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Exploring the experiences of family caregivers, Cape Cod's invisible workforce: upholding the promise of Olmstead for people with Alzheimer's and Dementia-related diseases

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EXPLORING THE EXPERIENCES OF FAMILY CAREGIVERS, CAPE COD'S INVISIBLE
WORKFORCE: UPHOLDING THE PROMISE OF *OLMSTEAD* FOR PEOPLE WITH
ALZHEIMER'S AND DEMENTIA-RELATED DISEASES

A dissertation presented

by

Molly Perdue

to

The Law and Public Policy Program

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ABSTRACT OF DISSERTATION

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Abstract

Due to a lack of formalized long-term care options in the community, dementia care for people living at home is primarily the responsibility of informal family caregivers. This informal family care goes unnoticed; the provision of informal care is “invisible” because the real work of family caregiving takes place in our most intimate and private of places, our homes. This dissertation utilized ethnographic methods to examine the real-life experiences of family caregivers providing dementia care in the community, and examined the applicable laws and long-term care policies and supports.

The U.S. Supreme Court’s 1999 *Olmstead* decision reinforced the right of people with cognitive impairments to be in as integrated a setting as possible for as long as they may safely do so with the necessary supports. Family caregivers are, in a myriad of ways, the “necessary supports” for their family members with dementia.

Because family caregivers provide a beneficial and cost-effective means of meeting the requirements set forth in the *Olmstead* decision, the provision of community care should be the subject of high-priority policy supports.

The findings of this research demonstrated significant caregiver burdens experienced by caregiver study participants caring for a family member with dementia in the community. Despite evidence of significant financial, social, physical, and emotional burden, my findings showed caregivers demonstrated a firm commitment to keeping their family members in the community; additionally, they expressed the desire to delay the institutional placement of their family member with dementia for as long as possible. This exploration of the culture of family

caregiving in the context of the community expands our current knowledge of informal family caregiving and offers suggestions for policy to better support families in this situation.

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In memory of my mother Virginia “Gaga” Perdue Pickard (1923-2009), who lived with Alzheimer’s disease in our home with dignity. Our time together continues to guide me.

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Chapter 1: Introduction Background

It is the intent of this study to explore the depth and complexity of family caregiving for family members with Alzheimer's or a dementia-related disease. We are just beginning to understand how Alzheimer's disease (AD) and related dementias affect the family unit, and by extension, affect the family caregiver. In order to broaden our knowledge we must transcend the confines of our research labs and go into homes and communities where the first symptoms of dementia occur. It is there, outside the institution, where families begin to assist, and in that moment, often without having been planned for, family caregiving begins.

The titles—*caregiver* and *care-recipient*—that we use when discussing this complex enlistment of family members into roles necessitated by AD and the related dementias merely categorize the caregiving roles; these terms do not convey the depth of what is a very complex and rich caregiving relationship.

In 2009, 30 percent of American households reported they provided unpaid care for a family member at some interval during the year (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2009). Informal family caregivers constitute an unpaid workforce of 52 million people in the United States (AARP, 2006; Houser & Gibson, 2008). This unpaid workforce's societal contribution is substantial; in dollar terms, the total value of unpaid informal long-term care provided by friends and family members in the United States in 2007 was greater than the 2006 Medicaid spending for both institutional and in-home care (AARP, 2006; Houser & Gibson, 2008). In our communities, where 83 percent of Americans with long-term care needs reside, family caregivers deliver the majority of care (Spillman & Black, 2005; Tumlinson, Woods, & Avalere Health, 2007).

Family caregivers play an important societal role in the provision of community care: their labor amounts to 12.5 billion hours per year of unpaid care to people with AD or a related-dementia, with a dollar value of \$144 billion annually (Alzheimer's Association, 2011, p. 23). It is estimated that, at any one time, 70 percent of the approximately 5.4 million Americans with AD or dementia live at home and are cared for by family members (Alzheimer's Association, 2011; Bynum, 2009). Informal family caregivers, numbering from 11 million to 15 million, provide a range of health care and supportive services (without pay and without training) for their relatives with dementia (Alzheimer's Association, 2011).

Family members who take care of their relatives with dementia are not just unpaid providers of care; they are spouses, sons, daughters, in-laws, grandchildren, friends, and sometimes neighbors (NAC & AARP, 2004, 2009). Family caregivers are inextricably connected to the people they are caring for, which means they carry the weight of the financial, health, employment, social, emotional, and relational responsibilities for the caregiving unit as well as the actual day to day activities of care (Zarit, Femia, Kim, & Whitlach, 2010).

If family caregivers were paid workers, employment laws and policies would protect them (Bookman & Harrington, 2007). They would have access to support services and be adequately trained to handle the difficult behavioral aspects of dementia care, and they would never be expected to go weeks or months and sometimes years without a day off from their caregiving responsibilities (Levine, Halper, Peist, & Gould, 2010). However, family caregivers are not paid employees; therefore, their caregiving efforts are not formally supported (Bookman & Harrington, 2007). Since family caregivers operate largely outside of the medical

establishment, the care they provide is not regulated, monitored, or supervised, nor is it well integrated within the formal care network (Institute of Medicine [IOM], 2008).

It is difficult, if not impossible, to quantify the personal toll extracted by this informal “system” of family caregiving: each person caring for a dementia-affected family member at home would have a unique and important story to tell. This qualitative dissertation will explore the lives of family caregivers in the context of their community, in relationship to their family member with dementia, and in terms of the current laws and policies relevant to the caregiving experience.

Dementia, Alzheimer’s, and an Aging Population

According to Census projections, in 2030 there will be 72 million Americans over the age of 65, a significant increase from the 35 million Americans in this age bracket in 2000 (Wan, Sengupta, Velkoff, & DeBarros, 2005). The number of persons with dementia will rise in concert with the increasing age of the population (Brookmeyer et al., 2011; Hebert et al., 2003; Plassman et al., 2007). These increases will amplify the need for additional caregivers and some type of affordable long-term care within our communities (Allen, 2001; IOM, 2008).

AD is the most common form of dementia, accounting for at least 60 percent of all cases of dementia (Mace & Rabins, 1999; Rabins & Lyketsos, 2010). In the United States, the prevalence of dementia in seniors over age 71 is estimated to be 13.9 percent (Plassman et al., 2007). Depending on the age bracket studied, estimates of the total number of Americans living with Alzheimer’s disease or some other type of dementia range from 3.4 million (in the over-71 age bracket; Plassman et al., 2007), to 5.1 million (when speaking of the over-65 age bracket; Alzheimer’s Association, 2011; Hebert et al., 2003). In the under-65 age bracket, 200,000 have a

form of AD called “early-onset” or “younger-onset” dementia (Alzheimer’s Association, 2011; Hebert et al., 2003).

Because this dissertation focuses on caregivers of people with dementia, and because dementia as a symptom of Alzheimer’s disease is the most common type of dementia, the terms *Alzheimer’s disease (AD)*, *dementia*, and *dementia-related disease* are used interchangeably. The reader should keep in mind that there are many other diseases and conditions that may cause dementia; other types of dementia include vascular dementia, Lewy body dementia, Parkinson’s disease, front temporal dementia, Creutzfeld-Jacob disease, and normal-pressure hydrocephalus (Alzheimer’s Association, 2011; Mace & Rabins, 2006). The science of diagnosing and specifying the causes of dementia continues to evolve. Although the identification of AD has become increasingly reliable by the use of better neurological imaging, diagnosis is still based on the cognitive and behavioral symptoms as the hallmarks of the disease; it is only after death that a definitive AD diagnosis can be obtained by autopsy (Rabins & Lyketsos, 2010).

Unique Challenges of Caring for a Person with Dementia

Almost a quarter of all family caregivers interviewed in a national survey said they were caring for a family member with some level of cognitive impairment or dementia (NAC & AARP, 2009). Cognitive impairment is associated with a high risk for AD or dementia (Alzheimer’s Association, 2011; Rabins & Lyketsos, 2010). Plassman and colleagues, in their nationally represented study, also diagnosed 22 percent of participants over the age of 71 with cognitive impairment; these figures suggest that in addition to the numbers of Americans living with AD or dementia (listed in the previous section), 5.4 million people in the United States have

cognitive impairment, which puts them at high risk for an eventual dementia diagnosis in the future (Plassman et al., 2007).

Given the increasing numbers of people with dementia or cognitive impairment who will need some form of assistance, it is imperative that we consider the needs and concerns of family caregivers caring for family members with dementia or cognitive impairment in the United States (NAC & AARP, 2009). Providing care for a family member with dementia and cognitive impairment is associated with a higher level of caregiver stress than caring for someone with normal cognition (Cuijpers, 2005; NAC & AARP, 2009; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Vitaliano, Zhang, & Scanlan, 2003). Because the number of people with AD and other dementias is increasing, many large studies have focused on the efficacy of caregiver interventions designed to support family caregivers (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman, Haley, Clay, & Roth, 2006).

A family member's desire to help a relative remain outside of institutional care may be a motivating factor for family caregivers who take on the role of "caregiver." The motivation to delay institutionalization for a family member with dementia needs to be more fully explored within caregiving and may account for the tremendous hardship many caregivers endure. Unfortunately, for many informal family caregivers, the unpaid care provided to others exacts a deleterious toll on their own health (Norton et al., 2010; Vitaliano et al., 2003).

Recently, research has focused on the neuropsychiatric symptoms of dementia as one of the leading causes of caregiver burden, making dementia caregiving more onerous than other family caregiving roles (Kochhann et al., 2011; Lyketsos & Miller, 2012). A national study

found that family caregivers who provided care for a family member with Alzheimer's disease helped with more activities of daily living, committed more hours a week to caregiving duties, and remained in the caregiver role longer than people caring for someone without dementia or AD (Alzheimer's Association & NAC, 2004; Evercare & NAC, 2009).

The toll that stress exacts on caregivers has been well documented within the available literature, and it has been linked with a higher rate of institutionalization of care-recipients, and yet evidence-based interventions designed to decrease caregiver burden and stress have not been addressed within U.S. long-term care policies (Spillman & Long, 2007, 2009).

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) of 1990 includes an “integration regulation” requiring that “individuals with disabilities receive public services in the most integrated setting appropriate to their needs.” This integration mandate can be applied to the setting in which people receive their publicly funded long-term care (ADA, 1990). The ADA of 1990 defines disability as “a physical or mental impairment that is serious enough to limit a major life activity, such as caring for oneself, walking, seeing, hearing, speaking, breathing, working, performing manual tasks or learning” (Allen, 2001, p. 5). Surely, given such a broad definition, citizens with cognitive impairments or dementia qualify for legal protections under the ADA. A perceived violation of the ADA law was the impetus for the original *Olmstead* lawsuit; thus, the legal foundation of the *Olmstead* decision was built on the ADA (discussed in detail later in this chapter).

The ADA of 1990 applies to all ages and to any person who qualifies by meeting the disability test, which means any impairment that impedes an activity of daily life. Although the

ADA does not list dementia or AD specifically, they are progressive cognitive disorders, which are covered under the general category of physical or mental impairment; in this regard, the law is agnostic, covering all disabilities. What we know of the progression of dementia is that as the cognitive impairment increases, so does the need for assistance with activities of daily life (Rosenbaum, 2001).

Currently our governmental long-term care policies do not address issues related to family caregivers and their care-recipients who are trying to remain in the “least restrictive” setting for as long as feasibly possible (Allen, 2001). Policies are not in place to assist family caregivers in the delivery of at-home care safely, effectively, and affordably to a family member with dementia to ensure they receive the necessary community supports so that continued care in the community exists as a viable alternative. Perhaps if health care took a more “person centered” approach to dementia care, the rights of those persons living with dementia in relationship to their family caregivers, who offer both care and relative independence in the community, would become more a consideration to policymakers (Zeisel, 2009).

Long-Term Care and Dementia

A national plan to address the needs of families caring for a family member with AD or another type of dementia is long overdue. In the words of President Obama (2009), “Every day, millions of American families experience the difficult realities of Alzheimer’s disease. The physical and emotional demands of caring for a loved one with Alzheimer’s can be overwhelming, but no one should face this disease alone.”

On January 4, 2011, President Obama signed the National Alzheimer’s Project Act (NAPA) into law (National Alzheimer’s Project Act, 2011). This act allows for the establishment

of the Advisory Council on Alzheimer's Research, Care, and Services to advise the Secretary of Health and Human Services on the creation and eventual adoption of a National Alzheimer's Plan (Advisory Council, 2011). However, public policy still does not have a coordinated effort regarding long-term care planning for the many families who face the harsh realities of AD alone in the community without assistance. This is the fate of millions of Americans who are currently providing informal care to family members with dementia in their homes and communities without caregiver training, support, respite, or formal assistance (Alzheimer's Association, 2011; MetLife Mature Market Institute [MetLife], 2006; NAC & Evercare, 2007).

Statement of Problem

This qualitative dissertation will use an interdisciplinary approach to explore informal family caregiving (specifically, for a person with Alzheimer's disease or a related dementia). This research will include an examination of the applicable and existing U.S. laws and long-term care policies and programs explored through qualitative social science methodology. This review of the legal framework, long-term care programs and policies, and their current efficacy in serving our communities and family caregivers, will provide insight into the specific policy-related needs that would more effectively address issues related to in-home family caregiving for someone with dementia or AD in the United States.

Why are informal family caregivers providing the majority of long-term care in our communities without formalized support? The policy debate has centered on the question of responsibility: should the government provide long-term care to the citizens or is it a family or individual responsibility? (Feder, 2001; Weiner, 2003). This long-standing argument has been framed along ideological lines: Republican policymakers have long ignored the public's need for

a long-term care program and Democrats have not succeeded in pushing forward any innovative solutions that are feasible or fiscally sound (Miller, 2011; Moon, 1996). In simplest terms: why should policymakers grapple with the issues concerning long-term care in the community, when family caregivers are providing the lion's share of care for free? The Alzheimer's epidemic changes the long-term care equation, because informal dementia care is not free—the associated costs of caregiving are only deferred to the family caregiver. Research supports the argument that informal dementia caregivers carry a greater caregiver burden, have a high incidence of associated health problems, and respond positively to evidence-based interventions (Burns et al., 2003; Covinsky, Newcomer, Dane, Sands, & Yaffe, 2003; Mittelman, Epstein, & Pierzchala, 2003; Mittelman et al., 1996; Nichols et al., 2011; Norton et al., 2010). Given the growing body of evidence concerning the health impacts of high-stress caregiving, there is a burgeoning need for long-term care policies that address the issue of long-term care (Feder & Komisar, 2009; Weiner, 2003).

While the debate about long-term care in the United States remains mired in the differences of competing political philosophies, the economic realities of the lack of affordable long-term care in the community will continue to negatively affect American families. As more and more baby boomers retire on fixed incomes and care costs continue to rise, the stark fiscal reality of dollars and cents may at some point overshadow the long-standing political impasse around long-term care. The fact is that the majority of Americans simply cannot afford to pay the expenses of long-term care. If you were to analyze the assets of seniors you would discover that a majority of Americans (about two-thirds) have the financial resources to cover a little less than the cost of a 1-year nursing home stay (Lyons, Schneider, & Desmond, 2005).

Family finances play an important role in the family caregiver dynamic: a more efficient use of family financing can help a family support the long-term care needs of their family member with dementia longer. No matter the family's financial resources, AD is one of the more costly diseases, surpassed only by cancer or heart disease; however, unlike cancer or heart disease, the options for a person with AD do not include costly medical treatments or surgery, only a progressing need for long-term care (Koppel, 2002). Informal family caregivers allow the person with dementia to remain in the community longer. When the person needing long-term care remains in the home, his or her family's long-term care costs during the length of the illness could be reduced; also, for many Americans with limited financial resources the provision of informal care in the community by a friend or family member exists as a less expensive alternative to institutional care (Komisar, 2009; NAC & AARP, 2009).

In fact, the majority of American families caring for a loved one with any chronic illness such as AD that requires years of care would generally not have the financial resources available to pay for extended long-term care (Feder & Komisar, 2009).

For example, if you are an elderly female, widowed or unmarried with dementia, and without children, you run the greatest risk of institutionalization in your age bracket (Lyons et al., 2005). In fact, having a spouse reduces your risk of nursing home placement by 41 percent and having a daughter reduces the risk of placement by 27 percent (Charles & Sevak, 2005). This means that the likelihood that an elder will be institutionalized is not determined by his or her urgent need for skilled nursing care, but because the elder may not have any availability of care in the community or the financial resources to afford the care he or she may need (Lyons et al., 2005). It is the availability of informal family care in the community that may be a major

determinant in deciding whose relative gets to remain in the community and who will be institutionalized (Luppa, Luck, Brähler, König, & Riedel-Hella, 2008).

Given the progressive cognitive impairment associated with dementia-related disease, the decision to institutionalize a relative with dementia will rest at some point on the family caregiver or on other family members who can no longer provide the care that is needed in the community (Mace & Rabins, 1991, 2006). The caregiver's role in determining the institutional placement of a family member with dementia is currently unrecognized in the medical community in the form of any formal supports, education, respite services, or counseling programs. Given the lack of available caregiver supports within the medical community, in light of the seriousness of family caregivers' responsibilities the "invisible" status of family caregivers becomes incongruous at best (Bookman & Harrington, 2007).

Informal family caregivers could be described as the de facto liberators of institutional care for their relatives with dementia, but without caregiver supports in place, there are caregiver costs associated with the provision of liberation; these costs will be discussed throughout this dissertation (Kiecolt-Glaser et al., 2003). It makes sense that long-term care policies consider these trade-offs; given the increasing societal need for family caregivers in the community, perhaps policymakers can find enough common ground to begin dialoging about these issues (Stone, 2002).

Greater Caregiver Burden

The specific burdens associated with caring for a family member with AD should influence the policy debate around long-term care issues because we know that caring for a person with dementia is different than caring for a person without cognitive impairments because

of the associated behavioral problems (Mace & Rabins, 1991, 2006; Mittelman et al., 2003). In fact, new research has suggested that a major determinant of caregiver burden correlated with the severity of the neuropsychiatric symptoms associated with dementia (Kochhann et al., 2011; Lyketsos, & Miller, 2012). We know that informal family caregiving is a complex social phenomenon and we know that the caregiving burden for family caregivers is greater because of the complexity and difficulties associated with dementia care (Evercare & NAC, 2006; MetLife, 2006).

Is it reasonable to expect family members to be the sole providers of long-term care for their family members with dementia—given the disease progression that could last anywhere from 2 to 20 years—without any respite, training, or formalized long-term care supports?

Given what we know about the high rates of caregiver depression, associated health issues, and co-morbidity affecting informal family caregivers, we need to consider the less obvious human costs of informal family caregiving in contrast to the societal and familial benefits (Arno, 2002; Evercare & NAC, 2007; MetLife, 2006). What is striking to many researchers who study informal family caregiving is the strength of the commitment and dedication family caregivers demonstrate toward their care-recipients in spite of such obvious hardship (Max, Webber, & Fox, 1995). Bittman, Fast, Fisher, and Thomson (2004) referred to “informal care” as the provision of care provided mostly within the community by a care-recipient’s friends and/or family, and “formal care” as care provided by service organizations or institutions. Informal caregivers receive no formalized training to become caregivers; they usually assume this role out of necessity. Compared to other family caregivers, those caring for a family member with AD or dementia spent more time providing care, had a higher degree of

stress, had more health-related issues, and a higher risk of employment problems; also, caregiving costs are three times higher (Evercare & NAC, 2009; Koppel, 2002; MetLife, 2006).

Dependency on informal family caregivers is quite pervasive (Houser & Gibson, 2007). Feder, Komisar, and Friedland (2007) pointed out that 85 percent of the elderly with long-term care needs are already receiving care in the community from unpaid informal family caregivers. These facts speak to the tremendous provision of free care family caregivers contribute to society. And yet, because the care is unpaid, government policymakers tend to overlook family caregivers, and support for this group is largely absent from public policy, even though researchers have published numerous studies purporting the health risks associated with informal family caregiving (Centers for Medicare and Medicaid Services [CMS], 2010).

Many Americans will not only face the harsh realities of the progression of AD without receiving caregiver education or training, but will also spend all their expendable resources in the provision of dementia care (Evercare & NAC, 2009). Currently, the impoverishment of a care-recipient could signal some relief for caregivers: if a person with AD becomes Medicaid-qualified, he or she becomes eligible to receive a continuity of formalized care that may reduce the actual burden of informal care. To qualify for Medicaid a care-recipient must first meet requirements concerning income restrictions and assets (usually limited to \$2,000); if the care-recipient is married, then income restrictions and asset allocation must be met by the spouse too (Mace & Rabins, 2006). Although meeting the definitional requirements for poverty may not sound like a positive achievement, in this case the Medicaid-qualifying result is a positive outcome because of the support it will provide—the inherent stresses and strains of providing

AD care for a person who may need 24-hour care can be overwhelming, especially when a caregiver is untrained and in need of AD education.

