</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>76.5%</td>
</tr>
<tr>
<td>Cognitive status score (range=0-32)</td>
<td>14.2 (6.9)</td>
</tr>
<tr>
<td>Problematic behavior score (range=14-56)</td>
<td>28.8 (8.2)</td>
</tr>
<tr>
<td>Personal activities of daily living score</td>
<td>1.8 (1.8)</td>
</tr>
<tr>
<td>Instrumental activities of daily living score</td>
<td>10.1 (3.9)</td>
</tr>
</tbody>
</table>
Nearly one-half (45%) of caregivers reported that the diagnosis of Alzheimer’s disease or other type of dementia had been made less than 1 year before the interview; 24% said 1-2 years before; and 31% reported more than 3 years before.

5.4. Quality of Physician Advice and Guidance about Dementia

As discussed, a twelve-item measure was developed in this study to represent family caregivers’ appraisals of the quality of advice and guidance provided to them by physicians to care for their relatives with dementia. Twelve items tapped physician advice and guidance about dementia symptom management (three items), medication management (three items), support service linkage (three items), and emotional support (three items). Table 3 summarizes descriptive results of each of these twelve items as well as the twelve-item overall quality scale and the four subscales.

Results of the individual items indicate that physicians were most likely to have provided advice and guidance related to medication management, with 79% of caregivers reporting that physicians gave them instructions on how their relative should take his/her medications. Although 57% of caregivers reported that physicians gave them advice about support services, far fewer (17%) said that the physician gave them specific advice how to arrange for these services. About 42% of caregivers reported that physicians had given them advice about handling any symptom management problem. Sixty-four percent
of caregivers reported that physicians had reassured them that they were doing the right things for the patient.

To investigate the factorial structure of the quality items, an explanatory factor analysis was performed on all 12 quality items, which identified four factors, explaining 73% of the variance. All items loaded on the predicted factors. The post-rotation loading of each item on each factor, eigenvalue and percent of variance accounted for are presented in Table 4. The four identified factors and the items’ loadings on each factor were interpretable and conformed to the expected components reflecting the quality of care domains according to Fortinsky’s (2001) Health Care Triad theoretical framework. In addition, the model fit the data well. The quality of dementia care items were measuring four factors, each representing one of the four quality of care domains. Factor analysis suggested that there were four separate subscales. An overall measure of quality of physicians’ dementia care was created by summing all twelve items, yielding scores that range from 0 (caregivers indicated “no” to all items) to 12 (caregivers indicated “yes” to all items). The overall quality score was computed by adding together the respondent’s scores for the twelve quality items. The overall quality score ranges from 0 to 12, with 12 representing the highest quality of care score. Cronbach’s coefficient alpha for the 12 item overall quality scale was 0.76. Results indicate that the overall quality of care scale can reliably assess four factors and that it highly correlated with both global satisfaction variables, indicating validity.
Table 3. Caregiver perceived quality of physicians’ dementia care

<table>
<thead>
<tr>
<th>Items*</th>
<th>Frequency “Yes” (%) (N=204)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom management domain</strong></td>
<td></td>
</tr>
<tr>
<td>MD gave you advice about handling any problems</td>
<td>86 (42.2%)</td>
</tr>
<tr>
<td>MD gave you advice about what problems to expect in future</td>
<td>78 (38.2%)</td>
</tr>
<tr>
<td>MD gave you ideas how to keep your relative independent</td>
<td>55 (27.0%)</td>
</tr>
<tr>
<td><strong>Medication management domain</strong></td>
<td></td>
</tr>
<tr>
<td>MD provided you with information about possible side effects</td>
<td>128 (62.7%)</td>
</tr>
<tr>
<td>MD made sure you know the number of medications your relative is taking</td>
<td>155 (76%)</td>
</tr>
<tr>
<td>MD gave you instructions on how your relative should take his/her medications</td>
<td>161 (78.9%)</td>
</tr>
<tr>
<td><strong>Support service linkage domain</strong></td>
<td></td>
</tr>
<tr>
<td>MD provided you with information about available services</td>
<td>116 (56.9%)</td>
</tr>
<tr>
<td>MD provided you with information about how to arrange for services</td>
<td>35 (17.2%)</td>
</tr>
<tr>
<td>MD provided you with information about ways to pay for services</td>
<td>8 (3.9%)</td>
</tr>
<tr>
<td><strong>Emotional support domain</strong></td>
<td></td>
</tr>
<tr>
<td>MD gave you chance to talk about fears or anxieties</td>
<td>95 (46.6%)</td>
</tr>
<tr>
<td>MD reassured you about doing right things</td>
<td>130 (63.7%)</td>
</tr>
<tr>
<td>MD asked you how you are doing</td>
<td>107 (52.5%)</td>
</tr>
<tr>
<td><strong>Overall quality 12 item composite</strong></td>
<td></td>
</tr>
<tr>
<td>Mean, SD, Range</td>
<td>5.64, 2.81, (0-12)</td>
</tr>
<tr>
<td>Cronbach’s alpha</td>
<td>0.76</td>
</tr>
</tbody>
</table>

* See text for variable definition

**Sum of "yes" responses to the 12 quality items
Table 4. The post-rotation loading of each item on each factor, factor eigenvalues and the variance accounted by each factor

<table>
<thead>
<tr>
<th>Item</th>
<th>Medication Management</th>
<th>Emotional Support</th>
<th>Support service linkage</th>
<th>Symptom management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice handling any problem</td>
<td>-0.031</td>
<td>0.335</td>
<td>0.097</td>
<td>0.708</td>
</tr>
<tr>
<td>Advice about what to expect in the future</td>
<td>0.192</td>
<td>-0.029</td>
<td>0.190</td>
<td>0.808</td>
</tr>
<tr>
<td>Ideas how to keep relative independent</td>
<td>0.349</td>
<td>0.244</td>
<td>0.070</td>
<td>0.682</td>
</tr>
<tr>
<td>Information about available services</td>
<td>0.172</td>
<td>0.044</td>
<td>0.789</td>
<td>0.212</td>
</tr>
<tr>
<td>Information about how to arrange for services</td>
<td>0.340</td>
<td>0.233</td>
<td>0.810</td>
<td>-0.051</td>
</tr>
<tr>
<td>Information about ways to pay for services</td>
<td>-0.045</td>
<td>0.393</td>
<td>0.690</td>
<td>0.254</td>
</tr>
<tr>
<td>Information about possible side effects</td>
<td>0.755</td>
<td>0.188</td>
<td>0.206</td>
<td>0.145</td>
</tr>
<tr>
<td>MD made sure you know the number of medications your relative is taking</td>
<td>0.839</td>
<td>0.245</td>
<td>0.122</td>
<td>0.128</td>
</tr>
<tr>
<td>MD gave you instructions on how your relative should take his/her medications</td>
<td>0.867</td>
<td>0.127</td>
<td>0.115</td>
<td>0.163</td>
</tr>
<tr>
<td>MD gave you chance to talk about fears or anxieties</td>
<td>0.158</td>
<td>0.790</td>
<td>0.224</td>
<td>0.282</td>
</tr>
<tr>
<td>MD reassured you about doing right things</td>
<td>0.204</td>
<td>0.697</td>
<td>0.286</td>
<td>0.323</td>
</tr>
<tr>
<td>MD asked how you are doing</td>
<td>0.396</td>
<td>0.791</td>
<td>0.104</td>
<td>-0.016</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice handling any problem</td>
<td>2.557</td>
<td>2.230</td>
<td>2.019</td>
<td>1.979</td>
</tr>
<tr>
<td>Advice about what to expect in the future</td>
<td>21.309</td>
<td>18.582</td>
<td>16.824</td>
<td>16.496</td>
</tr>
<tr>
<td>Ideas how to keep relative independent</td>
<td>2.230</td>
<td>2.019</td>
<td>1.979</td>
<td></td>
</tr>
<tr>
<td>Information about available services</td>
<td>2.019</td>
<td>1.979</td>
<td>1.879</td>
<td></td>
</tr>
<tr>
<td>Information about how to arrange for services</td>
<td>18.582</td>
<td>16.824</td>
<td>16.496</td>
<td></td>
</tr>
<tr>
<td>Information about ways to pay for services</td>
<td>1.979</td>
<td>1.879</td>
<td>1.719</td>
<td></td>
</tr>
<tr>
<td>Information about possible side effects</td>
<td>16.824</td>
<td>16.496</td>
<td>16.146</td>
<td></td>
</tr>
<tr>
<td>MD made sure you know the number of medications your relative is taking</td>
<td>16.496</td>
<td>16.146</td>
<td>15.832</td>
<td></td>
</tr>
<tr>
<td>MD gave you instructions on how your relative should take his/her medications</td>
<td>16.146</td>
<td>15.832</td>
<td>15.522</td>
<td></td>
</tr>
<tr>
<td>MD gave you chance to talk about fears or anxieties</td>
<td>15.832</td>
<td>15.522</td>
<td>15.238</td>
<td></td>
</tr>
<tr>
<td>MD reassured you about doing right things</td>
<td>16.496</td>
<td>16.146</td>
<td>15.832</td>
<td></td>
</tr>
<tr>
<td>MD asked how you are doing</td>
<td>16.146</td>
<td>15.832</td>
<td>15.522</td>
<td></td>
</tr>
</tbody>
</table>
Next, four subscales were created using quality items with factor loadings higher than .50 that correspond with the expected factors – one for each domain – symptom management, medication management, support service linkage, and emotional support. Each of the subscale scores was computed by adding together the respondent’s scores for the three quality items in each subscale. Each subscale score ranges from 0 to 3, with 3 representing the highest score. The means for each of the four subscales are provided in Table 3.