Nevertheless, becoming Medicaid qualified does not necessarily guarantee that community care is readily available. For example, Medicaid does not pay for social daycare, home modification, or periodic respite care (A. Rogers, unpublished interview, September 8, 2010). In addition, many Medicaid home-based programs are considered “optional,” which means their continued funding is dependent on their inclusion within state budgets. In some instances, “optional” programs are eliminated or cut, leaving Medicaid care-recipients with the sole option of going into more expensive nursing home care to receive the formalized care they need (*V.L. et al. v. Wagner*, 2009).

The inclusion of better community care does not negate the need for nursing home care, but it may delay placement and by doing so, decrease the overall care costs for a family or individual. Institutional care is a very important option for families, but fortified care in the community could become a more viable option.

According to an AARP (2009a) survey, 89 percent of Americans over 50 preferred to remain in their homes as long as they could, even if they needed help caring for themselves. In that same survey, AARP (2009a) stated that an estimated 11 million Americans who need long-term care services in the community may need nursing home care because community care is not available. The financial repercussions are obvious:

Cost estimates comparing Medicaid residential and home care costs have indicated that three people can be served in the community for every two who receive services in nursing homes in Indiana. While officials in Washington estimate that [in that state] the cost of caring for people in a nursing home is equal to the cost of providing services for two to four people at home. Estimates from Pennsylvania indicate that under the state’s

Aging Waiver, on average 2.2 people can receive services in the community for each aged individual receiving services in a nursing home. (Summer, 2005, p. 4)

Although care costs vary among U.S. states, as does the availability of home and community-based services, it is reasonable to assume that the cost savings realized in Indiana, Washington, and Pennsylvania could be realized in other states as well (Houser & Gibson, 2008).

The philosophical underpinnings behind the idea of spreading financial risk go all the way back to the funeral societies of the ancient Greeks, when all residents shared the cost of family burials when families did not have the available means for proper funerals. The concept of shared risk is the foundation on which the Medicare program was established in 1965 (Corning, 1969). The question of cost is obviously pertinent to any debate about long-term care policies, as are the principals of liberty and efficiency (Stone, 2002).

If actual care costs were measured in relation to the personal sacrifices associated with family dementia caregiving, we would be paying a high price for our human capital (Kiecolt-Glaser, 2009; Norton et al., 2010). Given the societal benefit that unpaid informal family caregivers provide, it only makes sense for governmental support to help reduce the potential costs to caregiver health (Vitaliano, Young, & Zhang, 2004). At the very least, informal family caregivers deserve a place in the discussion about the future of national long-term care policies (Houser & Gibson, 2007).

The lack of long-term care supports in the community has made informal family caregivers de facto arbiters of the liberty or confinement of their care-recipients. Supporting the informal caregiver not only makes sense as a way to improve the general well-being of the caregiver, but studies have demonstrated that counseling the caregiver increased the duration of

time the caregiver continues to provide care by an average of 1.5 years (Mittelman et al., 1996, 2006). This suggests that by providing a better support structure for Americans with cognitive disabilities like dementia, which includes supporting their family caregivers, people with cognitive disabilities may be able to remain in their homes and communities for a longer period of time.

The *Olmstead* Promise of Community Care

In 1999, the U.S. Supreme Court issued a ruling that is of vital importance to any discussion of policy issues related to long-term care for people with disabilities. The Court's decision in *Olmstead v. L.C.* reaffirmed the ADA's "integration regulation" concerning the rights of people with disabilities to remain in the community, in "the most integrated setting appropriate" to their needs (*Olmstead v. L.C.*, 1999; ADA, 1990). The *Olmstead* decision framed the absence of care in the community as an institutionalized injustice for those who, with some assistance, could safely remain in their neighborhoods. The Court's *Olmstead* ruling essentially categorizes unnecessary institutionalization of individuals with cognitive disabilities as a form of discrimination. The concept of "most integrated setting" aligns perfectly with a recent study, which found 84 percent of AD caregivers reporting that they became family caregivers to keep their family members out of a nursing home (Shriver & Alzheimer's Association, 2010).

The 1999 *Olmstead* ruling is applied to publically funded programs; Medicaid and Medicare are the largest payers of long-term care costs in the United States (Feder et al., 2007; Komisar, 2009). The plaintiffs in the suit were two women with mental illness with cognitive impairment whose doctors recommended that a community placement would be appropriate, but

because none existed at the time, and the women were in publicly funded programs, they remained institutionalized (Allen, 2001).

The scope of *Olmstead* is very broad both in its application and in its interpretation of disability. The Court required that community-based services be made available by the state, but ADA regulations do not require states to “fundamentally alter” existing programs. Rather, states were required by the Court to make “reasonable progress,” and in response to the ruling, states created *Olmstead* plans (Rosenbaum, 2001; *Olmstead v. L.C.*, 1999). The Massachusetts *Olmstead* Plan (2008) states the need for an increase in community care, but the plan does not include support programs to assist family caregivers in the community. Without informal family caregiver support, family members will continue to “wear out,” signaling the time when many nursing home placements occur (Mittelman et al., 2006; Rabins & Lyketsos, 2010).

The family caregiver plays a critical role as a provider of necessary community support to a cognitively impaired person so he or she may remain safely in the community. Consider this critical support in the same regard as we have come to understand the need for wheelchair ramps in public buildings as a critical accommodation for accessibility for the mobility impaired. Unfortunately, in many instances family caregivers, without needed supports, become the second victim of dementia-related disease (Norton et al., 2010; Kiecolt-Glaser, 2009; Vitaliano et al., 2004). Given these substantiated concerns, informal family caregivers should be an important part of any long-term care policy discussion.

Definition of Terms

This study explores the caregiving experiences of family members caring for a relative with AD/dementia and investigates the current long-term care policies that support the provision

of care. The following terms, defined in this section and used throughout this dissertation, are of great importance to the discussion: *caregivers*, *caretakers*, and *care partners*; *informal family caregivers*; *caregiver burden*; *dementia*; *AD and dementia-related disease stages and progression*; *respite care*; and *long-term care*.

Caregivers, Caretakers, and Care Partners

How do we most accurately describe what family members do when they care for a person with dementia? According to *Merriam-Webster Dictionary Online* (2011) the term *caretaker* is defined as the following: “one that gives physical or emotional care and support.” Although this term correctly depicts both the physical and emotional aspects involved in caring for a person with dementia, it still falls short. A more accurate description of this relationship would entail the use of the word *caregiver*, which is defined as: “a person who provides direct care (as for children, elderly people, or the chronically ill) (*Merriam-Webster Dictionary Online*, 2011). *Caregiver* seems the best name for this caring relationship, and although care requirements for children, the elderly, and the chronically ill vary widely, there is often at least one similarity: the caregiver is shouldering a grave responsibility with little or no pay.

As our understanding of this important role continues to evolve, the terminology used to describe it may also change. The term *care partner* has been suggested as a name that may depict a more equitable relationship and is a term we may use in the future; the phrase perhaps describes a more idealized care paradigm than currently exists. According to Eden Alternative Care (2009): Care partners are defined as “those who work together effectively and respectfully for the long run . . . care partners include family, friends, neighbors, volunteers, home health professionals, and the Elder herself” (pg. 1).

As caregivers emerge as a recognized entity, and we begin to recognize that dementia care in the community is most effective in the long term when the burden of care is shared and acknowledged, *care partner* may well come to replace *caregiver* as the term of choice.

However, in order for such a term to be accurate in the current care paradigm, the health and well being of family caregivers would have to be addressed. Given the current crisis facing those providing care for people with dementia, the term caregiver unfortunately continues to be a more accurate moniker: today's caregivers still lack the visibility necessary to be partners in care. It is for this reason that the term caregiver is the one employed in this paper.

Informal Family Caregivers

Two years of fieldwork by Bookman and Harrington (2007) revealed that “. . . family caregivers—untrained, under supported and unseen—constitute a ‘shadow workforce’ acting as geriatric case managers, medical record keepers, paramedics and patient advocates to fill dangerous gaps in a system that is uncoordinated, fragmented and often depersonalized” (p. 1005). Although all family members face challenges in caring for their sick relatives at home, the dedication of those caregivers whose family members have AD or dementia is quite extraordinary, given the fact that the job is born out of necessity, arrives unexpectedly, and requires dealing with a disease progression that is not widely understood and is the result of a terminal and debilitating illness (Max et al., 1995). The Alzheimer's Association and the National Alliance for Caregiving (Alzheimer's Association & NAC, 2004) found that caregivers of people with dementia carried the heaviest burden of care when compared with other caregivers. They helped with more activities of daily living (ADL) than other caregivers, handled

more difficult tasks, committed more hours a week to caregiving, and remained in the caregiving role for longer duration than caregivers of people without dementia.

According to the NAC and the American Association of Retired Persons (NAC & AARP, 2009), the characteristics of unpaid caregivers in the United States include the following:

Caregivers are predominantly female (66%). They are 48 years of age, on average. One-third takes care of two or more people (34%). Large majorities of caregivers provide care for a relative (86%), with over one-third taking care of a parent (36%). One in seven care for their own child (14%). Caregivers have been in their role for an average of 4.6 years, with three in ten having given care to their loved one for five years or more (31%). When these caregivers are asked what they perceive to be the main reason their recipient needs care, the top two problems they report are old age (12%) and AD or dementia (10%). (p. 4)

An early caregiver study also found that community caregivers were more likely to be female or spouses, and they had been caring for the AD care-recipient for an average of 3.7 years. While the AD care-recipients who were no longer residing in the community were older and more likely to be female, their caregivers had been caring for a total of 6.3 years, 2.6 years longer than the community caregivers in this study (Max et al., 1995).

Informal family caregivers are usually employed outside the home at least part-time when they take on the additional role of providing care to a family member or friend (NAC & Evercare, 2007). The informal provision of care may come at a very high cost to the family caregiver in the form of what is now termed caregiver burden (Vitaliano, Young, & Russo, 1991; Zarit & Orr, 1985).

Caregiver Burden

Caregiver burden refers to “the physical, psychological or emotional, social and financial problems experienced by family members caring for impaired older adults” (George & Gwyther, 1986, p. 253). In addition, family caregivers often end up missing time from work as a result of

their increased responsibilities, and become isolated from friends and family (NAC & AARP, 2009; Zarit & Orr, 1985). Yet, informal caregivers persist in the provision of care even when they are cognizant of their own unmet needs (NAC & AARP, 2009).

A distinction can be made between *subjective caregiver burden*—which is brought on by the feelings evoked by caregiving events such as feeling trapped, overburdened, or invisible—and *objective caregiver burden*—which could describe financial concerns, the health problems of the caregiver, or the responsibilities of providing care—by pointing to different ways these burdens can be alleviated (Vitaliano et al., 1991). Differentiating between these two burdens is relevant to this study because they suggest different needs, which could be addressed by more formalized care. For example, the availability of more formalized care in the community, for instance a home health aide to assist with toileting, bathing, and dressing responsibilities, aids a caregiver with the *objective burdens* of caregiving, while the provision of more formalized caregiver counseling assists caregivers with the emotional or *subjective burden*.

Since the “burden of care” seems to be a contributing factor in the decision to institutionalize a care-recipient, it is possible that the provision of more formalized care in the community could lighten this burden (Zarit, 2006; Zarit, Gaugler, & Jarrott, 1999). One theory which explains how burden influences the decision to institutionalize is the “wear and tear hypothesis” that interprets the duration of care as a contributing factor to caregiver burden, and a factor that spans the entire caregiving experience (Gaugler, Kane, Kane, Clay, & Newcomer, 2005a).

Given the demands of this invisible, unpaid workforce, Gaugler et al. (2005a) found that “those individuals who utilized in-home help services earlier in their dementia caregiving career

were more likely to delay institutionalization” (p. 1). This means that addressing the needs of caregivers early on in the provision of care could possibly keep a care-recipient in his or her community longer (Zarit et al., 1999). Various studies link delays in institutionalization with caregiver supports such as better in-home services; they also confirm a causal relationship between early caregiver interventions and reduced caregiver burden (Weimer & Sager, 2009).

What will become evident in Chapter 2 is that evidence-based interventions can also influence the length of time a person with AD or a related-dementia can live in the community and delay expensive nursing home placement (Mittelman et al., 1996). These findings become important policy considerations because they offer a way to control long-term care costs for both Medicare and Medicaid and reduce caregiver burdens for informal family caregivers.

Dementia

Although Alzheimer’s disease includes a range of symptoms, the most well known symptom is dementia. According to the Alzheimer’s Association (2011), AD is the most common cause of dementia, accounting for 60 to 80 percent of all dementia cases. The National Institute of Neurological Disorders and Stroke (NINDS, 2010) defined dementia in this way:

Dementia is not a specific disease. It is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. People with dementia have significantly impaired intellectual functioning that interferes with normal activities and relationships. They also lose their ability to solve problems and maintain emotional control, and they may experience personality changes and behavioral problems such as agitation, delusions, and hallucinations. While memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia. Doctors diagnose dementia only if two or more brain functions—such as memory, language skills, perception, or cognitive skills including reasoning and judgment—are significantly impaired without loss of consciousness. (p. 2)

If the dementia-related disorder is primary, the loss of functioning is progressive (NINDS, 2010).

Other common types of dementia include vascular dementia, Lewy body dementia, Parkinson’s

disease, front temporal dementia, Creutzfeld-Jacob disease, and normal-pressure hydrocephalus (Mace & Rabins, 2006; Alzheimer's Association, 2011). AD and other dementia-related diseases progress in stages; and as the stages of the disease advance so increases the need for assistance (Mace & Rabins, 2006).

AD and Dementia-Related Disease Stages and Progression

Understanding the stages of AD and dementia-related disease is critical to any discussion of long-term care policy because as the disease progresses through different stages, different levels of care are required (Mace & Rabins, 2006). In addition, unlike people suffering from other debilitating illnesses, the majority of people with a dementia-related disease will reside in the community until well into the mid-stage of the disease (Alzheimer's Association, 2011). The course of dementia-related diseases will vary among individuals, progressing from the first symptoms of memory loss to an end-stage where both cognitive and physical functioning is lost and care is necessary (Mace & Rabins, 2006; Mittelman et al., 2003).

The progression of AD, the most common type of dementia, typically takes from 3 to 12 years—documented cases have spanned as little as 1 year or as long as 20 years as the disease progresses (Mittelman et al., 2003). Other studies have found that when caregivers had an easier entry into the role of caregiving early on in the disease, the care-recipient had a lower rate of nursing home placement during a 3-year period (Gaugler, Pearlin, & Zarit, 2003). Thus, caregiver interventions and early identification of AD and dementia could be considered possible cost-saving measures for Medicare, and it could even be seen as fiscally irresponsible to ignore these options (Weimer & Sager, 2009).

In the early stages of AD and dementia, people need little assistance, they may have short-term memory loss, or difficulty finding the right words or completing routine tasks; the cognitive loss is dependent on the area of the brain that is affected (Rabins & Lyketsos, 2010). In most instances, people with AD or related dementias are living in the community when their symptoms begin. The majority of caregivers surveyed in the Alzheimer's Association/NAC study (2004) reported that 23 percent of people with AD resided in the same household with their caregiver, 22 percent lived alone, 14 percent lived with a spouse, and 7 percent lived with someone else. Only 12 percent resided in nursing care and the remaining 7 percent lived in an assisted living facility (Alzheimer's Association & NAC, 2004, p. 7).

As AD progresses, so does the need for care. Caregivers of a person with AD must help with instrumental activities of daily living (IADLs), tasks such as paying bills, driving to doctor's appointments, and shopping. As the disease progresses, people with AD or a related-dementia will need assistance with more labor-intensive activities of daily living (ADLs), such as bathing, dressing, eating, toileting, and ambulating. When a person with AD requires nonmedical assistance or a companion, he or she needs "custodial or companion care" (Alzheimer's Association, 2011; Mace & Rabins, 2006).

As a person enters the middle or moderate stage of dementia-related disease, more supervision is required to provide safety and care in the home. Behavior cues become increasingly necessary to remind people with AD to eat, bathe, and dress appropriately. Wandering and disorientation may occur in greater frequency as well as hallucinations, agitation, delusions, or disrupted sleep patterns (Rabins & Lyketsos, 2010).

Because AD is a progressive neurological disorder, cognitive function declines to the point where a care recipient will require complete assistance with bathing, toileting, walking and eating, eventually requiring 24-hour care (Alzheimer's Association, 2009). In the late stage, the person with AD may lose the capacity to speak, to walk, to sit, to eat or to swallow without choking, and may become completely incontinent in the final stages of the disease when skilled nursing care is required (Rabins & Lyketsos, 2010).

Respite Care

Respite care offers the family caregiver a rest from his or her caregiving duties (Lund, Wright, Caserta, & Utz, 2006). Without respite care, many family caregivers go 24 hours a day, 7 days a week, without a break (Bookman & Harrington, 2007). A national study identified respite as the most important support for caregivers (Caserta, Lund, Wright, & Redburn, 1987). The need for respite care increases as the care-recipient's disease symptoms worsen (Family Caregiver Alliance, 2006; NAC & AARP, 2004). Respite services may include in-home respite, adult daycare services, as well as temporary residence in overnight facilities for multiple days (Lund et al., 2006). A 2008 report on respite care in Massachusetts showed that the state needed to provide more respite services in the form of adult daycare (Silverstein, Wong, & Brueck, 2008).

Long-Term Care

The Kaiser Commission (2009a) estimated that more than 10 million people in the United States need long-term care services and assistance with their activities of daily living. According to the Centers for Medicare and Medicaid Services (2010):

Long-term care [is defined] as a variety of services including medical and non-medical care for people who have a chronic illness or disability. Non-medical care includes non-

skilled personal care assistance such as help with everyday activities like dressing, bathing and using the bathroom. Medicare and most health insurance plans, including Medigap policies, do not pay for this type of care, also called “custodial care” (p. 100).

Medicare was not designed to cover long-term or “custodial” care, but it is the second largest funding source compared to Medicaid for long-term care in the United States (Feder et al., 2007). In addition to medical care, Medicare covers limited post-acute and short-term spending for home care or for skilled nursing care following hospitalization or as ordered by a medical doctor (CMS, 2010). Medicare also covers hospice care. The Alzheimer’s Association (2011) estimates that Medicare spending is three times as high for people with AD than the average costs per client without the disease (Bynum, 2009). This increased spending demonstrates a rise in the acute care costs of a person with AD along with an elevation of expenditures by the utilization of the short-term rehabilitation benefit following an acute illness (Bynum, 2009). The high costs of acute and long-term care associated with AD and dementia have critical policy implications for governmental programs like Medicaid and Medicare (Bynum, 2009; Alzheimer’s Association, 2011). The associated costs of dementia-related disease will profoundly increase expenditures of individuals and families who we have now identified as needing an extended duration of long-term care. In the dementia population the risk of needing long-term care is not uncertain; this is an identified portion of our population that we know will need long-term care services. Without insurance or Medicaid, a families care costs are not spread out but condensed (Alzheimer’s Association, 2011; Kemper et al., 2005).

It was reported that in 2005, only 3 percent of the adult population had private long-term care insurance and those without private long-term care insurance relied on publicly funded programs like Medicaid and Medicare for 69.3 percent of the financing of long-term care, with

only 18 percent spending out-of-pocket (Feder et al., 2007). In 2009, those figures remained relatively consistent, with a slight increase in out-of-pocket expenditures from 18 percent to 22.6 percent (National Health Policy Forum, 2011). Because so many Americans turn to public sources to fund their long-term care needs, these figures point to an important policy question: how can we finance public and private long-term care efficiently, while at the same time investing in our largest provider, our nation's informal family caregivers?

Purpose of Study

This study focuses on informal family caregivers because they are the “shadow workforce” that allows persons with AD or dementia to remain safely in the community as their symptoms worsen and they need 24-hour “custodial care” (Bookman & Harrington, 2007). Due to a lack of formalized care in the community, dementia care for people living at home is mostly the responsibility of informal family caregivers (NAC & AARP, 2009). My study examines the real-life experiences of informal family caregivers in their homes and neighborhoods, and investigates the formal and informal care structures that families use in the provision of community care. To identify gaps in long-term care policies, this dissertation utilized ethnographic methods to define the specific burdens of care that affect informal caregivers who provide at-home health care for family members with AD or another type of dementia.

The purpose of this study is to explore the experiences of family dementia caregivers and to examine current U.S. long-term care policies that affect this dementia population. My findings will be compared with the existing literature with the purpose of identifying the long-term care programs and policy supports that should be made available to both persons with dementia and their informal family caregivers.

My findings will reveal gaps in current policy; the analysis will evaluate the current long-term care policies within the existing body of literature and offer policy recommendations. Informal caregiving of people with dementia is a complex and multifaceted social phenomenon, with many questions still to be addressed: Should the burden of caring for someone with dementia in the community remain the sole responsibility of informal, untrained family caregivers? How does a lack of formalized care in the community affect the relationship between family members? Is it the absence of a formal network that creates the roles of the caregiver and the care-recipient with dementia? The work of informal caregivers has been well documented, but what long-term care services could support both caregiver and care-recipient within the community?

Finally, because *Olmstead* makes it a right rather than a privilege for persons with cognitive disabilities to be in as integrated a setting as possible for as long as they are provided with the services and care they need, the provision of community care should be the subject of high-priority policy supports. After all, almost a third of our long-term care population is receiving publically funded care, which therefore affords them the right manifest in *Olmstead*: the right to community care (*Olmstead v. L.C.*, 1999). A community option does not diminish the need for nursing home care. Skilled nursing care will be an important option for families caring for a family member with dementia, but an additional choice could be a network of community care. Using the 1999 *Olmstead* decision as the catalyst, could a naturally occurring partnership be explored between formal and informal care in the community? Could a coordinated network be created to include a combination of both formal and informal care and services and supports in the community?

Research Questions

Given the nature of exploratory research, my research questions will serve as an organizational tool to better understand and explore the complexity of family dementia caregiving from an interdisciplinary perspective. The existing body of research surrounding family members caring for a family member with dementia in each of the disciplines of law, policy, and society is quite extensive and could be the subject of three distinct papers. These questions attempt to distill what I found as the most significant and meaningful parts within each of the three paradigms, which were subsequently synthesized into the questions below. These are the five research questions guiding my study:

1. What are the “caregiver burdens” for each participant in my study? Specifically, what are the economic burdens of care for the family caregivers in my study caring for their family member with AD or dementia? Are there out-of-pocket costs or loss-of-income/employment costs associated with family caregiving?
2. What were the current home- or community-based services that the family caregivers and care-recipients in my study relied on? Are these services adequate?
3. If a study participant has utilized a nursing home placement for his or her care-recipient, what were the reasons for placement? Did the “caregiver’s burden” influence the need for placement?
4. Do current state and national long-term care policies address the needs of people with AD or dementia living in the community? Does a bias exist within current long-term care policy toward the provision of formalized long-term care in institutions?

5. What alterations in more formalized care services or in additional support services could alleviate “caregiver burden” particular to people with AD or dementia living in the community?

Summary

My research questions will help to frame my analysis of the current long-term policies as interwoven in real-life narratives of family dementia caregivers in Massachusetts. Further, I will analyze the adequacy of the long-term care policies currently in operation by examining the home-based services available for persons with dementia in Massachusetts.

Toward my study’s goal of understanding how long-term care services are provided, I will use qualitative methodology to interview and collect information from informal family caregivers and officials in appropriate state offices such as Massachusetts Elder Services and Elder Affairs. Finally, my research will identify current long-term care policies and provide recommendations to assist informal family caregivers in the provision of care for people with dementia in the community.

Chapter 2: Literature Review

Introduction

Focusing on informal family caregivers who provide care for family members with AD or a related-dementia, my exploratory study will complement and build on an existing body of related research. Many studies have examined institutionalized and home-based care generally, but very few have used a sustained qualitative approach to examine informal dementia caregiving in its natural context, much less explored the experiences of family caregiving pragmatically, in relationship to the promise of the 1999 *Olmstead* decision and the current long-term care policies.

A large portion of our knowledge about family caregiving has come from quantitative research. Studies have typically depended on some type of empirical measurement (e.g., surveys and standard instruments and scales) as a way to understand the caregiving experience (Butcher, Holkup, & Buckwalter, 2001). Much of the research included in my review utilized evidence-based measurements; these findings, which are very important to our understanding of the family caregiving experience, could be even more helpful if they were to be explored further using qualitative methods (Globerman, 1994, 1996).

My review of the literature will draw on research and findings from the disciplines of law, policy, and social science. This interdisciplinary approach, combined with qualitative research methods, will allow for a more nuanced exploration of family caregiving and long-term care; the resulting conclusions related to this timely topic will be applied toward suggested policy recommendations.

It is important to mention that much of the literature included in this review is specific to informal dementia caregiving, and was collected from a body of knowledge related most specifically to AD or dementia-related diseases.

Although previous research has consistently suggested that there is a substantial burden carried by family dementia caregivers, researchers have not yet interfaced family caregivers and long-term care within a qualitative exploration of family caregiving within the community context.

Beginning with much earlier studies and continuing to the present day, informal family caregiving has mainly been described in terms of burdens; although burden is an important aspect of caregiving, it may not be the only perspective (Pearlin, Mullan, Semple, & Skaff, 1990; Salva & Molenaar, 2011; Vitaliano, Young, & Russo, 1991; Zarit & Orr, 1985; Zarit, Femia, Kim, & Whitlach, 2010). Plenty of studies have focused on the psychological and financial aspects of informal caregiver burden, but few have taken the next step to relate their findings to a policy agenda to support caregivers or to explore whether more formalized care should be made more available in the community.

The contribution of my exploratory research will be to increase our understanding of the experiences of family caregivers in their natural context using an interdisciplinary perspective, including an evaluation of the current long-term care policies in conjunction with the legal precedents set in the *Olmstead* decision.

The *Olmstead* Decision

Informal family caregivers are the bulk providers of the reasonable and safe care that supports family members with dementia in the community. The cornerstone of the 1999

Olmstead decision is the “integration mandate” of the Americans with Disabilities Act (1990).

This mandate made care in the community a right for disabled citizens as long as they can reasonably and safely be accommodated in the community. Rosenbaum (2001) stated this concerning the 1999 U.S. Supreme Court ruling in the *Olmstead* decision:

The medically unjustifiable institutionalization of persons with disabilities constitutes a violation of the ADA of 1990 (422 U.S.C. 12201 et seq.). The ADA is civil rights law, which prohibits discrimination against “qualified persons with disabilities.” It ruled that when a state’s own medical professionals reasonably conclude that an individual is able to reside in the community, the state must make reasonable modifications to furnish community services in the most integrated setting unless the state can prove that to do so would require a fundamental alteration of its program. (p. 1)

Given the progression of dementia-related disease, an individual’s level of cognitive impairment can preclude him or her from participating rationally in a placement decision (Mace & Rabins, 2006). The placement decision is undeniably one of the most difficult and complex decisions that informal family caregivers must make for a family member with dementia. As dementia progresses, somewhere during the moderate stage of the disease safety becomes an important issue for family caregivers; this is the time at which many caregivers begin the dialogue about an institutional placement (Mace & Rabins, 1991, 2006; Mittelman, Epstein, & Pierzchala, 2003). Because there are numerous safety concerns born out of the progressing cognitive deficits, informal family caregivers determine whether or not a family member with dementia can safely stay in his or her home or will need to move into a nursing or residential facility.

Dementia placement decisions are not based exclusively on the need for higher skilled care, but on other factors as well (Lyons, Schneider, & Desmond, 2005).

In the current literature, cognitive impairment correlated strongly with a higher risk of institutional placement (Gaugler, Duval, Anderson, & Kane, 2007). This does not imply that there is anything wrong with a family making a placement decision to place an individual with cognitive impairment into nursing care. Nursing care is an important component of the continuum of care in relation to dementia-related diseases. However, the decision to institutionalize a family member has been correlated with higher stress levels in family caregivers (Spillman & Long, 2009).

Consider *Olmstead* in contrast to the caregiver burdens associated with informal dementia caregiving. The responsibility for deciding on institutional placement is usually handled by an informal caregiver, making family caregivers the de facto arbiters of independence for their family members with dementia. Given the importance of this family decision in context of the *Olmstead* decision, it only makes sense that family caregivers would receive support including information pertaining to the current long-term care programs available in the community (*Olmstead v. L.C.*, 1999).

The expansion or exploration of alternative long-term care options in the community does not imply institutional care is not an important option for families, but it does suggest that better community supports, including formalized services for family caregivers, should co-exist alongside institutional care as equally viable options.

Informal Family Caregivers

Informal family caregivers are the largest workforce of long-term care providers in the United States (Houser & Gibson, 2008; Komisar, 2009; National Alliance for Caregiving [NAC] & AARP, 2009). In their groundbreaking research about family caregivers, Zarit and Orr (1985)

helped to define the burdens of caregiving by delineating the various aspects of burden; this approach gave researchers a more organized way to understand the burdens associated with family caregiving (Zarit, 2006).

Another way to analyze caregiver burden (discussed briefly in Chapter 1) considered categorizing burdens according to two distinct domains: *objective* burden and *subjective* burden (Vitaliano et al., 1991). This clarifies the concept of caregiver burden even further. For example, if the caregiver's *subjective* burden (i.e., feelings of separation, concerns about the quality of care) is not addressed, a respite program, which takes care of a caregiver's *objective* burden (having time to go the grocery store, take a break), may be underutilized. Differentiating between these two distinctly different types of burdens can help with the formulation of specific caregiver interventions to better address family caregivers' needs.

Unmet Needs of Caregivers

Family caregivers have well-documented burdens and needs that are currently not being addressed by the available long-term care supports within the community. For example, a study focused on informal caregivers of people with dementia found:

74% of Alzheimer's caregivers report unmet needs. Specifically, they need more time for themselves (36%), help managing stress (34%) and information on managing challenging behaviors (31%). Despite heavy burdens and unmet needs, 47% of Alzheimer's caregivers report having used no paid help in the past 12 months. (Alzheimer's Association & NAC, 2004, p. 3)

As noted in these findings, a large number of family caregivers have identified many unmet needs and yet family caregivers have documented difficulty using respite support. The unmet needs of caregivers and their lack of utilization of formal care supports needs to be better understood within the current literature. Why family caregivers are not turning to available

resources for support is a complicated question because accepting care and needing care present different problems for policy. A gap exists in our current knowledge about why family caregivers underuse formal support services, including respite services offered as a part of a research study; these unknowns allow room for interpretation. Caregiving is a very complex phenomenon. Using a more in-depth method of discovery may allow me to uncover or make sense of inconsistencies and shortcomings within the current literature, so our generalized knowledge of family caregiving may become more specific (Alzheimer's Association & NAC, 2004).

Dementia Family Caregiving

Dementia caregivers help with more activities of daily living (ADLs) than other caregivers, they handle more difficult tasks, they commit more hours a week to caregiving, and they remain in the caregiving role for longer duration than non-dementia caregivers (Alzheimer's Association & NAC, 2004). Caring for a person with dementia is different from caring for a person with other illnesses; the strain of dementia caregiving makes it a more difficult job.

The associated behavioral changes and cognitive impairments inherent in symptoms of dementia make dementia caregiving more stressful than other caregiving (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). The cognitive declines associated with dementia (which can include personality changes, behavioral problems, loss of executive functioning, and aphasia) as well as insomnia, anxiety, hallucinations, and incontinence, are not easy issues for untrained family caregivers to address (Mace & Rabins, 1999, 2006; Mittelman et al., 2003). The progressive neurological decline eventually robs not only a person's cognitive abilities but his or her physical

functioning as well; eventually round-the-clock care is needed, making dementia caregiving more onerous than that of other illnesses (Mace & Rabins, 1991, 2006; Mittelman et al., 2003).

These findings speak to both the cognitive declines and the eventual physical declines that are also associated with AD or dementia; at a point in the disease progression care-recipients need help with bathing, toileting, eating, and ambulating. Informal family caregivers whose care-recipient has dementia carry a greater burden than other family caregivers (Norton et al., 2010; Vitaliano, Zhang, & Scanlan, 2003). As dementia progresses in most instances, a family member is charged with imposing the behavioral restraints on the person with AD, for instance deciding when the person with dementia cannot be safely left alone or how to keep him or her from wandering out at night (Mace & Rabins, 2006; Mittelman et al., 2003). We know that the executive functioning and reasoning abilities of a person with dementia decline, yet the informal caregiver receives no formalized training in how to deal with the resulting difficult behaviors. At the same time, such restraints, such as keeping the person with dementia from driving when driving is no longer safe, provide a benefit to the community at large (Rabins & Lyketsos, 2010).

At some point in the disease progression, a person with AD will need 24-hour “custodial care.” This care becomes necessary when a person with dementia is no longer safe alone. A person with dementia may also need some type of monitoring during the night (Mace & Rabins, 1991, 2006). These factors increase the caregiving burden in comparison to the informal care received by elders with normative cognitive functioning. Studies have demonstrated that dementia caregivers carry a greater caregiver burden than other caregivers (Ory et al., 1999).

Relational Considerations in Case Studies

As mentioned previously, Zarit and Orr (1985) created a measurement of caregiver burden that focused on specific aspects of caregiving; but they also stated that the prior relationship the caregiver had with the patient before the onset of illness is an important consideration. For instance, Chou, Zarit, and Chiriboga (2009) found that wives and daughters may approach respite care from different perspectives: daughters may utilize respite care as a way to keep their mothers in the community, while wives may approach respite care as the first move toward nursing home placement. In other words, the relational issues between caregiver and AD care-recipient continue to influence the dynamics of the caregiving experience. These familial and relational factors need to be included in policy deliberations to address the real-life issues of family caregivers; otherwise, the policy intervention may not have positive outcomes.

Relational issues point to the multifaceted complications of family caregiving and the need for a method of research to specifically consider the many different ways burden can be influenced concurrently (Zarit & Orr, 1985). For example, a brief 10- to 20-minute survey may not uncover the specific issues that lead to difficulties for a caregiver providing personal care for a family member, just as such a short interview may not be ample enough time for a caregiver to clarify feelings of discomfort or grief associated with caring for someone in physical and cognitive decline. Certainly, the information we might offer a complete stranger is sometimes different from the information we share when trust has been established. Sustained caregiver discussions may demystify relational issues inherent in the culture of caring informally for a person with AD.

Dedication of Informal Caregivers

The dedication of informal caregivers to their care-recipients is worthy of mention. Many family dementia caregivers continue to provide community care even after their family member has become Medicaid qualified; achieving Medicaid status means that institutionalized care will not be an out-of-pocket expense (Max, Webber, & Fox, 1995). The fact that many family caregivers opt for the added financial costs of keeping a family member in the community along with continuing in their high-stress job of providing in-home care when institutional care could alleviate both the stress and expense is remarkable and probably somewhat confounding to policymakers (Max et al., 1995). The dedication of caregivers toward AD care-recipients speaks directly to the consideration of relationship and the value we place on family and community. These relational issues will be explored through my use of ethnographic interviews, participant observations, and diary writings. The use of ethnography and case study as methods to draw out nuanced information further inform my policy recommendations.

Gender

Gender is a topic that cannot be ignored when discussing issues of caregiving. “In virtually every way, long-term care is a women’s issue. Because of greater longevity, long-term care is primarily needed by elderly women, and women are overwhelmingly the main providers of both formal and informal care” (Weiner, 2003, p. 19).

A recent telephone survey identified 60 percent of family dementia caregivers as female (Shriver & Alzheimer’s Association, 2010). Women also run a higher risk for developing AD than men: nearly 65 percent of people with dementia-related disease are women (Alzheimer’s Association, 2011). Consider those numbers along with an estimated projection that 80 percent

of women over 65 will need some type of long-term care support in their lifetime (Johnson, 2011). It has been estimated that 28 percent of those women over 65 will need 5 or more years of long-term care, in contrast to 11 percent of men (Kemper, Komisar, & Alexih, 2005). This suggests that many women who have provided care will become the care-recipients of tomorrow, and without a network of long-term care supports in the community women will continue to face higher percentages of institutional placements.

In a study that produced a profile of the most likely characteristics of elderly nursing home residents, 75 percent were female and 83 percent did not have a family member to care for them; 50 percent had some form of dementia (Kasper, 2005; Lyons et al., 2005). Since the majority of men (75 percent) remain married after the age of 65, they are more likely to have a spouse available to care for them in the community; this is not the case for 44 percent of women (Johnson, 2011).

Men are more likely to become caregivers if their wife needs assistance. Husbands account for 41 percent of spousal caregivers; but only 30 percent of male children provide care to a parent, while daughters and daughters-in-law report providing more hours of care to a parental care-recipient than sons or sons-in-law (Johnson & Weiner, 2006).

The stress spousal caregivers face when providing care for a spouse with dementia is well documented. Dementia caregivers have reported being on duty 24/7 during their last year of caregiving (Alzheimer's Association, 2011). In this instance, gender roles may be more detrimental to males with little or no previous caregiving experience. The Cache County study found that people caring for a spouse with dementia had a higher risk of developing dementia than others in their age bracket, and husbands caring for a spouse with dementia had the highest

risk of all (Norton et al., 2010; Treiber et al., 2011). Another study investigating the health care costs of AD family caregivers found a 25 percent increase in annual health care costs, but most striking were the facts that these AD caregivers showed a steady decline in cognitive testing over an 18-month period and 80 percent of these caregiver participants were female (NAC, Schulz, & Cook, 2011). Dementia caregivers would most likely agree that informal family caregiving is not an easy job for any gender, but as women age they may be more profoundly impacted by the disease. Given the high stress of dementia care, training and better support services are needed to protect the health of *all* family caregivers.

Caregiver Health

Vitaliano, Young, and Zhang (2004) have written extensively on the negative impacts caring for a person with dementia or AD have on the health of the family caregiver due to the various health risks associated with high-stress caregiving. An earlier study used a meta-analysis that compared dementia caregivers' health status to non-dementia caregivers; in previous studies the findings reported that dementia caregivers had a 23 percent higher level of stress hormones and a 15 percent lower autoimmune response than caregivers caring for a family member without dementia (Vitaliano et al., 2004).

The Cache County study that identified the elevated risks of cognitive impairments in spousal caregivers, coupled with the NAC study that also identified cognitive decline in AD caregivers, should give us pause concerning the health risks associated with family dementia caregiving (NAC, Schulz, & Cook, 2011; Norton et al., 2010). Dementia caregivers have also been found to have much higher rates of depressive symptoms than other caregivers (Covinsky, Newcomer, Dane, Sands, & Yaffe, 2003). Depression, cognitive impairment, high blood

pressure, lowered immune response, and sleep deprivation have been associated with the stress of family caregiving (Beeson, 2003; Kiecolt-Glaser et al., 2003; Vitaliano et al., 2004).

Currently new interventions are being researched that are designed to reduce the stress of informal caregiving by reducing caregiver stress and depression, thus improving the quality of a caregiver's life. A program called "powerful tools for caregivers" (PTC) demonstrates promise; the program teaches self-care and improves psychological well-being by lowering health risks for family caregivers (Won, Fitts, Favaro, Olsen, & Phelan, 2008). Indeed, given what we know about the health risks associated with high-stress caregiving, the dementia caregiver of today may well become the care-recipient we will need to care for tomorrow.

The evidence-based interventions discussed in the next section may provide some illumination concerning how to best support family caregivers in the community.

Evidence-Based Intervention Studies

Caring for the caregiver was the foundation of the New York University (NYU) caregiver study. The study consisted of a counseling intervention focusing specifically on spousal caregivers (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman, Haley, Clay, & Roth, 2006). The long-term results of this study strongly demonstrate the effectiveness of psychosocial interventions, including both individual and family counseling, in maintaining the mental health of the spousal caregiver, thereby allowing caregivers to keep spouses with dementia or AD home longer.

The NYU caregiver study began in 1987 and ended in 2009. The study focused on 406 people caring for their spouse with AD in the community. Caregiving dyads were split into two groups; one group received the counseling interventions. The study found that the treatment

group had less of a reaction to problem behaviors and fewer symptoms of depression, as well as a higher degree of satisfaction with the emotional and social supports from friends and family (Mittelman et al., 1996). The NYU study found that by caring for the caregiver, the intervention delayed the institutionalization of the care-recipient by 1.5 years, or 557 days, compared to the control group (Mittelman et al., 2006). The cost savings per family is roughly \$112,500, if you calculate 1.5 years using the yearly average cost of nursing care (MetLife, 2009).

A nursing home placement occurs when a family caregiver can no longer provide adequate care. A nursing home placement is a vital option for both the care-recipient and the caregiver (Mittelman et al., 2003). In fact, elderly spousal caregivers have a higher rate of mortality than others in their age group, which underscores how important it can be for a family caregiver to have access to institutional care if needed (Mittelman et al., 1996, 2006). The high cost of institutional care is a concern for many family caregivers and could be perceived as a deterrent (Long, 1997). What the NYU study successfully demonstrated was that counseling the caregiver decreased caregiver burden, delayed institutionalization, and at the same time provided family caregivers with support (Mittelman et al, 1996).

Resources for Enhancing Alzheimer's Caregiver Health (REACH) was another nationally funded research initiative; it examined a behavioral education and stress reduction program for AD caregivers (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003). This seminal multiple site study was based on the previous work of Mittelman et al. (1996).

The REACH study tested two different caregiver interventions. One group of caregivers received 4 hours of behavioral management training and a stress management intervention. The other group received 3 hours of behavioral management training. Both interventions were

administered in brief sessions (approximately 20 minutes per group). The REACH study demonstrated how even very brief interventions—20 minutes in duration for a total of 4 hours spaced over 2 years—positively impacted the lives of family caregivers, lowered stress, and reduced depression scores (Burns et al., 2003).

The most recent REACH study, conducted by the Veterans Affairs (VA), provided a similar caregiver intervention protocol over 6 months through 24 VA medical home care programs across the country (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). The findings reported that 96 percent of the caregivers who participated in the study wanted to see the program implemented as a VA program. Yet, these results—from the REACH, the REACH-VA, and the NYU study—have made little impact on current long-term care policies to date, regardless of the repeatedly positive outcomes (Burns et al., 2003; Mittelman et al., 2006; Nichols et al., 2011).