Results of the twelve-item overall quality of care scale in Table 3 reflecting sample caregivers’ ratings of the quality of physician advice and guidance about dementia care indicate a mean score of 5.64 (SD=2.81). The mean score suggests that the average ratings of physician advice and guidance about dementia care fell in the middle ranges on the numeric scale (range 0-12).

The relations among the four quality of care subscales and the overall quality of care scale were important to consider in the methodological assessment of the scale. As is indicated in Table 5, Spearman correlations between subscales and subscales and overall scale were all significant at the 0.01 level. All correlations among subscales were fairly low, positive correlations. The correlations among the subscales were much lower (rho=0.26-0.37) than the correlations with the overall quality of care score (rho=0.60-0.79) to which all sub-scales significantly contribute, showing that the subscales of domains were really independent from each other (as was suggested by the factor
Table 5. Correlations between the four quality of care subscales and the overall quality of care scale

<table>
<thead>
<tr>
<th></th>
<th>Quality of medical encounters</th>
<th>Symptom management</th>
<th>Support service linkage</th>
<th>Medication management</th>
<th>Emotional support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of medical encounters</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom management</td>
<td>.684(**), 1.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support service linkage</td>
<td>.597(<strong>), .262(</strong>)</td>
<td>.262(**)</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication management</td>
<td>.679(<strong>), .285(</strong>), .274(**)</td>
<td>.285(**)</td>
<td>.274(**)</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>.789(<strong>), .368(</strong>), .339(**)</td>
<td>.368(**)</td>
<td>.339(**)</td>
<td>.358(**)</td>
<td>1.000</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
analysis) and as would be expected according to the Health Care Triad theoretical framework.

5. 5. Global satisfaction with Physician Advice and Guidance about Dementia

Table 6 shows the results for caregivers’ global satisfaction with physicians’ care for the patient, and with physicians’ help for the caregivers. More than 80 percent of caregivers were at least satisfied with the physician’s care of the patients, whereas about 70 percent were at least satisfied with the help the physician had given to them.

Table 6. Caregiver satisfaction with physicians’ dementia care

<table>
<thead>
<tr>
<th>Items</th>
<th>Frequency “Yes” (%) (N=204)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied is caregiver with physician care of patient</td>
<td></td>
</tr>
<tr>
<td>Very satisfied</td>
<td>82 (40.2%)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>91 (44.6%)</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>23 (11.3%)</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>5 (2.5%)</td>
</tr>
<tr>
<td>How satisfied is caregiver with help the physician has given the caregiver</td>
<td></td>
</tr>
<tr>
<td>Very satisfied</td>
<td>68 (33.3%)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>82 (40.2%)</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>34 (16.7%)</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>9 (4.4%)</td>
</tr>
</tbody>
</table>

There were strong highly significant positive associations found between global satisfaction with physicians’ care for the patient and the four subscales of quality of physicians’ dementia care, and between global satisfaction with physicians’ care for the caregiver and the four subscales of quality of physicians’ dementia care (Table 7).
Table 7. Correlations between the overall quality of care scale, the four quality of care subscales and global satisfaction with physicians' care for the patient and for the caregiver