The erroneous assumption that support programs for family caregivers will dissuade these informal caregivers from providing free care is unsubstantiated and disproven by every evidence-based intervention; what has been replicated is the finding that caregiver support programs lead to delays in institutional placements for study participants (Levine, Halper, Peist, & Gould, 2010). In fact, given the evidence we have compiled from caregiver intervention research, I suggest that by *not* offering support services to primary caregivers we may be limiting the length of time a person with dementia has in the community.

If caregiver stress and caregiver burden factors into the decision to institutionalize a family member with dementia, we have evidence-based research that supports the efficacy of

counseling interventions for caregivers (Burns et al., 2003; Mittelman et al., 1996, 2006; Nichols et al., 2011).

Influence of Caregiver Stress on Institutional Placement

The decision to institutionalize a care-recipient is not a simple equation; it is influenced by a multitude of factors. These factors have more to do with the quality of life of the informal caregiver than the declining physical health of the care-recipient (Cohen et al., 1993; Spillman & Long, 2009). Dementia caregivers spend an extensive amount of time caregiving without a break, so they are more adversely affected by their caregiving responsibilities (Ory et al., 1999). Given the difficulties associated with the behavioral and personality changes that accompany dementia-related disease, coupled with the fact that family caregivers are not trained or supplied with any mechanism for taking a break, is it any wonder that people with dementia are institutionalized at such a high rate? A systematic review of 42 studies found a 20 percent rate of institutionalization in the dementia population in the first year following their dementia diagnosis; that rate increased to 50 percent after the next 5 years and to 90 percent after 8 years following diagnosis (Luppa, Lucka, Brähler, König, & Riedel-Hellera, 2008). Spillman and Long (2007) studied how caregiver stress in the community influenced institutional placement and found that a high degree of caregiver stress influenced a caregiver's decision to institutionalize. If caregiver support programs could positively affect stress levels of family caregivers, the entire caregiving unit would be better off.

High levels of caregiver stress correlate with the physical strain of caregiving, poor or declining health of the caregiver, sleep disturbances, as well as a constant worry about money. Other intangible factors—such as health of the caregiver's relationship with the care-recipient, or

the existence of many unmet caregiver needs—influenced institutional placement (Luppa et al., 2008).

Caregivers that have experienced large amounts of stress are far more likely to have utilized formalized care such as adult daycare, respite, or home services, and they are far more likely to admit they need help, which concurs with the findings of Chou et al. (2009). In addition, many highly stressed caregivers have no one else to provide care in their absence and are more likely to have care-recipients who need 24-hour care (Chou et al., 2009).

Reducing the physical and financial burdens of caregiving should decrease a portion of the stress, and an array of caregiver interventions (e.g., caregiver training or in-home support) could be employed to reduce more generalized caregiver stress (Spillman & Long, 2007). Most caregiver research concurs that when the majority of caregivers use in-home care services for their family member with dementia, the risk for institutionalization is reduced (Luppa et al., 2008).

Respite Care

Conlin, Caranasos, and Davidson (1992) measured whether the provision of respite care could influence the burden of stress for a person caring for a family member with AD. This study followed 15 caregiving dyads over a 10-week period. The participants were split into a control group and a study group. Only the study group received respite care, averaging 15.3 hours per week: five care-recipients received in-home care and two care-recipients received respite care in an assisted living facility. Researchers found that respite care produced measurable changes in caregiver stress, demonstrated by a better outlook, fewer negative feelings toward the care-recipient, and a sense of increased confidence and mastery over the situation. Yet earlier research

findings on respite care are mixed, since many studies have demonstrated that almost half of dementia caregivers resist participating in community-based services even when they could use services (Gaugler, Kane, Kane, Clay, & Newcomer, 2005).

Many caregivers wait too long before turning to adult daycare or respite services for a cognitively impaired care-recipient. Cho, Zarit, and Chiriboga (2009) found that family caregivers who were slow to access respite care for their care-recipients with dementia had much higher levels of unmet needs. Unmet caregiver needs have been identified as needs that caregivers have not been able to address, such as not having enough time or information (NAC & AARP, 2004). Higher unmet caregiver needs correlates with a higher risk that their care-recipient will go into a skilled nursing facility. This means that many caregivers may use respite services too late in the disease cycle, after the “wear and tear” of caregiving has already become too much to handle (Cho et al., 2009). A systematic review of nursing home placements found 20 percent of those diagnosed with dementia went into nursing care during the first year after diagnosis, and 50 percent were placed in care 5 years later (Luppa et al., 2008). These early placements may be indicative of a lack of long-term care dementia services and supports in the community rather than a care-recipient’s need for skilled nursing care.

Policymakers often overlook the need for family caregivers to have access to quality respite care, even though informal family caregivers identify respite care as a very important and critical support service in the community (Lund, Wright, Caserta, & Utz, 2006).

In-Home Care

The costs of home care services are calculated hourly. Given those costs, in-home help adds up quickly for those who pay out of pocket. In 2009, the average hourly cost of a home

health aide was \$20, and \$19 for companion services (MetLife, 2009). It is not surprising that the majority of elders needing long-term care rely primarily on informal family caregivers.

A study exploring the use of in-home services found that only 35 percent of family caregivers paid for an aide or housecleaner outside of their family unit, while 68 percent reported receiving help from a secondary unpaid informal caregiver. This information was gleaned from a national study in which 1,480 caregivers were interviewed; 78 percent of the caregivers said they needed additional help related to their caregiving role and only 36 percent felt they could turn to a professional health provider for assistance (NAC & AARP, 2009). The provision of case management to families caring for a family member with AD might increase the likelihood of those families accepting services in the home, but currently case management is only available in the home if you pay privately; case management is not a billable service (Newcomer, Spitalny, Fox, & Yordi, 1999).

Adult Daycare

One affordable care alternative in the community is adult daycare. Adult daycare services follow either a social or a medical model, depending on the type of care needed; daycare costs average around \$67 a day (MetLife, 2009). If there were some type of mechanism to help connect informal family caregivers to formal services like adult daycare earlier in the disease progression there might be a greater utilization of adult daycare services earlier in the disease progression (Gaugler et al., 2005). However, currently there is no formal care network to tie caregivers into services (Weimer & Sager, 2009).

Home- and Community-Based Long-Term Care

Home- and community-based services provide care in the home for those with long-term care needs. The majorities of home- and community-based long-term care services are financed by Medicaid or Medicare or are paid for out of pocket (Kemper et al., 2006). The 1999 *Olmstead* ruling required the provision of more community-based services so that institutionalization was not the only option for reasonable care. This shifted public funding to include home care programs in the community. Progress has been made toward a greater array of home and community services, but this progress has been slow; the majority of public dollars continue to be funneled into nursing home care (Summers, 2006).

Home- and community-based health services have become a federal priority and states will need to address the growing need for care services in the community (Ng, Harrington, & Watts, 2009). As demand for community care grows, 44 states faced budget deficits in 2011. This bleak fiscal reality put social service programs at risk and, for 2012; already 29 states have projected shortfalls (McNichol, Oliff, & Johnson, 2012).

In a 2009 survey of 1,005 family caregivers, 36 percent reported that government agencies were less able to offer help or services during the last year; despite this drop in available support, 78 percent reported that the quality of that care did not decline during this time period (Evercare & NAC, 2009).

As of 2009, approximately 2.8 million people in the United States were receiving Medicaid home- and community-based services, and 300,000 people were on a waiting list (Ng et al., 2009). Waiting lists signal that Medicaid-qualified care-recipients with long-term care needs in the community do not have access to adequate care. Paradoxically, in an effort to

control Medicaid costs, about one-third of the states use more restrictive financial eligibility standards, and in 14 states, home-care waivers require functional eligibility, which means a person must demonstrate a greater need to qualify for home services than is necessary to qualify for nursing care (Ng et al., 2009).

The Current Partnership Between Formal and Informal Care

Formalized care in the community includes agencies that provide in-home health aides or companions, outside the home community-based adult daycare, or social day programs (Derence, 2005; Silverstein, Wong, & Brueck, 2008).

Early identification and treatment of AD may allow care-recipients to remain in the community longer; this means that identifying and supporting families earlier on can impact how well a family does years later during the disease progression (Gaugler et al., 2005). Studies that have provided informal caregivers with formalized case management found a greater utilization of home- and community-based services (Gaugler et al., 2005; Jansen et al., 2005; Newcomer et al., 1999). Better use of home- and community-based services has been effective at delaying the use of nursing home placements (Charles & Sevak, 2005).

Because of the informal and arbitrary nature of informal family caregiving, family caregivers can recede within their own community; there is no bridge to connect family caregivers with the social services infrastructure (Levine et al., 2010). Without long-term care supports or services in the community, family caregivers are left without a structure through which to access the education and training they need. Instead, it is the family caregivers' responsibility to seek out assistance. Without a formal care structure in the community, we are bereft of a mechanism for timely evaluation of a care-recipient's needs, or a system to deliver

respite care when it is most needed (Levine et al., 2010). And without a care network to coordinate care, we cannot provide the support and respite services to the largest group of long-term care providers, our informal family caregivers (Houser & Gibson, 2008).

The National Long-Term Community Survey (NLTCS), which collects information on Medicare recipients 65 and older with disabilities residing in the community, found that most formalized care in the community is obtained within assisted living facilities, not in the home, where many elderly need more formalized care to remain in the community (Spillman & Black, 2005). This study found that only 6 percent of seniors needing long-term care received formalized care services in the home, while 60 percent of seniors needing assistance received formalized long-term care in a residential or assisted living facility (Spillman & Black, 2005).

Almost half of the seniors in this study who needed services received help primarily from informal family caregivers, and a fifth received a mix of formal and informal care; mostly the seniors receiving formalized care were residing in a residential placement with some type of informal care being provided by a family caregiver (Spillman & Black, 2005). Most striking was the fact that 8 percent of those with long-term care needs received no care at all; these people typically had fewer disabilities, no spouse or children, and little financial support. As these findings demonstrate, formalized care is not readily available within our communities, even if we include assisted living, daycare, or home care services (Spillman & Black, 2005).

Without a formalized care structure put in place in the community, informal family caregivers are virtually on their own, isolated and disconnected from more formalized care supports, and without a mechanism to tie them in to services (Bookman & Harrington, 2007; Levine et al., 2010). Publically funded caregiver supports in the community and in the home

could be an effective way to combine formal and informal care in the community while delaying costly institutionalizations (Charles & Sevak, 2005).

Institutional Costs

An elderly person with AD has a 5 times greater risk of being placed in a nursing home than an elderly person without dementia, so the need for institutionalized care is great for the AD population (Mittelman et al., 2006). The availability of well-trained institutional caregivers is another important consideration, because as the symptoms of AD progress, untrained and inadequately supported family caregivers become overwhelmed and must rely on institutional care to meet the needs of a family member with AD.

The MetLife (2009) survey of long-term care costs found that, in 2009, nursing home prices ranged anywhere from \$79,935 annually for a private room, to \$72,270 annually for a semi-private room in a skilled nursing facility. The per-year cost for specific Alzheimer's units was approximately \$5,000 higher. Assisted living facilities averaged around \$37,572 yearly, while assisted living facilities with dementia units were priced at about \$53,200 yearly (MetLife, 2009).

Although most Americans have almost enough savings to pay for 1 year of nursing home care, the average stay is almost 3 years (Komisar, 2009). This time span is consistent with the Centers for Disease Control (CDC) and Prevention's National Nursing Home Survey (2004), which estimated the average nursing home stay for all illnesses in 2004 to be 2.5 years. The CDC 2004 survey also found that 16 percent of those diagnosed with AD upon admittance were still in nursing care 3 to 5 years later. In fact, the Alzheimer's Association (2011) reported that 50

percent of people with AD currently residing in nursing home care used Medicaid to pay their care costs.

Long-Term Care Financing

The biggest financial risk Americans over the age of 65 will face is the financing of long-term care (Kemper et al., 2005). How to pay for long-term care is an important consideration for families caring for a family member with dementia (Mace & Rabins, 2006). We know that nursing home placements contribute to the overall costs associated with dementia care (Long, 1997). Across the population, time spent in long-term care averages 3 years, but for females, the average is 3.9 years (Kemper et al., 2005). Despite what we know of the financial burden of caregiving, we still know very little about how the costly expense of long-term dementia care influences the day-to-day decisions of family caregivers (Zarit & Orr, 1985).

Public policy experts from Georgetown University described the American public's status related to long-term care financing as "unsatisfactory" (Feder, Komisar, & Friedland, 2007). Americans pay out of pocket until they are out of money and then must rely on public funding to pay for the remainder of the care they need. This puts a tremendous financial burden on every family who needs long-term care, without any assurance a family will receive care when they need it. Especially as state and federal governments face increasing fiscal burdens and growing budget deficits, government becomes reluctant to spend more on long-term care and public funding becomes limited, which only shifts the financial burden back onto the family.

Private Financing

According to a 2009 report, private, or "out-of-pocket," spending paid for 28 percent of long-term care costs for that year (Komisar, 2009). The out-of-pocket costs for caregivers of

family members with dementia are higher than those for families caring for someone without dementia (Alzheimer's Association, 2007). In an earlier caregiver study, 49 percent of non-spousal family caregivers reported spending out of pocket for their care-recipient (Alzheimer's Association & NAC, 2004). Out-of-pocket spending increased for 60 percent of the 1,005 caregivers who were interviewed in a 2009 family caregiving study, and during the current economic downturn, almost half of those who reported this increase had to use their savings or increase their debt to support their provision of care (Evercare & NAC, 2009). According to the Kaiser Commission on Medicaid and the Uninsured report:

Most elderly do not have assets that would enable them to pay for one year of nursing home care. Two-thirds of those 65 and older living in the community have resources equal to less than one year of the cost of nursing care, which is estimated at \$70,000 annually. (Lyons et al., 2005, p. 3)

And asset levels are even lower for those 65 and older living in the community who already have functional or cognitive impairments, which puts them at a higher risk for nursing home placement (Lyons et al., 2005; Summer, 2005; Weiner, 2006). The majority of Americans just do not have the savings to afford more than 1 year of nursing care. Given the average 3- to 12-year progression of dementia symptoms (Mittelman et al., 2003), many families become impoverished as they struggle to provide long-term care to a family member with dementia.

Long-Term Care Insurance

One way to finance long-term care is to purchase private long-term care insurance. However, Feder et al. (2007) reported that only 3 percent of the adult population has private insurance to pay for long-term care costs. Private long-term insurance pays for long-term care after a buyer qualifies for services; usually an "elimination period" must elapse before a buyer can receive benefits (Tumlinson, Aguiar, & Watts, 2009). Unfortunately, individual buyers with

pre-existing conditions may be denied insurance or be subject to a waiting period for benefit coverage. Policy prices vary, as do benefits. For example, not all long-term care policies include home care, and most have caps on spending.

In 2005, the cost for a basic long-term care policy was estimated to be \$6,178 yearly for a 70-year-old buyer and \$2,447 if the purchaser was 50 years old (Feder et al., 2007). This basic plan offered 5 years of coverage, a \$150 daily benefit, a 90-day elimination period, and was regulated depending on inflation. Unfortunately, even if they have the money to buy long-term care coverage, individual buyers with pre-existing conditions may be denied insurance or be subject to a waiting period for benefit coverage.

The National Association of Insurance Commissioners (NAIC) advised buyers to have at least \$35,000 in assets before purchasing long-term care insurance; and they advised that private insurance is not for everyone (Feder et al., 2007). Many people who need long-term care insurance cannot afford to purchase it, and an additional 28 percent of seniors who may have the assets available would not qualify due to the underwriting process that assesses a client's medical risks (Komisar, 2009).

Interestingly, a MetLife (2006) study showed that families caring for a family member with AD who were fortunate enough to have long-term care insurance still carried a heavier burden than caregivers of people with other illnesses, even when the financial concerns of long-term care had been addressed. Financing of long-term care for people with AD may be an important consideration for family caregivers, but this study demonstrated that having long-term care insurance had little success in reducing the overall burden of informal dementia caregiving (MetLife, 2006).

Informal Family Caregiver Costs and Benefits

Informal family caregiving is rarely discussed by using a cost/benefits analysis; this may be due to the fact that family caregiving has no monetary rate attached to the services provided and that care services can be quite variable depending on the need. It is an erroneous assumption to presume that informal care is actually “free.” Nonetheless, policymakers do not consider any real cost to be attached to the provision of informal family care. On the other side of that equation, for families who provide informal dementia care in the community, those informal costs are significant (Burns et al., 2003). Informal caregiving, though unpaid, still accrues costs (Levine et al., 2010). If the uncalculated societal benefits received from informal caregiving could be accurately quantified, their value would be better understood (Bookman & Harrington, 2007). Max et al. (1995) collected information on all formal and informal care used by research subjects who had an AD diagnosis in Northern California over one year. All study subjects had a primary or secondary caregiver. Caregivers self-reported, in monthly phone interviews, the hours they spent engaged in care activities. Informal caregivers in the community provided their AD care-recipients an average of 70 hours per week of informal care, or 286 hours per month, with 249 of those hours provided by the primary caregiver; a secondary caregiver provided 36 hours of care per month. If these families had hired outside help to provide comparative, paid care in the home, it would have cost them \$34,517 in 1990 dollars (Max et al., 1995). The valuable benefit provided by unpaid family caregivers, when calculated in terms of what it would cost these families to hire paid caregivers, is clear.

Another study showed that a 1-month delay in nursing home placement, made possible by family caregivers, would lead to a substantial savings for the family in long-term care costs

(Leon, Cheng, & Neumann 1998). These researchers calculated the total benefit of informal care, when accounting for these 1-month delays in nursing home care, to represent a potential savings of \$1.12 billion annually (Leon et al., 1998). Studies such as this point to the potential cost savings that the addition of innovative community programming could contribute to the private and public pool of long-term care funds. Since institutional costs have been cited as the main reason for the high cost of dementia care, a more efficient use of the available informal, private and public long-term care financing could make funding available for more innovative programs that provide additional cost savings by creating a brief nursing home delay (Hux et al., 1998).

Public Financing of Long-Term Care

Medicaid has become the single largest financer of long-term care in the United States (O'Brien, 2005). Medicaid began in 1965 and originally it paid only for long-term care in nursing homes (Reinhard, Kassner, & Houser, 2011). Kathryn Allen, the director of Medicaid Health Care, testified before the Special Committee on Aging in the U.S. Senate, and had this to say:

Historically, Medicaid has financed long-term care primarily in nursing homes and other institutions. While Medicaid spending for home and community-based services is growing, these are largely optional benefits that states may or may not choose to offer, and states vary widely in the degree to which they cover them as part of their Medicaid programs. Consequently, the ability of Medicaid-eligible people with disabilities to access care in the home and community-based settings varies widely from state to state and even from community to community. (Allen, 2001, p. 2)

On average, 50 percent of all nursing home residents have some form of dementia, and nearly 50 percent of all nursing home residents rely on Medicaid to pay for nursing services (Alzheimer's Association, 2011). Medicaid provides both medical and long-term care for low-income persons, who must qualify by meeting income and asset limitations; applicants are also

subject to a review of their assets over the past 3 to 5 years, to ensure they did not spend down their assets illegitimately to make themselves “medically needy” (Centers for Medicare and Medicaid Services [CMS], 2010). The basic asset limit set for Medicaid qualification for long-term care is \$2,000 for a single person, and the income limit is set at 100 percent of the federal poverty level, but states now have flexibility to expand waiver programs to increase the pool of Medicaid beneficiaries (CMS, 2010). This is why Medicaid has been described as the “payer of last resort”: a person must become almost destitute before qualifying to receive long-term care.

In 2006, the 39 percent of Medicaid beneficiaries who were residing in institutional settings used 61 percent of total Medicaid spending (Ng et al., 2010). One policy expert summarized the relationship between Medicaid and long-term care this way: “There is a well known bias in Medicaid policy that steers people with long-term needs into an institutional setting while most beneficiaries would prefer living in their own homes or community while receiving services” (Watts, 2009, p. 1).

Despite its history of preferring institutionalization, the 2009 Medicaid expenditures begin to reflect a possible shift in policy, with 55 percent of long-term spending going toward institutional care and 45 percent paying for home- and community-based care (O’Shaughnessy, 2011). As recently as 2006, however, Medicaid payment numbers were still telling a lopsided story: on a per-person basis for that year, Medicaid paid out \$13,300 for community-based services and \$33,000 for institutional care (Ng et al., 2010). Another study estimated institutional costs as high as 5 times the cost of community care for those who paid out of pocket, and 3 times the cost for those using public funding (Kaye, LaPlante, & Harrington, 2010). The cost differential is generalized at roughly a 3-to-1 ratio; this means that Medicaid (and by extension,

the American people) can provide services for three beneficiaries in the community for the same amount of money it would cost to institutionalize one person.

The *Olmstead* Plan in Massachusetts

In response to the Supreme Court's *Olmstead v. L.C.* (1999) ruling, Massachusetts Governor Deval Patrick created an Olmstead Planning Committee to develop a compliance strategy beginning in 2008 (Massachusetts Olmstead Plan, 2008). The timing of the Massachusetts plan followed the *Hutchinson v. Patrick* (2008) lawsuit, in which the creation of a newer Olmstead plan had been negotiated in a settlement agreement (*Hutchinson v. Patrick*, 2008).

Included in the Massachusetts Olmstead plan was recognition of the fact that the elderly and disabled are hampered by a lack of available care options in the community (The Community First Olmstead Plan, 2007). It should be noted here that the intent of the Supreme Court's *Olmstead* decision was never to denigrate nursing home care or institutional care, but to ensure that the choice of remaining in the community was available for those who wished to do so, if reasonable care made that option possible.

In 2007, *Hutchinson v. Patrick* (2008) was filed in a Massachusetts District Court claiming the Commonwealth had violated the rights of people with acquired brain injuries under the ADA (*Hutchinson v. Patrick*, 2008). The case was settled rather quickly, and the impetus of the agreement was to ensure that community services would be more readily available to residents with acquired brain injuries in the community. The *Hutchinson v. Patrick* (2008) settlement did not positively impact those with other disabilities in Massachusetts, only the brain injured.

Currently, lawsuits and complaints filed against various states for access to services continue to claim violations of *Olmstead* (Allen, 2001). For example, three briefs have been filed by the Department of Justice in three separate cases—in Florida, Illinois, and New Jersey—citing the *Olmstead* decision in support of ending discrimination and integrating persons with disabilities within their communities (U.S. Department of Justice, 2010).

In *V. L. et al. v. Wagner* (2009), 130,000 elderly and disabled Medicaid-qualified Californians who received in-home services, which were later terminated or reduced, filed a suit. Although this lawsuit did not single out exclusively plaintiffs with dementia, Medicaid beneficiaries with dementia were not excluded or restricted from having standing to go forward, nor were beneficiaries with dementia excluded from relief in relationship to the injunction (*V. L. et al. v. Wagner*, 2009). Since Medicaid is a jointly funded program utilizing both federal and state money, state government and officials will be required to become more inclusive of informal caregivers in their implementation of long-term care policies. States are responsible for the implementation of the principles included in the ADA, which is confirmed in the *Olmstead* decision (Rosenbaum, 2001).

The 1999 *Olmstead* promise is agnostic; in other words, it needs to address all disabilities in an equitable plan of community care (McGuire, personal interview, Dec 6, 2010). A partnership between informal caregivers and publicly funded long-term care services could potentially help policymakers better actualize the promise of community care manifest in the *Olmstead* decision and better utilize publically funded long-term care expenditures.

Long-Term Care in Massachusetts

Currently, 63 percent of Medicaid dollars spent in Massachusetts goes to institutional care; funding is slowly beginning to shift toward the provision of more community care (Palmas & Allen, 2010). As demands for community care grow, Massachusetts and 48 other states are facing budget deficits that make expansion or addition of *any* programs a difficult sell.

The Massachusetts Budget and Policy Center (2010) reported \$21.7 million cut from the Home Care Program, which translates into 2,500 frail elders a month who will not receive care in the community in 2011; and the cut puts another 2,700 elders on the waiting list. The Family Caregiver Program has been discontinued, and money for adult daycare hours servicing adults with quite severe cognitive impairment has been cut by \$15.3 million (Mass. Budget and Policy Center, 2010). For a 24-hour-a-day family caregiver, keeping a care-recipient with AD safe in the community is not optional; but a state legislature faced with the challenge of budget cuts and deficits considers adult daycare hours optional, even if the daily cost of daycare is minimal compared to the daily cost of nursing care.

So how does a care-recipient remain in the community when money to pay for his or her home care is cut? One policy expert explained it quite clearly:

For people who need help toileting, not getting the help they needed meant they would often wet or soil themselves. For people who needed help to eat, it meant they could not eat when they were hungry. If we genuinely had them in our consciousness, I believe we would have a very different perspective on the urgency of improving our long-term care system. (Scanlon, 2003, p. 2)

If we focus specifically on informal family caregivers who are caring for someone with dementia, we would find that 234,497 unpaid family caregivers provided more than \$3 billion worth of free dementia care in Massachusetts in 2009 (Alzheimer's Association, 2011). Given

these numbers, it becomes clear that family caregivers play an important role in the provision of care in Massachusetts, as well as a critical role supporting their family member with dementia (Mace & Rabins, 1991, 2006; Mittelman et al., 2006).

Discussion

Due to the confluence of several factors—America’s aging demographic, the escalating prevalence of dementia, the lengthy time frame of the disease progression, and the absence of comprehensive long-term care policies in the United States—the nation’s current long-term health policies are inadequate to support the increasing numbers of elders who will require long-term care services. The Patient Protection and Affordable Care Act (2010) was a very large policy shift in the right direction. The Community Long-Term Assistance Services and Supports (CLASS) program, which had been part of this legislation, could have provided some relief to families with long-term care needs in the community, but it will not be enacted as part of the Affordable Care Act of 2010.

One recent development that points to the possibility for change is the National Alzheimer’s Project Act (2011). The creation of a National Alzheimer’s Plan could have a profound impact on the progress of policies related to long-term care services and supports in the United States. Working groups have begun to engage in discussions and are drafting a policy framework within which to evaluate long-term care services and supports in the community in relationship to dementia-related disease. Family caregiving support needs have been included in the policy discussions about long-term care supports in the community—but the plan has a long way to go. Caregiver support and respite services should be a vital part of any long-term care plan (Levine et al., 2010). Since family members provide the bedrock of care in the community

(Houser & Gibson, 2008), the care family caregivers provide is vital in keeping family members with cognitive disabilities safe and at home in the community. The *Olmstead* decision was to ensure a place of inclusion within our communities for those who need care. Providing the long-term respite care services and caregiver supports in the community for families who provide informal dementia care may delay costly institutionalizations and uphold the community care mandate expressed in the *Olmstead* decision (*Olmstead v. L.C.*, 1999).

The current fiscal situation is not going to improve anytime soon. Given the reality of our aging population, coupled with budget shortfalls and projected increases in long-term care costs of 200 percent over the next 40 years (Kaye et al., 2010), this nation is in need of some innovative policy solutions to handle our rapidly aging population.

Chapter 3: Methodology

Introduction

The contribution of my work is an exploratory study of the experiences of family caregivers, specifically, those who are caring for a family member with Alzheimer's disease (AD) or dementia. My study looks at these experiences through two lenses: (1) the mandates put forth in the U.S. Supreme Court's 1999 *Olmstead* decision and (2) current long-term care policies designed to support caregivers engaged in dementia care. My qualitative study is exploratory, which means my research perspective is open to new findings rather than constrained by predictive outcomes based on a structured hypothesis (Stebbins, 2001).

Exploratory Study

This research sets out to explore the experiences of family caregivers; the goal is to make new discoveries or make the familiar more knowable (Stebbins, 2001). The point of an exploratory approach is not to begin with an inordinate amount of prescription, but rather, to start out along the lines of a more general rationale and direction, even if it is discovered later that the initial assumptions were incorrect (Yin, 2003). My research is focused on the everyday phenomenon of informal family caregiving and the existing long-term care policies that support people who are caring for a family member with AD in the community. By examining the day-to-day experiences of family caregivers, I hope to offer new insights and alternative perspectives on family caregiving (Boss, Dahl, & Kaplan, 1996).

In addition to providing an intimate, nuanced portrait of family caregiving as a social phenomenon, my exploratory case study could potentially set the stage for future research by presenting new information or alternative perspectives that could better inform policymakers.

This exploratory study allows for an investigation of both the context and the culture of family caregiving, as it exists today in the United States. To examine the complexities inherent in these two aspects of informal family caregiving, this exploratory study will use an ethnographic case study approach (Trauth & O'Connor, 1991).

Use of Ethnography

Studying family caregiving in context means going into the home or nursing facility where caregiving is experienced (Boss et al., 1996). The use of ethnographic methods allows for a combination of various types of data collection and source materials, such as interviewing, diaries and logs, and newspaper articles or public records (Boss et al., 1996; Stebbins, 2001).

Berg (2007) summed up the key advantages of the ethnographic approach:

... the important point of the concept of ethnography, regardless of one's language and terminological preference, is that the practice places researchers in the midst of whatever it is they study. From this vantage, researchers can examine various phenomena as perceived by participants and represent these observations as accounts. (p. 172)

This is of course a feminist perspective, to explore the world with us in it. My study's ethnographic account of the day-to-day experiences of a few informal family caregivers gives more depth and content to what we currently know about informal family caregiving. Experience has shown that a small number of samples studied closely can reveal nuanced and detailed information (Boss et al., 1996). By looking closely at the lives and narratives of a few informal family caregivers, I hope to shed light on the larger context in which they operate and the relationship between caregivers and the larger community. Whether current government policies are effective in supporting family caregivers in the provision of AD or dementia-related disease care is another question I hope to address.

Case Study Approach

My use of case study is consistent with my need to draw out the complexity of the social phenomenon of informal family caregiving (Yin, 2003). In brief, using the case study method to organize my study subjects has allowed me as an investigator to record the holistic and meaningful characteristics of each caregiver's real-life situation through their voices (Kaufman, 1990).

Each case has unique circumstances, providing valuable insights (Stake, 1995). The specific challenges each of my study subjects faced as a family caregiver are exactly what I set about to uncover. My use of the case study approach as an exploratory tool allowed me to better understand the issues that family caregivers regularly encounter; this approach was also helpful in clarifying the reasons my study subjects do what they do. Family caregiving will be explored and organized in individual case studies, using an ethnographic approach to investigate the topics of informal family caregiving and long-term care policy (Yin, 2003). According to Guba (1990), case study is compatible with ethnography when the subjects studied are understood from a holistic approach.

Research Design

As a qualitative researcher my proximity or stance of engagement in the field was quite close to the participant caregivers because I engaged with them in their homes; however, I sought to maintain a safe distance that would allow for a free flow of information (Padgett, 1998). Placing myself in the middle of the informal family caregiving experience seemed like the best way to access the ideal observatory vantage point; being this close allowed me to see the kind of intimate details that will make compelling additions to our existing research and knowledge base

(Boss et al., 1996). The key is to acknowledge subjectivity as a part of the human landscape not to disown it. The caregiving experience is complex and usually private; my research design allowed for firsthand observation of phenomena that are typically experienced only by family or close friends in the privacy of the home or in a nursing facility. Such proximity to my subjects allowed me access to aspects of the caregiving experience that other research approaches would never have permitted me to observe or address. In formulating interview questions, I sought to give enough structure so that the exchange of information would be meaningful for both the study participant and the researcher (Denzin & Lincoln, 2008). This research design allows for direct observation of participants and informal or open-ended interviews with family members, health care professionals, and policymakers. It was, and is, my hope that this type of in-depth analysis will uncover new information and so add insight to the myriad dimensions of informal family caregiving, thereby better informing future long-term care policies.

For example, my study examines the importance of distinguishing between community and institutional placements of dementia care-recipients—i.e., whether they receive care at home or in a nursing home. The differences between at-home care and institutional care are profound. Where the family member with dementia receives care greatly affects both the care-recipient and the caregiver. Nonetheless, researchers studying caregiving have often looked at the phenomenon in general terms, failing to address the differences inherent in at-home and institutional care. By making this distinction in my study, I hope to add a more accurate picture of our understanding of the day-to-day experiences of family caregivers, which will increase what we know about how and why institutional placement occurs as well as better depict the needs of people providing care in the community.

By including care-recipients that reside in an institution, this study will investigate the effects of a nursing home placement on family caregiving. Also, my findings could provide valuable insights into what we already know about a caregiver's burden and why caregivers continue to provide care in the community when residential care is readily available. Looking at family caregiving as it relates to these various qualitative dimensions will bring a fresh perspective to this subject.

Given the complexity of the family caregiving experience, a qualitative and exploratory case study approach was the best way to make a sustained examination of the culture of informal caregiving (Boss et al., 1996; Geertz, 1973; Stebbins, 2001). This will be my key issue: the culture of informal family caregiving. Patricia Mannix McNamara's (2009) exploratory study identifying the support needs of lesbian, gay, bisexual, and transgender youth demonstrates the power of qualitative exploration. Through my exploration of the family caregiving experience, I hope to identify and better understand the support needs of the caregiving population.

My approach is guided by the work of Kathryn Edin (1993), who conducted a highly regarded case study of welfare mothers. My interest in her work is in the structure of her research, the organization of her narratives, and her writing style, not necessarily her subject matter. She used an ethnographic approach to explore the causalities and motivations of welfare mothers so she might better understand the choices and actions of her study participants. This exploratory approach should add clarity to our understanding of the motivations of family caregivers and to the deeply personal experiences of caregiving. This approach works well as a method for understanding complex phenomena, which may be better understood holistically and contextually, rather than through dissection into parts (Yin, 2003). Although Edin's writing style

is somewhat journalistic, her approach worked well toward increasing our understanding of poverty, marriage, and parenthood (Edin & Kefalas, 2005), and her work later became useful in the development of public policy.

I am hopeful that the deep experiences of family caregivers will continue to be explored and that these explorations will impact public policy. Edin and Kefalas (2005) discussed the disconnect between public policy and the realities those policies wish to address:

What is striking about the body of social science evidence is how little of it is based on the perspectives and life experiences of the women who are its subjects. Survey data can, of course, teach us a great deal, but surveys, though they have meticulously tabulated the trend, have led us to a dead end when it comes to fully understanding the forces behind it. (p. 5)

The culture and complexity of unmarried mothers and their views on marriage and motherhood required a qualitative design that captured and clarified this uniquely human subject. Focusing on the subject of family caregiving, I want to shed light on this deeply personal and intimately human subject. Edin's groundbreaking research gave social scientists a better understanding of the interrelated complexities of many of the issues affecting motherhood, such as poverty, marriage, and motherhood, utilizing the same framework I want to use to focus on the issues affecting family caregivers, such as isolation, sleep deprivation, and health (Edin & Kefalas, 2005). Edin's methods and elements of her design remain relevant and applicable to my study of informal family caregivers, although we diverge on subject matter.

Cohen and Court (2003) described the difference between ethnography and case study by saying that ethnography involves trying to understand a phenomenon by looking inside the culture, and case study involves looking outward at a phenomenon by conducting an in-depth investigation. My study, which combines these two types of qualitative methodology, provides

“thick descriptive” information about family caregiving, including firsthand observations, open-ended interviews, and diary writing; these methods of data collection allow a more intimate and holistic approach (Geertz, 1973, p. 5–6, 9–10). My combined perspective explores the nuance, richness, and depth of the family caregiving experience from both inside and out. Currently, more qualitative research on family caregivers is needed to enable a richer examination of the familial relationships, motivations, stresses, interventions, and burdens that may influence future long-term care policy considerations in this area.

Units of Study

Yin (2003) discusses the need to assess a unit of analysis, which refers to the need to define what a researcher intends to analyze. My unit of analysis is three-pronged and includes (1) each primary family caregiver working with a family member with dementia, (2) the care-recipient, and (3) secondary caregivers.

To further define my unit of analysis, I categorized caregivers according to the current placement of the person being cared for, as well as their relational characteristics. The use of caregiver narratives moves this work beyond categories to blended concepts used to examine caregiver experiences. My inquiries spanned the entire caregiving experience, from onset of symptoms to the present time.

Stake (1995) recommended the use of collective case study as a research design for understanding the complexities of experience, and suggested a researcher not attempt to overreach, but supply enough cases to show the complexities of the subject. Given these methodological considerations, I settled on three case studies from which to collect and analyze data.

Trauth and O'Connor (1991) clarified the idea that research should influence the methods used in a study. Because Alzheimer's progresses over the course of 1 to 20 years, the length of time required to follow a single case throughout the various stages of the disease would be prohibitively long. Therefore, I chose to limit the period of the study to 6 months, during which I would follow three caregivers as they provided care to a family member with dementia, each in the middle stage of the disease. My plan was to identify and conduct in-depth case studies with these three families, compiling ethnographic notes from interviews conducted with caregivers. I used open-ended interviews, knowing this method would provide a rich amount of qualitative data (Rosenblatt & Fischer, 1993).

Demographical Information

The caregivers and care-recipients in my study all were residents of Massachusetts from different towns across Cape Cod. The Cape Cod region, all of which is contained within Barnstable County, consists of 15 towns, each governed locally by town committees or selectmen (Barnstable County, 2010). The population of Cape Cod is considerably older than the rest of Massachusetts: 24.5 percent of the population is over the age of 65 as compared to 13.6 percent in that age group for the entire Commonwealth (Barnstable County, 2010). Also, the median household income for Barnstable County (2009) was \$57,379 as compared to \$65,304 for all of Massachusetts, and 13 percent of all households in Barnstable County (2009) reported being a primary caregiver for an aged or disabled person.

Older populations have a higher rate of AD or prevalence of dementia: within the 85 and up age group the prevalence of AD or dementia is nearly 48 percent, and this expanding segment of our population will nearly double by 2030 (AARP, 2009a; Alzheimer's Association, 2011).

The population of the lower Cape, including the towns of Orleans, Chatham, Wellfleet, Eastham, Truro, and Provincetown, already has a higher percentage of the oldest old (85+) than the state average (Barnstable County, 2009). In 2007, by using the current overall rate of AD prevalence, Alzheimer's Services of Cape Cod and the Islands estimated there were 8,117 people living in Barnstable County suffering from AD or dementia (Alzheimer's Association, 2009). Because it is an aging microcosm, Cape Cod may help us glimpse our future aging demographic in light of the long-term care supports available in the community.

Statewide, Massachusetts in 2009 had 234,497 unpaid dementia caregivers; their services were valued at more than \$3 billion (Alzheimer's Association, 2011). Massachusetts also had 103,502 nursing home residents, with 42 percent having moderate cognitive impairment and 24 percent showing mild impairment (Alzheimer's Association, 2011). These numbers demonstrate the importance of this exploratory study—the issue is a timely one and the corresponding policy implications could affect many people.

In 2006, Massachusetts allocated 78 percent of its Medicaid long-term care spending to nursing homes, while only 2 percent went to waivers and 21 percent to personal care services. In 2007, 76 percent of spending went to nursing home care (AARP, 2006, 2009a, 2009b). This suggests funding is slowly trickling into programs that support home- and community-based services. Massachusetts's Medicaid averages suggest that three people can be cared for in the community for what it costs to take care of one person in a nursing home (AARP, 2009a). These numbers confirm the potential usefulness of an exploration into the issue of informal family caregiving in the community.

Identification of Participants

I contacted the local Alzheimer's organization on Cape Cod and Councils on Aging (COA), and spoke with executive directors and/or outreach workers about my proposed study. Personal disclosure is inescapable in the qualitative exchange between researcher and study participant; given this reality I self-identified as a former family caregiver as well as a student researcher during my first exchange with gatekeepers and potential study participants (Padgett, 1998).

In the hope of attracting referrals, I provided Alzheimer's Services of Cape Cod and the Islands (ASCCI) with a copy of my research proposal. The regional Cape Cod newspaper, the *Cape Cod Times*, published a half-page story about my study, which included my contact information so family caregivers could reach me. The response was very exciting; 30 family caregivers contacted me after seeing the article. The number of participants included in my study was dictated by the number of participants who met the criterion for participation and could be available for 6 months on a biweekly basis (Padgett, 1998). Following the publication of the article, I was invited to talk about my study to caregiver support groups at a local COA and an assisted-living facility. I later facilitated a discussion and conducted an interview session for a group of caregivers with family members residing in the dementia unit of an assisted-living facility.

In all, 10 caregivers contacted me through social workers, COA directors, and Alzheimer's Services of Cape Cod; 30 as a result of the *Cape Cod Times* article; and 11 through my work at the assisted-living facility. I conducted 51 initial caregiver interviews by telephone in order to select three family caregivers to be the focus of my case studies.

Participant Criteria

The main criterion I used when selecting my study participants was the subject's ability to supply my study with distinct information about family caregiving so the sampling would actually have a purpose (Padgett, 1998). In this regard my sampling was purposeful; I chose participants with unique characteristics and distinctions I wanted to explore within the experiences of the context of family caregiving (Creswell, 2007).

My selection criteria further required that the person be the primary caregiver for his or her family member with dementia. If the family member lived in a residential placement, the caregiver still needed to be the primary caregiver. Also, the care-recipient had to have been diagnosed with AD or a dementia-related illness; this included Parkinson's disease and vascular dementia. Given the current difficulty of an accurate disease diagnosis, coupled with the fact that many people with AD have dementia, but have not been fully or accurately diagnosed, I identified subjects using the dementia criterion for my study.

A dementia diagnosis was confirmed by the primary caregiver and the caregiver had to answer affirmatively to a question concerning whether a medical doctor had prescribed medications to treat the subject's dementia. All care-recipients in my study had been treated for dementia with either Aricept or Namenda, which are the standard medical pharmaceutical interventions for AD or dementia-related disease.

The need for round-the-clock or "custodial care" signaled that all care-recipients would be somewhere near the midstage of their dementia progression (Faith, 2007). Estimating a care-recipient's stage of dementia is an imperfect science because every person with dementia progresses differently in relation to the duration and intensity of symptoms (Mace & Rabins,

2006). This informed the next criterion: all care-recipients had to require 24-hour care and each care-recipient must have resided in the community, either currently or for at least 3 years prior to residential placement. Another selection criterion was based on my desire to have my study represent a diversity of socioeconomic family situations. To explore the differences in available care options, I wanted at least one family with the resources to pay out of pocket for care, and at least one family that had declared their impoverishment to become Medicaid qualified.