<table>
<thead>
<tr>
<th>Overall quality of care</th>
<th>Global satisfaction with physicians’ care for the PATIENT</th>
<th>Global satisfaction with physicians’ care for the CAREGIVER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.388(**)</td>
<td>.467(**)</td>
</tr>
<tr>
<td>Medication management</td>
<td>.195(**)</td>
<td>.248(**)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>.384(**)</td>
<td>.482(**)</td>
</tr>
<tr>
<td>Symptom management</td>
<td>.205(**)</td>
<td>.205(**)</td>
</tr>
<tr>
<td>Support service linkage</td>
<td>.262(**)</td>
<td>.306(**)</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
5. 6. Bivariate Relationships among Study Variables

In Table 8 and in Table 9 results of single-order correlations between the overall quality of care scale, the four quality of care subscales, the two global satisfaction with dementia care variables and the patient and caregiver characteristics are summarized.

In **H1**, overall quality of care and global satisfaction with physicians’ care to the patient and global satisfaction with physicians’ care to the caregiver were the dependent variables and caregiver education was the independent variable. Negative relationships were hypothesized between these variables. As shown in Table 8, highly statistically significant results were found between caregiver’s education and global satisfaction with physicians’ care to the patient (\(-.233, p<0.001\)), and caregiver’s education and global satisfaction with physicians’ care to the caregiver (\(-.261, p<0.001\)), but not between caregiver’s education and overall quality of care.

In **H2**, a positive relationship was hypothesized between caregiver age and quality of dementia care scores, and caregiver age and global satisfaction with care for the patient and global satisfaction for the patient. Results in Table 8 show that none of the correlation coefficients between these variables were statistically significant.

In **H3**, no association was hypothesized between caregiver gender and caregiver ethnicity as independent variables and quality of dementia care scores, global satisfaction with care for the patient, and global satisfaction with care for the caregiver as dependent
Table 8. Single-order correlations between quality of dementia care scale and subscales, satisfaction with dementia care and caregiver characteristics.

<table>
<thead>
<tr>
<th>Caregiver Characteristics</th>
<th>Quality of physicians’ dementia care</th>
<th>Satisfaction with physicians’ care to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall quality scale</td>
<td>Symptom management subscale</td>
</tr>
<tr>
<td>Age</td>
<td>-.031</td>
<td>-.177(*)</td>
</tr>
<tr>
<td>Gender</td>
<td>-.078</td>
<td>-.103</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>.028</td>
<td>.043</td>
</tr>
<tr>
<td>Marital status</td>
<td>.141</td>
<td>.102</td>
</tr>
<tr>
<td>Relationship to dementia patient</td>
<td>.072</td>
<td>.220</td>
</tr>
<tr>
<td>Education</td>
<td>-.056</td>
<td>.002</td>
</tr>
<tr>
<td>Working for pay</td>
<td>-.008</td>
<td>.119</td>
</tr>
<tr>
<td>Working 40 hrs/wk or more</td>
<td>-.057</td>
<td>-.081</td>
</tr>
<tr>
<td>Total household income</td>
<td>.061</td>
<td>.106</td>
</tr>
<tr>
<td>Lives with patient</td>
<td>.125</td>
<td>-.052</td>
</tr>
<tr>
<td>Lives within ½ hour drive</td>
<td>.115</td>
<td>-.076</td>
</tr>
<tr>
<td>Caregiver involvement</td>
<td>.074</td>
<td>.135</td>
</tr>
<tr>
<td>Depressive symptoms*</td>
<td>.036</td>
<td>-.019</td>
</tr>
<tr>
<td>Physical health symptoms*</td>
<td>-.151(*)</td>
<td>-.166(*)</td>
</tr>
</tbody>
</table>

* See text for variable definition
* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed).
Table 9. Single-order correlations between quality of dementia care scale and subscales, satisfaction with dementia care and patient characteristics.

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Quality of physicians' dementia care</th>
<th>Satisfaction with physicians' care for:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall scale</td>
<td>Symptom management subscale</td>
</tr>
<tr>
<td>Age</td>
<td>.051</td>
<td>.123</td>
</tr>
<tr>
<td>Gender</td>
<td>.060</td>
<td>.059</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>.048</td>
<td>.027</td>
</tr>
<tr>
<td>Cognitive status score</td>
<td>.106</td>
<td>.030</td>
</tr>
<tr>
<td>Problematic behavior</td>
<td>.099</td>
<td>.089</td>
</tr>
<tr>
<td>score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal activities of</td>
<td>.241(**)</td>
<td>.149(*)</td>
</tr>
<tr>
<td>daily living score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instrumental activities</td>
<td>.238(**)</td>
<td>.135</td>
</tr>
<tr>
<td>of daily living score</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
variables. Results in Table 8 show no significant associations between the hypothesized variables.

The variables in H4 were patient cognitive status score and patient problematic behavior score, overall quality of physicians’ dementia care score, global satisfaction with physicians’ care to the patient and global satisfaction with physicians’ care to the caregiver. Results in Table 9 show that none of the correlation coefficients between these variables were statistically significant. These results indicate that severity of patient symptoms is not correlated to the quality of care and the global satisfaction with care ratings.

The independent variables in H5 were patient’s personal activities of daily living score (ADL) and instrumental activities of daily living score (IADL), while the dependent variables were overall quality of physicians’ dementia care score, global satisfaction with physicians’ care to the patient and global satisfaction with physicians’ care to the caregiver. A positive relationship was hypothesized between patient’s ADL and IADL and quality of dementia care and global satisfaction with care. As shown in Table 9, highly statistically significant results were found between patient’s ADL and overall quality of physicians’ dementia care (.241, p<0.001), and patient’s IADL and overall quality of physicians’ dementia care (.238, p<0.001), but not between patient’s ADL and IADL and global satisfaction with physicians’ care to the patient and global satisfaction with physicians’ care to the caregiver.
For H6, there were highly significant positive associations found between global satisfaction with physicians’ care for the patient and quality of physician dementia care ($r^2 = 0.388; p < 0.001$), and between global satisfaction with physicians’ help for the caregiver and quality of physician dementia care ($r^2 = 0.467; p < 0.001$).

5.7. Multivariate Analyses

To better understand the influence of quality of physicians’ dementia care on caregivers’ global satisfaction, ordinal regression analyses were performed. The results of these regression analyses are reported as odds ratios, which are the ratios of the odds that a caregiver with a particular set of explanatory variables is in a more satisfied category of physicians’ dementia care than a caregiver with another set of explanatory variables. Similar to logistic regression, statistical significance occurs when the odds ratio (OR) differs statistically from 1.00. However, in ordinal logistic regression the OR represents the increased (OR>1.00) or decreased odds (OR<1.00) of reporting a higher level of global satisfaction (e.g., satisfied versus very satisfied) that is associated with a one-point increase in the independent variable.

Two ordinal regression models were constructed – one for each global satisfaction variable:
Model 1 - with global satisfaction with physicians’ dementia care for the patient as the dependent variable and the four domains of physicians’ dementia care as the main independent variables. Based on the analysis, the significant variables in Model 1 were found to be caregiver education and emotional support domain of quality of care score.

Model 2 - with global satisfaction with physicians’ dementia care for the caregiver as the dependent variable and the four domains of physicians’ dementia care as the main independent variables. Variables found to significantly predict global satisfaction with physicians’ dementia care for the caregiver were caregiver education, symptom management and emotional management domains of quality of care scores.

The main independent variables in Model 1 and Model 2 were the four domains of quality of care – symptom management, support service linkage, medication management, and emotional support. In Model 1 only emotional support domain reached statistical significance (OR=1.78, p<0.001); while in Model 2, two of the domains reached statistical significance – support service linkage (OR=1.72, p<0.05) and emotional support (OR=2.39, p<0.001). The implication of these findings is that receiving social and emotional support significantly increases the likelihood of being in a higher global satisfaction category.

If a caregiver had lower education, this caregiver was likely to rate global satisfaction with physicians’ dementia care for the patient or global satisfaction with physicians’ dementia care for the caregiver higher (Odds Ratios shown in Table 10).
Table 10. Ordinal regression analyses predicting likelihood of caregivers' global satisfaction with physicians' dementia care