Where the care-recipients were living was a very important selection criterion. I wanted at least one person in an institutional placement so I could increase my understanding of how and why a nursing home placement occurred. I wanted the opportunity to delve into the caregiver's experiences of transitioning a family member with dementia from the community into a nursing home. My desire to explore the transitional experiences between community and nursing home care greatly influenced my selection of study subjects. Because my study's time span was to be only 6 months, I was not sure that if I were to select three families in the community that any of the caregiving dyads would be transitioning to a nursing home during that short an amount of time. Therefore, as my study subjects I selected two caregivers whose care-recipients (one with AD and one with Parkinson's dementia) were living at home and one caregiver whose family member with AD was already in a nursing home.

Another important factor in the selection process of the family caregiving dyads for my study was the presence of additional community supports, so the primary caregivers had the time to meet with me without their care-recipient. Because care-recipients needed 24-hour care, a secondary caregiver was a critical support to provide availability for interviews. In my initial interviews, it became quite apparent that many family caregivers do not have access to this kind

of backup support; in fact, this lack of secondary supports created an obstacle to interviewing primary caregivers. Given the burdens and high stress of caregiving for someone with AD in the community, it was essential that study participants had some type of support network so they could be interviewed bimonthly. Privacy was essential; I wanted the family caregiver to be able to talk freely about their burdens and experiences.

Another selection criterion was the familial relationship of the caregiving dyad. I wanted at least one child/parent dyad, and one spousal unit. According to a study by the National Alliance for Caregiving (NAC) and AARP (2009), 66 percent of caregivers are women, and female caregivers tend to do more of the actual hands-on work, spend more time caregiving, hire less outside help, and give up employment opportunities, in comparison to male caregivers. Given these gender differences, I wanted to include at least one female and one male caregiver to contrast similarities and differences of their experiences.

One final consideration I needed to address when selecting study participants involved access and availability: I would have to be able to have access to observe the caregiver and the person with dementia in placement, and the caregiver had to be willing to provide information about the caregiving experience.

After identifying my selection criteria, I made a checklist to help determine which of the 51 caregivers I had interviewed would meet all the criteria. Some characteristics automatically eliminated people from my selection pool: if a care-recipient had been newly diagnosed or was relatively early in the progression of dementia or AD, he or she would not qualify for my study. It became clear during most of my initial phone interviews with caregivers which subjects would

not meet my study criteria. (Table 1 lists the selection criteria for the three families I chose to be case studies.)

After analyzing my initial interview information, I was left with only a handful of caregivers who met all the selection criteria. Every caregiver I spoke with mentioned the difficulties associated with caregiving in the community. The high stress associated with caregiving was obvious by the tone of the conversations: many times caregivers became very emotional, and some cried as they shared their stories with me.

Ultimately, the most important distinction to be made when I was selecting study participants was the setting in which the person with Alzheimer's disease was living and receiving care. These differences made each case purposeful in the discovery process (Creswell, 2007; Padgett, 1998). The differences between having a family member in a nursing home and providing care in the community are profound. Comparing community versus institutional placement provided essential information with which to evaluate how current policies address the needs of family caregivers. Because one care-recipient in my study was already in a nursing home, I was able to explore the placement decision within the framework of my ethnographic case study. My observations gave insight into this difficult choice, and vividly illustrated the process—from symptom identification all the way to institutionalization—as one family experienced it.

Finally, after participant selection was completed, the study subjects were informed that if they decided on a nursing home placement during the course of the study, their continued participation for the study's 6-month time span would still be expected.

In the end, as mentioned earlier, I selected three families to be the focus of my study. The first two case subjects were family caregivers living in the community; one care-recipient had AD and one had Parkinson’s dementia. The third case subject was a primary caregiver whose loved one with AD was living in a residential facility. My three chosen study participants also had secondary caregivers, which meant they had enough support to meet with me for interviews without having to provide care for their care-recipient at the same time.

Table 1: Participant Selection Criteria Checklist

<u>Case #</u>	<u>Dementia</u>	<u>24h Care</u>	<u>Medicaid</u>	<u>Primary Caregiver</u>	<u>Second Caregiver</u>	<u>Place</u>	<u>Sex C/CR</u>
1	Yes	Yes	Yes	Yes: Partner	Yes: Friends	Community	F/F
2	Yes	Yes	No	Yes: Husband	Yes: Daughter	Residential Placement	M/F
3	Yes	Yes	Yes	Yes: Daughter	Yes: Son-in-law	Community	F/F

C/CR, caregiver/care-recipient.

Informed Consent

Informed consent aids the researcher in establishing a good relationship with study participants (Padgett, 1998). Northeastern University’s human subjects research division has a protocol that I used to create an informed consent form for my study participants. During the process of obtaining consent, I was able to explain the purpose of my study and answer any question participants may have had; study subjects were assured that confidentiality would be

maintained and privacy would be protected. Participants were informed that neither their names nor any defining characteristics of their identities would be revealed.

Direct Observation and Field Notes

Direct observation helps the researcher form interpretations of what is being observed; these interpretations take into account the various ways we make meaning (Geertz, 1973). This direct observation was an important part of my fieldwork (Creswell, 2007). This type of exploratory research allows researchers to engage and connect with their subjects; the researcher is no longer viewed as entirely separate from what is being studied (Stebbins, 2001). Field notes are an integral part of observation (Padgett, 1998). The gathering of field notes during direct observation gives the researcher the opportunity to listen to the “whole” of the experience, including voice inflections, mannerisms, and behavior that inform the researcher beyond the spoken word (Boss et al., 1996). This perspective allows for an integration of the holistic and discrete elements of experience; these elements taken together constitute context. My biweekly interviews in the homes of primary caregivers provided the ideal vantage point from which I could directly observe caregiver interactions and relational dynamics, all taking place within the context of the home. If the care-recipient was in a nursing home, I arranged for a visit to the nursing home.

Regarding the observatory approach, Becker and Geer (1969) stated:

... by participant observation we mean that method in which the observer participates in the daily life of the people under study, either openly in the role of researcher or covertly in some disguised role, observing things that happen, listening to what is said and questioning people over some length of time. (p. 322)

In addition to the standard qualitative methods I used, my study was also informed by my work with Alzheimer’s Services of Cape Cod and the Islands. During the course of the study, I

accepted a position with the organization as the director of family services; my duties include providing telephone and in-person consultation to family caregivers and their family members who are in need of support. In this role I have documented nearly 2,000 contacts with clients, mostly primary family caregivers, and I have provided support to nearly 500 families dealing with AD or a dementia-related illness on Cape Cod. Although my work with this organization does not constitute a formal part of my research or dissertation, I must disclose that my experiences with Alzheimer's Services of Cape Cod do inform my perspectives on the subject that I am studying. My professional position has granted me close proximity to the subject of family caregiving and what it means to be providing care to a family member with AD or a dementia-related disease. I must also disclose that I have personal experiences as a family caregiver and those experiences combined with my daily engagement with the issues and concerns of family caregivers have had a powerful effect on how I view the subject (Padgett, 1998).

Interviews

Interviewing can be structured in a systematic process (Creswell, 2007). Part of my preparation for conducting each interview was to create an interview guide. Rosenblatt and Fischer (1993) note that observation and in-depth interviews work well as research tools for understanding families. My plan was to use the interview process to probe deeper into the experiences of each family caregiver, and to examine both the particulars and the similarities of each case. According to Padgett (1998), the interview must have enough structure to maintain a fidelity to the researcher's interview goals; my interview research was structured in the following way:

My research began with the brief telephone interview of open-ended questions that I conducted to evaluate the criteria of prospective study participants. These surveys were conducted with the original 51 caregivers who were interested in becoming study participants. The initial interview process took from 30 minutes to an hour. My initial interview questions were:

1. Please tell me about the person you are caring for: has there been a diagnosis? Is he/she on any dementia medications? If so, what are they? Does your care-recipient require 24-hour care?
2. How long have you been a caregiver? What is your relationship to the care-recipient? Are there any other caregivers?
3. Does your care-recipient reside in the community or in a nursing home?
4. What types of long-term care services or supports do you have in place?
5. What do you want to tell me about your experiences as a caregiver?

These initial interview questions helped me to evaluate potential study participants in the context of my selection criteria. The realities of the high stress of caregiving for someone with AD were very apparent in these initial interviews, and I offered callers a referral to the manager of client services of the local Alzheimer's support organization. This connection to support services has been offered by other researchers doing similar studies in the field (Boss et al., 1996).

Once I had selected my three case study subjects, I developed an interview guide for subsequent interviews (Edin & Kefalas, 2005). Participants were informed from our first meeting that they could answer questions freely, and, although a majority of interviews were taped in

order to eliminate the need to take notes, I offered to turn off the recorder if the participant so desired. Like Edin in her study of welfare mothers, I used open-ended questions to allow for a fluidity of dialogue on the part of the caregiver participant.

I began with broader topics, which became more refined and specific as the interviews continued (Padgett, 1998), and I visited study participants at home to conduct in-person biweekly interviews for 6 consecutive months. The purpose of my interviews was to gather more detailed information than what could be gleaned from existing studies, most of which have not delved deeply into the experiences of caregivers' lives. Each generalized question directed my interviews toward specific questions in pursuit of a more in-depth case analysis, helping me to evaluate caregivers' experiences in light of current state and federal long-term care policies. The following are some general questions I used:

1. What was your relationship with your care-recipient before you became his or her primary caregiver? What is your relationship now? (The goal of this question was to capture how the nature of the relationship changed over time.)
2. Can you tell me the most difficult part of your day as a primary caregiver? What are your needs at these times?
3. Can you tell me the best part of your day as a primary caregiver?

Focusing on my research questions and the concept of financial, social, emotional, and physical family caregiver burdens, I formulated the following inquiries:

1. Do you have any children or siblings; if so, what is their gender? What types of assistance/support do they provide in caring for your care-recipient? Are there differences

in the roles that males and females perform in helping with care? How are the caregiving responsibilities apportioned in your family?

2. Do other members of your family/friends support you in your role as a family caregiver? If so, what type of support do they provide? If not, what types of support do you need?

3. Are you employed? If so, how has your work life changed since you became a caregiver? Do members of your family who are not living with your care-recipient provide financial support, if not actual care?

4. If you could have services available to support you, what would you want?

5. If your care-recipient resides in the home, would you consider institutionalizing him or her? Under what circumstances would you utilize a residential placement? Would this change if services could be provided in the home?

6. As you look into the future, what are your concerns about your ability to maintain your care-recipient in your home?

7. How important are financial considerations in the provision of care? If the cost of care were not a factor, what placement would you choose for your family member with Alzheimer's disease?

I created a series of guides for my interviews (Padgett, 1998). Biweekly interviews allowed for a continuity of contact. Given my own personal experiences of family caregiving, it seemed like the appropriate length of time necessary to catch any changes in the caregiving context. Each biweekly interview was conducted in the home, where I had the chance to observe the caregiver and care-recipient as they interacted, as well as the interactions of formal and

informal caregivers. I also observed the care-recipient who resided in nursing home care with one family caregiver as well as interactions of friends, family members, and more formalized caregivers.

Interview questions were always open-ended and designed to probe into the individual experiences of each caregiver. Themes extracted from the current literature contributed to questions about caregiving burden (Creswell, 2007). Issues arising from the social, financial, emotional, or physical burdens were explored, as was the concept of subjective and objective burden within the context of current long-term care supports either present or missing from caregivers' lives.

Many of my interview questions were intended to get to the specific needs of caregivers. These needs were then evaluated in light of the current policies that aid caregivers in the provision of care for their family members. As a trained counselor, I had professional experience in guiding interviews to extract pertinent information. My interviews were conducted in the homes of the family caregivers and, in the case of the one caregiver in my study whose care-recipient was in nursing care, occasionally in the nursing facility.

Journal Writing

Journal entries are one qualitative method of obtaining important ethnographic data (Padgett, 1998). Having study subjects keep a journal is another way of compiling a "thick" record of description (Carspecken, 1996). The methodology employed by Edin and Kefalas (2005) instructed participants to write in a journal. As part of my study, I asked participants to make weekly journal entries about their caregiving experiences, and I collected the journals periodically during the 6-month interview process. On occasion, subjects would be given a

certain topic to keep track of for a specific period of time. For example, I asked participants to record the amount of sleep they got each night for 2 weeks. For 2 weeks I had caregivers put in writing what they were doing every hour of the day using a simple time management sheet as their diary writing exercise. Then the following month, I had each caregiver keep track of his or her costs of caregiving. Another diary-writing exercise concerned caregivers' isolation and/or support they received from family and friends.

The information I gathered from my study subjects' caregiving journals will be included in the case studies presented in Chapter 4.

Cumulative Data

For 6 months I involved myself in the lives of three family caregivers, interviewing each in their homes. I interacted with their care-recipients. I met their families, cataloged the formalized care they received or had received in the community, and wrote or tape-recorded their individual stories about their caregiving experiences. After every interview, I read over interview notes and planned my next round of questions. I created a guide for my next interview (Padgett, 2008). I kept a running log of formalized care services received by each family caregiver and asked about any changes in long-term care that may have occurred. Journal entries were collected every few months. Participant caregivers were given my cell phone number and encouraged to call me if any important changes happened or situations arose that they wanted to tell me about or if they had some information or insight they wanted to share. My prolonged engagement with study participants helped foster a channel of trust (Creswell, 2007).

The ongoing nature of my contact with the participants was vitally important to my work; family caregiving is a 24-hour-a-day job and the experiences of both caregivers and care-

recipients change over time. While wanting to respect my study subjects' privacy, I needed to establish trusting relationships with them; it was on the foundation of these relationships that I was able to build a place from which to intimately observe their lives. From this vantage point I was able to gain a more detailed and nuanced view than if I had used a series of summary interviews, which would not have captured the immediacy, fluidity, and complex nature of caregiving over time.

Each interview and diary entry provided a potentially new set of data. By the end of the 6-month period, I had gathered the following data for each of my study participants:

30 diary entries \times 6 months = 180 entries

2 interviews per month \times 6 months = 12 interviews

This equals 192 data entries per family caregiving unit. Thus, with three families in the study, I had collected by the end of the study a total of 576 entries of data.

Data Analysis Strategies

My analysis looked at themes within each family caregiving case as well as themes that carried across all three cases (Creswell, 2007). After comparing and contrasting my three cases, I extracted the pertinent and nuanced information that was unique to each case. The primary purpose of my research is to expand our knowledge by conducting an in-depth analysis of the family caregiver narratives I obtained from the field. These case studies should provide detailed and in-depth content that will contribute to our understanding of the phenomenon we call family caregiving. Berg (2007) describes the contribution of this type of content analysis perfectly:

Researchers employing the social anthropological approach usually are interested in the behavioral regularities of everyday life, language and language use, rituals and ceremonies, and relationships. The analytic task, then, is to identify and explain the ways

people use or operate in a particular setting; how they come to understand things; account for, take action, and generally manage their day-to-day life. (p. 305)

After formulating an overall narrative for each of my three cases, I evaluated the caregivers' narratives based on themes. Themes were coded and then analyzed for similarities and differences among cases (Carspecken, 1996). In cases where I identified a shortage of formalized care, or if secondary caregivers were absent or missing, I explored the rationale for, or effects of, the absence of that care. By contrasting the information gathered from the three different families, I was able to discern two things: (1) the variability of the caregiving experience and (2) how many common concerns and needs dementia caregivers share. Family caregiving is difficult in a myriad of ways. It is a complex phenomenon with variations and demands requiring very intensive care and, at the same time, a flexibility and compassion to meet those demands. Family caregiving observed from a more pragmatic and practical vantage point makes no rational sense. Nonetheless, family caregiving, when observed through the personal relationship, is a rich, interesting tapestry, as diverse and emotionally laden as any intimacy. My contribution will be my insights and analysis of those complex sets of experiences that make up family caregiving.

Narrative analysis is best described this way: "The study of narrative is the study of the ways humans experience the world" (Connelly & Clandinin, 1990, p. 2). Analyzing caregiver narratives for content gives way to new and exciting insights into the experiences of family caregivers; this nuanced portrayal is of vital importance to policymakers who are formulating the long-term care services and support for community caregivers.

Triangulation

Triangulation is the simultaneous interplay of many different perspectives gathered together in the exploration of phenomena (Denzin & Lincoln, 2008). Trauth and O'Connor (1991) discuss triangulation as the comparison of data collected from different sources, which provides an alternative strategy to establishing reliability and validity. My study makes use of triangulation in this way; I used this method to analyze the validity of the information I collected from my research (Denzin & Lincoln, 2008).

Within the context of qualitative research, triangulation is the process of comparing information—that gathered from interviews, participant journal entries, and observations of the researcher (Padgett, 1998). I used these three qualitative data gathering methods in my research. Triangulation aided me in establishing the concept of reliability and validity by allowing for comparisons among my case study findings, field notes, and the existing literature.

Discussion

My study provides a narrative portrayal of the experiences of three family caregivers as they care for a person with dementia or AD, and the current long-term care policies that support them in the provision of care. In my research, case study was used as a qualitative method of inquiry into the subject of family caregiving (Padgett, 1998). The narratives of informal family caregivers provide valuable insight into the experiences of caregiving and complement the current research by giving us sustained observations, providing a deeper understanding of the experiences of family caregiving. Themes were coded and then analyzed based on insight and content then contrasted and compared among cases (Carspecken, 1996; Padgett, 1998). My use

of “thick description” paints a vivid portrayal of the current experiences of family caregivers as they provide care for a family member with dementia (Creswell, 2007).

Chapter 4: Case Studies

Introduction

Real-life narratives help us to clarify the complexities and structures of social issues because they are as complex as the people who create them. Qualitative research brings us closer to the actual firsthand knowledge of our subject. As Alfred Korzybski so eloquently stated: “A map is not the territory it represents, but if correct it has a similar structure to the territory, which accounts for its usefulness” (1933, p. 798).

The representational knowledge gathered via quantitative methods allows for the investigation of a much larger sample size than the more direct, firsthand knowledge obtained from qualitative methods. Exploring study subjects’ experiences personally through direct observation of behavior in its natural context can provide a level of detail that is not accessible when using quantitative tools (Stebbins, 2001). The value of qualitative research lies in the fact that information shared by study subjects, in my case the family caregivers, originates from firsthand knowledge of actual experiences. Taking each interview, journal entry, or observation into account produces a richness and depth of experience that is “thick description” . . . this is the genius of qualitative work (Geertz, 1973, p. 5–6, 9–10). Edin and Kefalas (2005) talked about the important role qualitative methods played in their study of impoverished women:

What is striking about the body of social science evidence is how little of it is based on the perspectives and life experiences of the women who are its subjects. Social science currently tells us much more about what *doesn't* explain the trend than what *does*, and it tells us next to nothing about what will make marriage more likely among single mothers. (p. 5)

The same holds true in relation to our lack of clarity concerning the policy needs of informal family caregivers. This large workforce of unpaid care providers exists within our

communities—in our neighborhoods and in our families—but these people are virtually invisible when it comes to public policy initiatives. The lack of societal supports exacts a profound personal cost; much evidence of this cost is evident in the narratives of the family caregivers in my study.

Anonymity

The first names of study participants have been changed to provide anonymity to participants. My intention was that anonymity would allow for a freer dialogue during interviews about services and programs in the community. I did not want family caregivers to worry or risk retribution if they shared a negative experience or an unfavorable opinion about a program or agency. Given the established fact that caregiving can be stressful, I did not want this study to add to the caregivers' stress level in any way; I was convinced that by keeping the identities of my subjects confidential, they would feel more comfortable and be able to fully and honestly participate in the study without worry.

As discussed previously, all caregiver participants agreed to a research schedule of biweekly interviews/observation and journal writing for 6 months. All caregiver participants were willing to share their stories and experiences and all had the capacity for both verbal and written expression. The informal family caregiving units are organized into three discrete case studies. Fictitious first names are added to allow for better description and readability, and the names of towns along with any other identifying characteristics have been omitted from all cases to protect the identities of my subjects. In the next section each case will be briefly introduced; later sections will identify and examine important caregiver information found in the case narratives.

Case One: Margie and Terri

Margie, age 63, is the primary family caregiver for her female partner, Terri, who is 80 years old. In 1989, Terri became partially blind; 10 years later, she was diagnosed with Parkinson's disease. At some point during the progression of her Parkinson's, Terri started exhibiting early signs of dementia. Many people with dementia have multiple health problems, and Terri is no exception: along with blindness, dementia, and Parkinson's, she also has diabetes.

Terri and Margie have been in a committed relationship for 31 years, they have lived together in a beautiful old Victorian-style house, which Margie is altering to accommodate Terri's progressing disabilities.

On my first visit to their home, I notice a metal handicapped-access ramp leading up to the front porch. As I approach on the ramp, I feel it give in the middle; unsupported, the metal bounces under my feet as it bows. To steady myself I grab a jerry-rigged handrail and make my way to the front door. I cannot imagine anyone going down that ramp in a wheelchair, but it looks like the only wheelchair-accessible entrance.