<table>
<thead>
<tr>
<th>Variable</th>
<th>Satisfaction with care for the PATIENT</th>
<th>Satisfaction with care for the CAREGIVER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Model 1</td>
<td>Model 2</td>
</tr>
<tr>
<td>Caregiver ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>1.15</td>
<td>1.81</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Relationship to care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>spouse</td>
<td>0.76</td>
<td>1.47</td>
</tr>
<tr>
<td>adult child</td>
<td>0.81</td>
<td>1.46</td>
</tr>
<tr>
<td>other</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Caregiver gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0.45*</td>
<td>0.60</td>
</tr>
<tr>
<td>Female</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Caregiver education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>2.67**</td>
<td>4.01**</td>
</tr>
<tr>
<td>Some college</td>
<td>2.47**</td>
<td>4.17**</td>
</tr>
<tr>
<td>Graduated college</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Caregiver age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40 or younger</td>
<td>0.74</td>
<td>0.66</td>
</tr>
<tr>
<td>41 to 55</td>
<td>1.06</td>
<td>1.03</td>
</tr>
<tr>
<td>56 to 70.00</td>
<td>1.19</td>
<td>0.93</td>
</tr>
<tr>
<td>71 or older</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Cognitive status of patient with dementia(0-32)</td>
<td>0.84</td>
<td>0.58</td>
</tr>
<tr>
<td>9 to 14</td>
<td>0.69</td>
<td>0.81</td>
</tr>
<tr>
<td>15 to 22</td>
<td>1.02</td>
<td>0.89</td>
</tr>
<tr>
<td>23 to 32</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Instrumental activities of daily living score</td>
<td>0.98</td>
<td>1.03</td>
</tr>
<tr>
<td>7 to 10</td>
<td>0.79</td>
<td>0.95</td>
</tr>
<tr>
<td>11 to 14</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Personal activities of daily living score</td>
<td>1.69</td>
<td>0.84</td>
</tr>
<tr>
<td>0 - 1</td>
<td>0.98</td>
<td>0.54</td>
</tr>
<tr>
<td>2 - 3</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Problematic behavior score (14-56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 - 20</td>
<td>1.18</td>
<td>1.65</td>
</tr>
<tr>
<td>21 - 28</td>
<td>1.55</td>
<td>1.26</td>
</tr>
<tr>
<td>29 - 36</td>
<td>1.15</td>
<td>1.19</td>
</tr>
<tr>
<td>37 - 56</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Domains of quality of care scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom management</td>
<td>1.28</td>
<td>1.17</td>
</tr>
<tr>
<td>Support service linkage</td>
<td>1.53*</td>
<td>1.72**</td>
</tr>
<tr>
<td>Medication management</td>
<td>1.13</td>
<td>1.10</td>
</tr>
<tr>
<td>Emotional support</td>
<td>1.78***</td>
<td>2.39***</td>
</tr>
<tr>
<td>chi^2</td>
<td>77.25***</td>
<td>85.19***</td>
</tr>
<tr>
<td>Pseudo R^2</td>
<td>0.373</td>
<td>0.404</td>
</tr>
<tr>
<td>-2 Log Likelihood</td>
<td>363.61</td>
<td>358.44</td>
</tr>
<tr>
<td>N</td>
<td>187</td>
<td>187</td>
</tr>
</tbody>
</table>

*p<0.1; **p<0.05; ***p<0.001
No other variables were significant predictors of global satisfaction with physicians’ dementia care for the patient and global satisfaction with physicians’ dementia care for the caregiver.

6. Limitations of the study

Findings of this study should be considered in light of several limitations. First, it is noted that the increased availability of community services and greater public awareness may have changed physicians’ referral patterns since these data were collected in the mid-1990s. Another concern that has been raised by researchers regarding patient satisfaction studies is the overestimation of satisfaction of many patients (Williams, Coyle et al. 1998; Crawford and Kessel 1999). Also, the advice and help received from physicians were self-reported and may not accurately reflect the actual care caregivers received. Another weakness is the limited geographic region of this study. It is possible that a study in wider geographic areas would show additional patient and caregiver characteristics associated with the quality and satisfaction of care. The measure of quality of physicians’ dementia care as perceived by caregivers of dementia patients in this study was new and untested in prior research. Further research needs to be conducted to validate the study findings. Finally, the data were limited only to family caregivers. Future studies should emphasize the triadic approach by involving all members of the triad – physicians, family caregivers, and patients.
In conclusion, one important function of this thesis is to provide useful information to help improve quality of physicians’ dementia care in the future. It is hoped that, despite the study’s limitations, the findings presented here can serve such purpose.

7. Summary and conclusions

Dementia is a disabling condition, a tragic example of ill health with aging, which has a devastating impact on patients and their families. Family caregivers provide vital support and care, which permit dementia patients to continue to live at home. The caregiver role is very demanding and often produces high levels of stress, leading to deterioration in caregivers’ own emotional and physical health and well-being. It is therefore crucial that the role of caregivers is not only well recognized but also very well supported.