As Margie opens the front door, my initial impression of her is that everything about her—her eyes, her smile, even her hands—look tired. Terri is sitting in front of a large television screen in the living room when I walk inside and Margie leads me to a small adjacent room that is her home office. Almost immediately, I notice Margie flinching every time she hears a loud noise coming from the other room. So I ask, what is going on? Quickly she responds by telling me that Terri is starting to forget she cannot walk. The first time this happened, Margie was in the kitchen, making dinner. She remembers hearing a loud crash and then a louder scream; she could not see Terri sitting in her chair so she ran into the living room to find Terri face down on

the ground, soot covering her face. “I never know when Terri will forget she can’t walk,” Margie explains; Terri is at risk for falling every time Margie or her caregiver leaves the room.

Like many families dealing with dementia-related disease, the bulk of the care falls on the spouse or partner who is the primary caregiver. Although Margie has good social support and numerous friendships, she has no secondary family caregivers to assist her. Terri has two children from a previous relationship, but Terri’s son and daughter live hours away from Cape Cod and they offer Margie and Terri very little care support.

Much of the caregiving assistance Margie receives comes from the Massachusetts Medicaid program MassHealth. Terri qualifies for MassHealth because she has less than \$2,000 in assets and receives only a very small income from Social Security. Margie and Terri have never married, although Margie has provided chronic care support to Terri for more than 12 years. Terri now requires 24-hour care due to the progression of her dementia. As Terri’s needs increase, Margie worries about having enough money to pay for the extra care she will need.

In addition, like many spousal caregivers, Margie has poor or declining health herself. During the course of this 6-month study, Margie reverts from cancer survivor back to cancer patient while Terri’s progressing nighttime confusion exerts more strain on Margie’s poor physical health. Finally, Margie’s doctor advises her to consider a nursing home placement for Terri. And, suddenly, after two decades of accommodating Terri’s disabilities, Margie is asked to choose one responsibility over the other, and make a choice between her own health and her partner’s. This is not a choice Margie wants to make, so she continues caregiving at the same frantic pace, in spite of her declining health.

Case Two: Greg, Jill, and Susan

Greg describes his wife, Jill, to me as “the love of my life for 62 years.” Greg, a retired World War II veteran, is 86 years old and Jill is 85. Jill was diagnosed with AD dementia at the age of 72. Greg is Jill’s primary caregiver and their adult daughter, Susan, who is 59, is the secondary caregiver. Susan, who works full time as a teacher at a local preschool, also provides a great deal of care and support to her father. Greg and Jill also have a married son who has not been around much since his mother’s AD diagnosis.

As Jill’s dementia progresses, Greg assumes more and more caregiving responsibilities in order to keep Jill safe. Many of these changes happen subtly; Greg gradually takes over household chores like cooking and Susan assumes smaller tasks like writing out the Christmas cards when her mother no longer can write. Other changes are more difficult to adjust to, such as the winter in Florida when Greg realizes it will be the last trip they will take because Jill cannot tolerate the unfamiliar environment.

Jill experiences a great deal of anxiety, which often accompanies the progressing stages of dementia. Much of Greg’s time is spent calming Jill down. “What [my father] was doing to survive was to take her out for rides in the car,” Susan tells me, “so they rode all over the lower Cape just going in and out of streets and talking and having the music going, probably from the forties, fifties.”

In the nine and a half years Greg cared for Jill at home as her health declined, he never had a full day off from his caregiving duties—never had a chance to go away on a fishing trip or to visit his son and grandson without juggling the care of his wife at the same time. Then the moment came when Greg could no longer continue providing care, and Jill was placed in a

dementia unit. Without long-term care insurance, Greg must pay out of pocket for his wife's long-term care. To date, Greg has spent almost \$400,000 for nearly 4 years of nursing care.

Greg lives in a small, very modest ranch house in what appears to be more of a year-round neighborhood than the more touristy section of town. His front yard looks like all the front yards on his street, but his backyard is very different. Greg is a gardener; I know because he tells me so, and then out the back window I notice the flowerbeds waiting to be tilled and the starter pots on the porch he soon will seed.

We walk into a small living space where Susan is seated. Greg offers me the chair next to his; I sense it was his wife's. I do not know for sure, but what I do know is that her absence still feels palpable; Jill has been in nursing care for almost three years. However, as Greg and Susan start talking about the nine and a half years that they cared for Jill, I sense their dedication to each other, and to Jill. Here is a family unit that did all they could do.

Thirteen years after Jill's diagnosis her health is still quite good; in fact, since her placement in the dementia unit her overall health has improved. Jill can still ambulate and communicate, although her memory loss is severe.

Case Three: Wilma, Kate, and Doug

Wilma is the primary caregiver for her mother, Kate, who is 97 years old. Wilma is 59 years old and married to Doug, age 68. Doug and Wilma live with Kate in her house on a quaint street in a small Cape Cod town. Kate previously lived alone; she struggled with her dementia for 8 years before Wilma moved to Cape Cod in February 2006 to care for her mother full time. Wilma's sister, who lives out of state, has a health condition of her own, which precludes her

from helping. Wilma also has an adult daughter who is married with a family of her own, which makes her unavailable to help.

Doug is stout and ruddy-faced. He is sanding his boat and smiling at me when I pull into his driveway to conduct my first interview. It is early March. Their house is modest yet beautiful in the way old houses on Cape Cod reflect the natural beauty surrounding them; my attention is drawn not to the faded shingles or unpainted trim but rather to Doug and his boat and the many bird feeders positioned around the yard. Doug, a lobsterman and fisherman by trade, has volunteered to be Kate's secondary caregiver.

Wilma yells from inside the house for me to come in; I can hear her through the open door. As I enter, she immediately offers to give me a quick tour of their home. They have converted the living room into a bedroom, which is cordoned off by two curtains hanging from the ceiling for privacy. Wilma's mother usually sits in a smaller adjoining room that they use as a sitting room, complete with her recliner, a television, and a bird feeder attached to a small window next to Kate's chair, so she may feed, watch, and hear the birds.

Wilma, Doug, and Kate's house is well lived in, especially the kitchen, which is cluttered with papers, medications, and the day-to-day paraphernalia of family life. Wilma invites me to sit down at a square table near a large window looking out into the backyard; there are three chairs at the table. Doug comes in and joins us at the kitchen table. I imagine the empty seat I occupy is Kate's, who at the time of the interview is at the local adult daycare center. In 2007, Kate qualified for a MassHealth program that pays Wilma a \$49-per-day stipend to provide care. This stipend is Wilma's only income. Before moving in with her mother, Wilma worked full

time as a licensed practical nurse (LPN); now that she is caring for her mother, she works more than twice the hours and is paid less than half what she earned as a nurse.

Kate is moving into end-stage dementia when my study begins in March 2010; by September 2010, she is non-ambulatory and is no longer able to chew solid food due to the progression of her disease. She has forgotten she cannot walk and periodically tries to get up from her wheelchair, which means she occasionally falls. Kate no longer sleeps through the night, which means that Wilma cannot sleep either. Kate qualifies for hospice care, a Medicaid benefit, which means Kate is in the end stage of the disease process and will now receive a minimal amount of in-home medical support. Wilma considers a nursing home a “last resort” for her mother. As Kate’s disease progresses, Wilma has to lift her mother in and out of bed, in and out of chairs, and on and off anything she sits down on. Wilma does this day and night until finally all the lifting takes its toll and she is hospitalized with the resulting physical injury. When Wilma is taken to the hospital, Kate is moved into a nursing home.

Analysis of Caregiving Narratives

Introduction

As I compiled and analyzed my caregivers’ narratives for thematic content, various themes emerged from my initial interviews, my ongoing case study interviews, the caregivers’ journal entries, other collected materials, and my field notes.

My caregiver interviews used a simple guide, were open-ended, and allowed for a certain amount of participant guidance concerning the direction of the interview (Padgett, 1998). These characteristics are consistent with exploratory research; guidance is necessary so that interviews do not become unwieldy but permit for a fluidity of dialogue that encourages each participant to

share his or her firsthand caregiving experiences beyond the scope of the researcher's guide. An exploratory study must be willing to take risks to make new discoveries (Stebbins, 2001). My study consistently used probing questions to explore the experiences of family caregivers and I wanted the caregiver to express freely his/her thoughts and feelings evoked by their personal caregiving experiences.

When formulating interview questions, I kept the concept of triangulation in mind. I asked the primary and secondary caregivers within each case study many identical questions so their answers could be cross-evaluated. Comparing participant information gleaned from journal entries, interviews, and field notes allowed for the triangulation of information among cases; as mentioned earlier, this process is a useful tool for establishing the trustworthiness of qualitative data (Creswell, 2007; Padgett, 1998).

Narratives were organized then examined for insights into the culture of family caregiving; these findings were then organized and examined for emerging patterns and themes. If possible, the reliability and validity of the various caregiver narratives were cross-referenced within and between cases. Themes were then established as well as contrasted and compared for important information (Padgett, 1998). The following sections of this chapter discuss the findings of my narratives.

Contrasts and Comparisons Among Cases

Dementia Diagnosis

A common problem that family caregivers face is the difficulty of obtaining a dementia diagnosis. This problem was an issue that emerged in all three of my case studies. The sense of

irritation in Susan's voice was still present although it had been 10 years since the day Jill received her diagnosis. This is how Susan explained it:

The first time we noticed it we didn't know it was AD, we just thought she was being forgetful. Mother was actually noticing it; she said, "Why do I always forget things?" And we said, "Well, you know, Mom, we all forget things, we just pooh-poohed it." And then you pooh-pooh it for a couple of years, and then it's not just a pooh-pooh anymore! I'm not sure what was going on, so we actually made an appointment for her [Jill] to see a doctor in Hyannis, and I was the one to go with her. Dad wasn't working at that point, so I don't know whether or not he didn't want to know the answer—but I went with her to the doctor's office. I remember very clearly sitting in his office and I felt the doctor was more eager to talk to me than my mother—"oh, you like sports?"—that kind of thing. We were having a conversation and my mother was being ignored, and finally when it got down to the test, he said, 'I want you to remember three things: window, door, and the color purple,' or something like that. And she couldn't remember any of them. And he said, 'Thank you for coming and yes I do think you have the beginning of AD.' And that was it. That was the whole thing.

Wilma talked about her utter frustration with her mother's doctor in obtaining a diagnosis for her mother Kate when she had become very nauseous, with a splitting headache. The emergency squad was called to her house three consecutive times before Kate was admitted to the hospital. Wilma's eyebrows raised in disbelief: "three times," she repeated to me as if she still could not believe the series of events her mother had to experience before getting the medical help she needed. This is how she described it:

My cousin calls and says, 'your mother says she has a splitting headache, can't get out of bed, she's nauseous. And I said, 'did you call 911?' And she said, 'No, I called you first!' And I hung up and called rescue and I had her taken to the hospital because it sounded like a stroke to me, and they released her—and they said 'Oh, she's fine, she's fine,' and I could hardly get her in the car, I could hardly get her out of the car, in the house, this was over Christmas—this was 2005—and right at the end of the year, and I'm still working, my sister's retired, and so I called her, and I said, 'Listen, you're gonna have to come down here and stay with her, because she can't do anything right now.'

Wilma's mother was released from the hospital without a diagnosis. Her sister drove down to the Cape to take Kate back to New Hampshire so Wilma could have a break. Then this happens:

That first night, Mother got up, got out of bed, and fell down, split her head open. So my sister had to call rescue and take her to the hospital, and they couldn't find anything wrong with her. And I said, 'how can that be?' So they sent her home with my sister, and my sister had the same problem—couldn't get her up, couldn't get her back upstairs—so she had her lying down on the couch, and she got her up again, and she fell down again. And this was all in a matter of about six hours. And she called rescue again, and they came and took her, and they admitted her, and they said she had a stroke. And they did an MRI, and it showed that there was evidence of a previous recent stroke—of course—so that's when the decisions started to come together there. They were really good up in New Hampshire, because she didn't have any backup insurance then, she just had Medicare, and she still had too much in the bank for MassHealth, and they said check with AARP and there were a couple of others, and they said get supplemental so it picks up some of our costs, thank God. So we filled out all that paperwork up in New Hampshire, and they transferred her down to Eagle Pond, and I have to drive her—I thought the ambulance would drive her!—but no, they put her in the car for me, and it was a five-hour drive. I stopped down in Norwell because I knew I could get her close to where the bathrooms are, and she wouldn't get out of the car, so I drove her all the way down to Dennis [on Cape Cod], and I had her admitted there. And I had her there the [allotted] Medicare days, and February 11, 2006, is when I came down and took over full time.

It was the MRI that Kate was given during her third hospital stay that identified her as having a previous history of vascular disease; this was a shock to Wilma, who had no idea about her mother's declining health. It took a critical health crisis before a dementia diagnosis was obtained. After Kate was stabilized she went into a nursing home to recover, until the restriction of her Medicare benefit expired; after Kate had used up her allotted 20 days she was discharged to her home in Wilma's care, without any long-term care plan in place. Medicare's only in-home benefit is short-term, with a maximum certification period of 60 days for in-home transitional care. One unintended consequence of the rehabilitation benefit for Medicare beneficiaries with

dementia is the potential for more frequent utilization of both hospital stays and the rehabilitation benefit following a 3-day hospitalization with no out-of-pocket costs (Bynum, 2009).

In Margie's case, Terri had been periodically falling down for a few years before she received a diagnosis of Parkinson's disease. Margie and Terri made frequent visits to see a doctor about her loss of balance. When her symptoms progressed, she received the diagnostic testing necessary to obtain a diagnosis. At that point, the doctor told her, she had probably had the disease for the last 7 or 8 years. After her release from the hospital her Medicare benefit provided in-home care for 60 days. However, Medicare is designed to meet only acute medical needs, not to supply care for a person with a chronic illness; thus, after 60 days, services in the home ended.

There are no frameworks in place for the provision of long-term care in the community when a person has a chronic disease such as Parkinson's or AD. After a person's acute care needs have been addressed following a hospitalization, Medicare services run out and are no longer available. The proverbial "bridge to nowhere" left Terri without services in the home following her hospitalization and diagnosis. Later when Terri started showing signs of dementia, Margie mentioned it to Terri's doctor. One researcher found that more than 70 percent of his study participants with Parkinson's disease developed dementia symptoms over an 8-year period (Aarsland, Andersen, Larsen, Lolk & Kragh-Sorensen, 2011). If dementia symptoms are frequently associated with a chronic disease such as Parkinson's, should families be educated and trained to handle the behavioral and cognitive changes that may accompany the disease? The following is what Margie said transpired during her visit with Terri to see the doctor:

The doctor would reason with Terri and tell her she shouldn't do what she was doing, and she could seem quite reasonable in the doctor's office. But when it came to her being in

the moment she had a different reasoning process. Who wants to have to convince a physician that their loved one has dementia?

Probably no one wants to convince a medical doctor that a loved one has dementia. Interestingly, Terri was given a prescription for Aricept, to help with her dementia symptoms a few years after she was first diagnosed with Parkinson's. Cognitive impairment is a major non-motor manifestation of Parkinson's disease.

Obtaining a diagnosis is a logical first step in dealing with any illness, especially an illness that is progressive. Studies show that nearly 50 percent of those with dementia have never received an official diagnosis (Alzheimer's Association, 2011). In Terri's case, Margie believed that the physician did not want to add cognitive impairment to Terri's already long list of Parkinson's symptoms. Margie posited this question: "Maybe there is a physician's denial, which impedes proper dementia care and treatment?" Alternatively, the disconnect could be some type of communication failure between the family caregiver, the care-recipient, and the doctor that occurs in the office or treatment room resulting in the dismissal of critical health issues. The exchange and dynamic in the doctor's office between this triad, and the power dynamics at play, may provide valuable information pertaining to how information gets transferred in the medical setting to the appropriate authority, which in this case is the doctor. For example, when does a person with dementia give the family caregiver authority to become his or her medical advocate during doctor's visits? What are the assumptions? Does the doctor defer to the undiagnosed dementia patient, who may in that immediate instance not have pain, or not remember why he or she is in the emergency room? The interactions between the medical community and the caregiving dyad should be a subject for additional research.

The frequency of beneficiary use of the Medicare in-home benefits may shed some light on the support needs of Medicare beneficiaries with dementia-related illnesses who do not receive in-home assistance outside of the 60-day certification period. This speaks directly to another area of potential cost savings; by having a network of long-term care supports and services in the community, families like Wilma's could be helped before thousands of dollars are spent on emergency room visits, ambulance rides, and rehab hospitals. It would be interesting to put a dollar amount on the cost of medical care incurred during the 2-year period before a person with dementia gets diagnosed.

Entry Into Family Caregiving

In each of my case studies, the dementia symptoms began in the community with the family member assuming the caregiving role out of necessity. The caregiver/care-recipient dyads in my study represented a diverse range of family relationships, including a lesbian couple, a husband caring for his wife (with the help of their daughter), and a daughter and her husband caring for her mother. Only Wilma had prior experience as a professional caregiver.

Margie had been dealing with Terri's Parkinson's symptoms for years before she started noticing her cognitive impairment, which seemed rather subtle at first or maybe it was easily hidden by her other disabilities and conditions. Margie described the first hint of Terri's dementia this way:

We had a wide circle of friends. And Terri was often the center of things. We would have friends over for dinner, and I remember one night there was a conversation at the table and all of a sudden she changed the subject. And then she did it again. She just wasn't following anything. It was coming out of left field.

This event signaled the beginning of a slow but progressive unraveling of Terri's life. Margie's health was starting to decline. A recent Alzheimer's caregiver study found 41 percent of female

caregivers surveyed felt that it was not a choice to be a caregiver; it was a necessity (Shriver & Alzheimer's Association, 2010). Margie and Terri were coupled; they had a commitment to each other, and that promise still existed between them along with Terri's disabilities.

Most families when faced with a chronic disease have few long-term care options; family caregiving is one option. Taking care of a family member with memory loss or a mild cognitive impairment happens somewhat seamlessly at first, but with every decline in ability the level of care increases; with each decline the challenge becomes more pronounced.

Jill began getting lost on her drive to the gym, and then she forgot where she parked her car. Both Greg and Susan tried to compensate, as many family caregivers do. Greg started offering to go with her to the gym or he would make a plan to meet for lunch. I asked Susan during our first interview how she and her father entered into their roles as caregivers and this is what she replied:

[Mom and Dad] were always walkers so they'd take at least two walks a day together in the neighborhood. Mom would go off swimming for three or four days a week. She loved it; that was her thing. People started telling us that they thought she was having a hard time finding the locker room, or there was some hesitation when she was finding her car, or turning into the parking lot, and they relayed that information to either Dad or I.

Wilma took on her role as her mother's caregiver because she knew that there was no one else who would do it. During our first interview I asked Wilma how she entered into caregiving; this was her response:

2006 is when I came down and took over full time. I had to leave my job, we were renting, thank god we were renting, and I was still trying to pay rent up there. We had only been married for eight years. There was just no big picture, no clear path to follow, it was daily. So, without me collecting a paycheck, my sister and I decided what Mother had left in the bank would go to me to pay my bills, and the household expenses here. Well, of course we went through that so quickly, and so then we got a reverse mortgage on the house here, which would supplement what I was losing from not working.

Wilma brings up the impact that caregiving has on her career and household finances. The absence of Wilma's paycheck is significant: she was unable to pay her own bills due to her caregiving responsibilities. The average hourly cost for formal in-home care is \$22 (MetLife, 2009). Informal care, though unpaid, nonetheless exacts a cost from the family member who provides the care.

Work-Related Issues

The occupations of the family caregivers in my study prior to their entry into caregiving were varied. Greg had been a military officer, Susan was a schoolteacher, Margie was a professional therapist, Wilma previously was a licensed practical nurse, and Doug was a fisherman. Greg was the only primary caregiver in my study who had been retired when his spouse (Jill) had become symptomatic. Jill's secondary caregiver, her daughter Susan, was still working:

Dad and I used to take turns picking her up (from daycare). Again, he'd have a longer time without her. She'd go at 8:30 and have breakfast there, and lunch, and then I'd go and pick her up at 1:00 when I got out of work [during her lunch break] and bring her home and that way he didn't have to be spending his day transporting her. Right. And I work till 5:30, so it's a long day.

Terri was 69 and Margie was 52 at the time of Terri's diagnosis. Margie had just finished her PhD, and had rapidly become a successful psychotherapist with a national platform.

Unfortunately, Terri's disease was progressing as rapidly as Margie's career, and Terri began to require more assistance. Margie told me she stopped traveling to national conferences and began working primarily out of an office in her house so she could be available for Terri's care provision. Margie is a practicing therapist who sees as many as eight clients a day in her home office. Her office occupies a small room next to the living room and the interior walls are thin.

During our interview I faintly hear the sound of a television from the other side of the wall. This was Margie's journal entry:

So far I've been interrupted 4 times . . . by Terri, by the formal caregiver, by a client calling and another text messaging me. It feels nice to write, but I'm so tired I just want to sleep.

There is no way to accurately calculate what Margie may have lost in terms of professional attainment by stepping off her early career path. What I witness in their presence is that Margie had embarked on a second demanding career as Terri's primary caregiver, which, at the time of this journal entry, she had been doing for 12 years.