Physicians play an important role in supporting family caregivers to care for dementia patients. By providing the appropriate help and advice physicians can reduce the negative impact of caregiving and thus avoid prematurely placing dementia patients into long term care. Caregiver perspectives are essential in judging how well physicians care for dementia patients and family caregivers. Data on caregiver ratings of quality and satisfaction with physicians’ dementia care provide information on the interaction and communication between physicians and caregivers, on different domains of dementia care, and on the extent to which caregivers believe that their concerns are heard and
addressed. Such information on quality and satisfaction with dementia care from caregivers’ perspective will result in a deeper understanding of the needs of this caregiver group. Learning how to enhance caregivers’ sense of satisfaction with physicians’ dementia care while increasing quality of care they receive from physicians is likely to provide the key to more successful physician-caregiver interactions.

This thesis was designed to contribute to the dementia care field and caregiving by applying the health care triad theoretical framework to the study of physicians’ dementia care, with specific objectives:

- To develop a measurement tool for understanding family caregivers’ encounters with physicians regarding dementia care.
- To assess caregivers’ global satisfaction with physician care.
- To identify patient and caregiver characteristics associated with caregiver reports of physician encounters and their global satisfaction with physician care.

As a result, a new psychometric-based measure of quality of physicians’ dementia care was developed. The quality of care was identified as consisting of four domains. Patient and caregiver characteristics which were related to quality of care and global satisfaction with physicians’ dementia care were identified. It was shown that global satisfaction with physicians’ care is significantly positively associated with quality of care and further two domains of physicians’ care were identified as associated with increased caregiver global satisfaction. The health care triad framework which was used
as a basis for this thesis was found to be appropriate and applicable in studying the quality of physicians' dementia care.

In examining caregiver characteristics, the findings of the present study were consistent with previous research reporting that caregivers are typically white and predominately female. Furthermore, this study indicated that 29% of caregivers are spouses; 58% are adult children; and 13% are other relative or friends. The mean age for caregivers was 56 years. Caregivers reported mild to moderate degrees of depressive symptoms.

In order to measure quality of care, a new scale for physicians’ dementia care was developed with four subscales representing the four domains of care and corresponding to the four factors identified through factor analysis. This study demonstrated good internal consistency of items in the scale and showed that caregivers’ global satisfaction with care was positively associated with the quality of care. This, and the fact that the development of the quality of physicians’ dementia care measure has been theoretical, based on the integrated theoretical framework regarding interactions among the participants in the health care triad (Fortinsky 2001) provide some evidence supporting the validity (construct and content, respectively) of this measure. The importance of a simple measure of dementia care is in providing physicians with valuable information. Such measure could be used to characterize and understand the features of the patient–physician–caregiver interactions and also to test interventions to improve the quality of dementia care. In this sample quality of physicians’ dementia care fell within the middle ranges of
the overall quality scale which offers an important target for developing and implementing effective and coordinated interventions to improve the delivery of dementia care.

In general, the global satisfaction with physicians’ dementia care was high. More than 30% of caregivers were very satisfied with the care physicians’ provide them to care for the patient and more than 40% of caregivers were very satisfied with physicians’ care for the patient. These findings are consistent with what has been found in the literature on satisfaction studies.

In this study, caregiver and patient age, caregiver reported depressive symptoms, and patient cognitive impairment were not correlated with quality of care and caregiver global satisfaction. Caregiver physical health was highly significantly correlated with overall quality of physicians’ dementia care indicating that caregivers in poorer physical health reported lower ratings of quality of physicians’ dementia care. Caregiver physical health was not correlated with caregiver global satisfaction with physicians’ help. Other factors related to overall quality of physicians’ dementia care but not to global satisfaction with care were patients’ autonomy in activities of daily living and patient’s autonomy in instrumental activities of daily living, indicating that patients with a greater degree of ADL and IADL impairment received better quality of physicians’ dementia care. Caregiver education was found to be highly related to global satisfaction with physicians’ dementia care, but not to quality of care.
One of the objectives of this thesis was to better understand caregiver

global satisfaction with physicians’ dementia care by identifying factors associated with
greater global satisfaction. One of the factors strongly associated with higher levels of
caregiver global satisfaction after controlling for numerous covariates was overall quality
of physicians' dementia care. Further, by estimating the effects of individual subscales of
quality of care, it was demonstrated that only the social support linkage and emotional
support domains reached significance. The results showed that higher scores on these two
domains increased the odds of being in a more satisfied group. Part of the increased
global satisfaction for caregivers reporting higher scores on social support linkage could
be due to receiving access to community support services, hence to more integrated
dementia care. This finding is in unison with previous findings that providing family
caregivers with information and referrals to community services along with emotional
support could improve their global satisfaction. It emphasizes again the need for
strengthening the links between physicians and community support services (Fortinsky,
1998).

The findings also suggest that physicians’ emotional support to caregivers is an
important determinant of global satisfaction. This is in accord with previous analyses of
quality of care interactions suggesting that physicians’ interpersonal skills and
communication style when interacting with the patients are good predictors for patient
satisfaction (Buller and Buller 1987) and that satisfaction is increased when physicians
provide more information and include more psychosocial counseling (Hall, Roter et al.
1988; Haley, Clair et al. 1992). Since medication management of dementia is still limited,
attending to the emotional needs of family caregivers is the biggest contributor to the caregivers feeling more satisfied with the care they receive from physicians. Usually these needs go unmet in busy physicians offices but physicians should recognize that attention to caregivers' emotional needs seems to be one of the competencies that falls right in the scope of caregivers' satisfaction.

These findings suggest the need for a better understanding of how family caregivers of dementia patients evaluate care and what they value in their interactions with physicians. Dementia caregivers appear to place greater importance on physicians' interpersonal skills, as opposed to technical skills, when asked for their global satisfaction with physicians' dementia care. The findings help to emphasize the importance of interpersonal aspects of care to caregivers' global satisfaction. Improvements, which address this domain of care, are likely to affect perceived quality of care. The recommendation emerging from this finding reinforces the importance of continuing to support physicians' skills acquisition of appropriate interpersonal communication and provision of psychological support.

Examples of best quality dementia practices should be those following guidelines for management of dementia patients and their families emphasizing psychosocial issues. Such guidelines have been found to be useful to physicians with dementia patients living in the community (Bridges-Webb, Wolk et al. 2003).

The factors identified in the study show meaningful influences on caregivers'
global satisfaction with physicians’ dementia care and are completely within physicians’
purview. These findings indicate the appropriateness of focusing on measuring and
improving the quality of these domains of physicians’ dementia care. The findings of this
thesis also suggest that further research be devoted to caregiver, physician and patient
perspectives as three members of the health care triad. Research on the determinants of
quality and satisfaction with physicians’ dementia care must be broadened to include
physician characteristics. The findings of this study suggest that caregiver reports of
global satisfaction with physicians’ dementia care may not reflect the actual quality of
physicians’ dementia care received. One explanation for this could be that caregivers may
have provided socially desirable answers rather than being completely truthful. Higher
caregivers’ ratings of global satisfaction compared to their rating scores of the quality of
physicians’ dementia care may also indicate that caregivers have fairly low expectations
when they visit physicians (hence, higher global satisfaction ratings). Another possible
explanation is that satisfaction with physicians’ dementia care may be overly based on
the interpersonal skills of physicians. In order to identify effective mechanisms and
ultimately increase quality of care, a continued investigation into the characteristics of all
members of the health care triad and their relationship with the quality of care and global
satisfaction is imperative.

In conclusion, it is an important public health duty to ensure the prevention,
screening, early diagnosis and intervention and the best quality of care to dementia
patients and their family caregivers. With an aging population and dementia becoming a
problem of truly epidemic proportions, the search for new approaches to improve the
quality of physicians’ dementia care has become even more important. A public health approach to dementia should encompass the concept of evidence-based and high quality physicians’ dementia care in order to maintain function and improve quality of life for dementia patients. Identifying key elements of effective dementia care requires a solid basis of research and theoretical knowledge. Further, disseminating research results and integrating them into physicians’ dementia practices is vital for family caregivers so that they can receive the help and resources they need to keep dementia patients at home. Strategies designed to respond appropriately to caregivers’ needs and improve quality of care and caregivers’ global satisfaction with care should be a public health priority.

It is hoped that this thesis contributes to the increasing recognition that taking into account caregivers’ perceptions plays an important part in improving physicians’ dementia care.
References