Wilma was 59 and making good money as a nurse when her mother, Kate, started needing more and more help. Wilma told me that after she had been helping her mother for a while she realized she would have to adjust her work schedule:

So finally I would have to start bringing my hours down from 30 to 24, and then I had to go to a private agency so I'd have that freedom [to be able to help my mother].

She helped her part-time as she tried to juggle the responsibilities of work and family. As Kate's dementia progressed, Wilma did more for her because she needed it; to be able to stay in her home she would require greater support.

The average age of a family caregiver is 48, which places most family caregivers in their peak earning years (National Alliance for Caregiving [NAC] & AARP, 2009). Monetary costs related to loss of retirement income, wages, and benefits for potential wage-earning family caregivers who give up their careers for caregiving duties are not easily calculated. Most studies use replacement costs when estimating the value of informal family caregiving. Replacement costs estimate the hourly cost of informal caregiving at the current rate paid to the average home health worker or companion, rather than estimating the actual costs associated with the loss of

employment by family caregivers in whatever occupation they held before they became caregivers. For example, the loss of income for Margie, a therapist with a PhD, would be higher than Wilma's loss as a licensed practical nurse.

Problem Behaviors Related to Dementia Care

Highlighting the difficulties associated with dementia care is essential to understanding the unique challenges faced by the dementia family caregivers in my study. Dementia care requires an understanding of the psychological manifestations of dementia symptoms; these psychosocial changes make dementia care more onerous than other illnesses because of the associated behavioral components. According to a recent study, the neuropsychiatric symptoms associated with AD and dementia symptoms are the major cause of increased caregiver burden (Kochhann et al., 2011).

More than Terri's blindness or loss of ambulation, it was her confusion and disorientation, the loss of her cognition, and the loss of her ability to communicate that brought tears to Margie's eyes when she talked about caregiving. By the time of my first interview, Terri had begun falling out of her wheelchair, and continued to fall throughout Margie's interviews. Margie looked increasingly tired as the weeks passed between our interviews. I wondered, how long could this go on? How long could someone endure chronic sleeplessness coupled with the repetitive nighttime behaviors, memory loss, and confusion? Margie kept going. This was her next journal entry:

After going to bed around 9 p.m., Terri called me every 45-60 minutes to ask me to take her to the bathroom, get her something to eat and to remind me that I needed to come to bed. Around 2 a.m. she took matters into her own hands and tried to get out of bed and into the wheelchair to come and make me go to bed. She fell, I couldn't lift her up so I called rescue and afterwards didn't dare attempt to finish my work.

The difficulty of Terri's nighttime confusion arose frequently during our interviews. Margie was a therapist by vocation, she was cognizant of the medical definition of dementia but she needed something more than an explanation; she needed help to alleviate her burden. Without any relief, these late-night episodes continued. She needed an intervention; but without a community structure, she was alone to handle the next level of Teri's care. She wrote about it again in another of her journal entries:

Last night when I went to bed around 11:30 p.m. Terri woke me up and asked me to help her get onto the commode. She had Depends on, but didn't want to urinate in them even though I said it was easier for me to change the Depends rather than to transfer her to the commode. She said she would prefer the commode so I complied. In the process she started urinating . . . soaked the Depends, the bed, my leg, the rug, and still had more to deposit into the commode. I was very embarrassed . . . I told her she was an old dog for peeing on my leg like that. We had a good hardy laugh together. I told myself that was the last time I was going to give in on the nighttime commode transfer. But I know I'll probably do it again.

As Margie told me the story of Terri's falls, I could see the residual evidence of worry on her face, knowing that Terri would most likely forget again, and because of her forgetting, would fall. In April, Margie wrote in her journal again:

Terri's fallen at least 4 times and I've had to have Rescue here to help 2-3 times. The last 2 times she's fallen were at night because of something to do with her concerns about me.

Chronic high stress can negatively impact the health of family caregivers (Vitaliano, Zhang, & Scanlan, 2003). The lack of predictability is one factor that makes caring for someone with dementia more stressful than caring for someone with other diseases: no one knows what the next precipitous cognitive decline in ability will look like, nor when the decline is coming or for how long it will last.

In Greg's case, one of his most disturbing moments was at mealtime. He talked about it with me and his daughter Susan:

. . . at the dinner table she wouldn't eat. She was always biting the inside of her mouth or her lips. Almost every dinner was becoming an episode, and she'd bleed. Starting to chew her food and then spit it out, which to see your mother do that it was really bothering me.

The difficulty with meals created an ongoing problem for Greg and Susan. They had no idea what to do. Food is a necessity; it is not optional. Greg was not trained in dementia care; the only credential he needed for taking on his wife's care was that he was willing. For Greg, access to caregiver education and training was not immediately available. Greg could have accessed help with family mealtime by calling his local Alzheimer's organization, but he needed to have accessed enough information to be aware that this option was available and he had not done that.

Wilma and Doug also had trouble during the night when many of Kate's difficult behaviors surfaced. Doug would usually sleep through the night, while Wilma would get up and go downstairs, to tend to Kate. Doug describes the difficulty he and his wife Wilma encountered during their first year with Kate:

When we first came down, and we would sleep across from her, upstairs, and she'd be up yelling, 'Alice, Alice'—Alice was her youngest sister—or 'Ma,' and she'd be yelling in the middle of the night and flicking her light on, I had a baby gate across the stairs so she couldn't get downstairs, and rattle, rattle, rattle, the gate, and oh man, it was . . . and Kate says, 'He's downstairs making all kinds of noise!' She's hearing music in her head. It's called musical ear syndrome, and it's either ringing in the ears, or music in the ears, and she fortunately got the music version! So she says, 'Doug's in here in bed with me!' But she could hear music . . . and it was driving her nuts, because it was over and over in her head, the same song, and I'd say, 'What is it, I can't hear it.'

Sleep Deprivation

People suffering from dementia may experience a disruption in their sleep cycles (Rabins & Lyketsos, 2010). This means that many family caregivers experience disruptions during their sleep as well. In fact, nearly 70 percent of family caregivers caring for a spouse with dementia in a Canadian study reported sleep disturbances with a significant impact on the cognitive and emotional health of the caregiver along with higher rates of depression (Creese, Bédard, Brazil, & Chambers, 2008).

The sleeplessness that Doug and Wilma were experiencing was distressing to Wilma. The lack of sleep surfaced as an issue of concern for all the family caregivers in my study. Sleep disturbances in care-recipients with dementia significantly affect the sleep of family caregivers; this issue is underemphasized within the existing literature given the frequency and commonality of the theme. Margie talked about how her life changed when she began to get some sleep:

I'm doing better because I did make arrangements to have a caregiver sleep with Terri four nights a week, and it's just having that time off has done wonders for me.

Sleep deprivation can have a deleterious effect on a person's health and sense of well-being. In Greg's case, he would go night after night without any sleep, until finally he would phone his daughter to say he could not keep going like this; but somehow he kept going. This is how his daughter Susan described it:

She [Jill] would wake up and not know where she was. Her back bothered her—aches and pains—wanted to go to the hospital . . . 'help me, help me, I need to go to the hospital.' She snored, my father snored. They were in separate bedrooms at that point but he still had an ear out for her—he'd be up half the night calming her down, or bringing her into his bed just to calm her.

Greg cared for his wife for 9 years in the home and he could not recall how many years he endured not getting a full night of sleep. After being separated from his wife for 2 years, he still could not sleep through the entire night.

The most telling information I collected about caregiver sleep deprivation was from a time management chart I gave to Wilma that logged Kate's hourly activities in 24-hour cycles for 14 days. During the 14-day period, Wilma had nine uninterrupted nights of sleep. The five nights Kate did not sleep were also telling. I measured time in sequential hours so I could see how many times in one night Wilma's sleep was interrupted. Each night of interrupted sleep meant Wilma would hear Kate's alarm, go downstairs, care for Kate, and climb back upstairs at least three times during the night. Wilma did not get a break until Kate was showered, toileted, dressed, fed, and on the bus to daycare.

Financial Burdens of Caregiving

The financial burden of caring for someone with dementia is not a small concern; how to finance care is a question that all families face. The caregivers in my study were not unusual in their circumstances. Financial burdens were self-identified in each of the three cases. For the family caregivers in my study, each bore a substantial financial weight, with particulars that were unique to their own situation. But they all had this in common: By the end stage of their loved one's illness, the three families in my study will have spent down all of their available resources—whatever savings they had started out with will have been spent on the provision of care. Wilma and Margie's care-recipient started my study Medicaid qualified, and Greg paid privately for Jill's placement in a nursing facility. A few years from now, Greg will have spent

enough of his savings so Jill will also qualify for Medicaid. These financial concerns surfaced frequently during my interviews.

For Margie the availability of additional resources means having money to pay for more in-home help. Margie must constantly weigh her own health concerns against the caregiving concerns of her partner. Because of the financial costs of formal respite care, Margie faces a tough choice: whether to pay out of pocket for the respite care she needs or to provide Terri's care herself despite the toll it takes on her own health. This is how Margie described the problem:

Doc wants to take me off meds that contribute to all three of my symptoms, but I need the meds to keep working . . . and the wheel goes round . . . And so I said to her, 'things are tight financially right now, so I can't really bring in another caregiver' [to get the rest she needs].

In Greg's case, he pays entirely out of pocket. His life's savings is dwindling and his daughter is concerned that in the next few years there will be little money left to pay for Greg's care. During one of our recorded interviews, Greg said this about Jill's expenses:

I've been to attorneys, all the help I can get—[the nursing home is] very, very expensive, they'll take all your life savings. It's terrible in that respect. He was advising me to buy a bigger house, protect my money. [The nursing home fees are] going up starting the month of June. I pay \$8,240 a month. Add that up for 2½ years . . . that's a quarter of a million dollars. And once you get down to \$110K—your house can be worth \$750K and they won't touch that—but you get to a point, one option you have is getting rid of this house and getting something more expensive; then when she passes on you go back to something smaller. And the other way is buying an annuity, but when I die you don't get a dime, they get everything, so you have nothing to pass on.

You can sense Greg's frustration. He is a man who believes in paying his own way.

In Wilma's case, the financial burden associated with her caregiving role is apparent in her W-2 form. Her earnings record shows a loss of income that can be calculated by comparing her yearly income before and after she started caring for her mother. In 2005, which was before

she became her mother's full-time caregiver, her earnings were \$39,779. In 2006, she earned \$4,498. In 2007, 2008, and 2009, she had no earned income at all. This loss of income will affect her social security payments when she retires. The Caregiver Homes program gave Wilma a stipend with a maximum of \$18,000 a year to provide 24-hour care for her mother. This stipend allowed her \$49 a day, a little more than what she was paying for her mother's daycare. How these choices will affect her nursing career later on is undetermined at this time.

Physical Burdens of Family Caregiving

The physical strains associated with caring for a family member with a dementia-related illness was a very common theme that ran through all three of my case studies. The progression of AD or a progressive dementia not only affects cognitive functioning but will affect the ability to walk, stand, sit, toilet, chew, and swallow (Mace & Rabins, 2008). Caring for a family member who at a point in the disease process will acquire this degree of impairment will take an increasing physical toll on the caregiver.

Greg was the only male caregiver in my study. In his interviews, he resisted complaining about any physical burdens he may have experienced while caring for his wife. Greg did not respond affirmatively to my questions about him experiencing any negative physical effects related to his caregiving. However, a careful review of his interviews found Greg told me this:

Towards the end I couldn't get any sleep, I'd be up all night taking her to the bathroom and not being able to get back to sleep. It was very difficult. Towards the end she wouldn't know how to dress herself, including the basics, you had to do everything.

The female caregivers seemed more overwhelmed by the physical strains of caregiving. This finding may hint at the need for a further investigation of the influence of gender on both real and perceived physical burdens of family caregiving. Margie has a great degree of physical

burden, and as they do for Greg and Wilma, many of these events happen at night. Margie explains:

Okay I have to wrap this up, it's a little after 10 p.m. now and I still have a couple of miles to go before I sleep, or before Terri wakes up and starts calling for me. Anyway, as for my own health, it continues to deteriorate . . . Weight still going up . . . Blood pressure up, irregular heartbeats up . . .

Margie's health was adversely impacted by her caregiving and yet she kept going. This was also true for Wilma:

I began hurting myself lifting my mother. I tore a ligament in my left arm. I was surprised at how much I actually used it when caring for her, until I had to baby it. I would put her on the toilet and have to pick her up. Make sure she was steady with my right arm, then wipe and clean up, pull up her diaper, and then pull up her slacks. I go to the drive-through window at the bank and it kills me to reach over to the drawer. The last straw for me was when I tore the abdominal muscle below my sternum. I finally woke up and realized I needed to take care of myself.

Wilma would rub her left arm during our interviews and then periodically let it rest on the table. She did not complain; she did not go back to see her doctor. In many ways her chronic back and arm pain became a part of the culture of caring. When she took her respite and got a break from caregiving, her body didn't hurt as much anymore.

Probably the most harrowing story, which demonstrates a profound lack of self-care, was Margie's:

I was back helping Terri into bed, and when I was lifting her up from the wheelchair I had a grabbing pain in my chest and got her in bed and the pain wouldn't stop. And I was sitting on the side of the bed crying and bent over with it. I called my brother-in-law, who's a doctor, to see if it could be anything easy. He said, 'Call the ambulance!' And then I still didn't call the ambulance—I did not want to go to the hospital. I couldn't. There wasn't anyone here. I didn't know how long it would take, I didn't know anything . . . So I took a handful of aspirin just in case, and I called my friends and they called the ambulance. This was a half an hour later. And by that time Terri was trying to get up to help me. And I was in denial. I was concerned that it was my heart.

Luckily for Margie it was not a heart attack, but she did have pneumonia, which required her to take 2 weeks off work. Since Margie was self-employed, that meant she did not earn any income for those 2 weeks. This made it difficult for her to pay for the additional help she needed to provide care for Terri so she could rest. The reality was that Margie's caregiving responsibilities made it difficult for her to stay in bed, to take the rest she needed to recover from her pneumonia. There is no mechanism in the community to help primary family caregivers when they become ill or have a medical emergency; there is no support for their care-recipients if they need to have a surgery or a medical procedure.

Social and Emotional Burdens of Caregiving

Social and emotional strain is another staple of the current literature related to family caregiving. These strains may pose a greater burden on caregivers than we understand. Isolation contributes to the emotional strain of caregiving, and family caregivers are prone to loneliness and depression (Beeson, 2003). Given the numerous difficulties associated with dementia care and the prevalence of strain within all my interviews, I can state with relative certainty after examining my notes that 51 family caregivers out of the 51 that I interviewed mentioned some degree of emotional or social strain experienced in their role as caregiver providing dementia care. These were not randomly identified caregivers that I was interviewing, so the number of positive responses carries little weight in terms of comparative analysis of my sample; however, the fact that 100 percent of my study participants were affected by this issue speaks to the depth of this problem for self-identified family caregivers.

Margie explained the emotional burden of caring for someone with dementia this way:

The emotional one that really got me was when I had a history of cancer, and I had a recurrence when I was caring for my partner, and I was really shocked that I had had a

recurrence, and when I told Terri about it what she said to me was, ‘Well, what will happen to me?’ It was so painful; because my experience with her had always been that she was always tuned in to whether I was okay. And I realized fairly recently that that type of response is something that makes sense for someone who has Parkinson’s disease and who has some cognitive impairments to go to that place, and it didn’t have anything to do with her not caring about me or being selfish; when you have dementia, that’s just how the brain works.

When I asked Greg and Susan during a joint interview about the support they received from the rest of the family, Greg did not answer; he deferred to his daughter. It seemed clear by his response he did not want to talk about it. Susan responded first by saying:

I would say, no. To be honest with you, no. My brother and his wife have been appreciative that I’m here, they give me that feedback, but they don’t bother to send Mom a birthday card or a Mother’s Day card; and they could call to talk to Mom instead of always just talking to Dad, that would mean a lot to her I think. Sometimes when the person is outside the situation on a daily basis you have a totally different view of it because you’re not involved in the crises, the daily routine of it. I don’t know about anyone else. I would like to have seen more friends willing to go up and see her. Dad will invite people to come with him and some have gone—I have an aunt who will go up, or my brother’s wife, but considering they had so much of a social life here I don’t see them seeking out to see her. It might be too hard for them. It’s like, out of sight, out of mind.

The difficulty of maintaining social and emotional support is probably attributable to a myriad of reasons. People can become isolated when they are caring for a family member with dementia (Mittelman, Haley, Clay, & Roth, 2006). Clearly this had happened to Greg. Should a range of social opportunities be made available in the community for family caregivers and their care-recipients with dementia?

In all three case studies, family caregivers had difficulty receiving support from other family members who were not involved in the day-to-day care. In Wilma’s case, she experienced difficulty getting her sister to visit, let alone help out. Her sister was retired and lived only a few hours away. This was how Wilma described her sister’s last visit.

She thought she was going to kill two birds with one stone and come for a christening and visit Mother, but we're not going to be here.

Wilma's sister will probably visit on Thanksgiving, according to Wilma. It was almost September and her sister had not helped out at all during the 6 months Wilma participated in my study. Unfortunately for caregivers like Wilma the only way she can get a break from caregiving is to wait for her mother's hospice respite benefit to kick in or to pay for care out of pocket.

Formalized Care in the Community

The current literature suggests that the majority of community-dwelling care-recipients utilize very little formalized care in the community (Spillman & Long, 2009), but there are vast regional differences in the availability of formal care in our communities. In Massachusetts, because of the Home Care Program, formalized care services are more readily available in the Cape Cod communities. All three of my case-study caregivers used formalized care in the community.

Terri became Medicaid-certified early on and began participation in the Options Personal Care Attendant program. Margie had navigated a handful of community services until she found a program that worked better given their situation. This is how Margie described being connected to formalized community care:

The first outside help I had was through the Family Care Program, which was basically a stipend we would get once a month—about \$500 a month—and that was through the state. I found out about it from working with people with AIDS, guys who were getting it for taking care of their partners. The office was at Cape Cod Hospital, and it was called the Family Support Program, or the Family Foster Care Program—that was back in 2000. I had that for a couple of years. As my partner's condition got worse and I needed more in-home help, one of our friends who was a social worker scoured the Internet and found a program for personal care attendants—the OPTIONS program. I was surprised that no one had ever mentioned it to us, and we applied for that.

Margie's professional connections assisted her in finding the right community program that worked best for her and Terri. The lack of organized, coordinated support and care services made the process of acquiring help seem rather arbitrary. Margie explained one intake process:

The intake person comes in from Elder Services and says, 'It looks like you're not getting enough services!' So by this time I've got OPTIONS, I've got Palliative Care—and so she's trying to do an assessment of what we might need, and I say, I can tell you what I need: after I get finished working all day, I have to go and cook dinner, and serve dinner, get my partner ready for bed, watch television with her for an hour, clean up, and all that kind of stuff—and then I have to go and stay in the bedroom with her. She can never be alone. We have a monitor, but she likes listening to the radio because she can't see. So I said, I would like someone to come in and cook, do the dishes—so they gave me three to seven, seven days a week. I feel like I died and went to heaven.

A blend of informal and formalized care seems to provide some much needed support for family caregivers like Margie who is employed full time while they are also working as the primary family caregiver.

The Medicaid program Terri was enrolled in gave her assistance; she had enough and severe enough disabilities to be enrolled in the OPTIONS program, which provides 44 day-hours and 14 night-hours a week for a personal care attendant to come into the home. As I began this study, Terri's dementia had already progressed to the point that she required 24-hour care. The state has been paying for 58 hours of care per week at \$12.50 an hour, which costs \$696 a week, or \$2,784 per month, with a slight increase on holidays. The average cost of skilled nursing in Massachusetts would be roughly \$91,000 a year. Given Terri's multiple health problems, the home care program she enrolled in costs much less than what skilled nursing care would cost.

Social and medical daycare programs provide a very important benefit for informal family caregivers in the community. The dementia care is affordable, costing around \$40 a day for 6 hours of care. The last 3 years that Greg cared for Jill at home, she attended a local adult

daycare at the Council on Aging (COA). Greg's daughter described her mother's care services in the community:

The last three years before she went into the nursing home we had her going first to the [nearby] COA once or twice a week for a morning program. Then we found out [the local] COA—because they lived in [that town]—would be cheaper, and had transportation though he would take her, I'm guessing three days a week to start. It may have increased to five days but I don't think so—seems to me it was three or four at the most. I would take turns to relieve Daddy. You could tell she was more anxious now because she was fighting it—'why do I have to go? I don't want to stay. Why don't you stay with me?' Once she got there she was her old self of being sociable, lovable. They had breakfast provided there. That was nice, so he didn't have to have a feeding—though breakfast was a pretty good meal for her, she'd eat her cereal and it wasn't the type of food she had a hard time chewing. But she liked breakfast food.

Wilma's mother also attended a social daycare program. In addition, she received support services in the community after she became Medicaid qualified and was enrolled in the Caregiver Homes Program. This is how Wilma described getting information about formalized care services:

In 2006, a social worker told me there's a program called Caregiver Homes. And there's also another program called Caring Homes, then something called Choices, and she said Caregiver Homes is what you want, they pay you to take care of your mother at home. So I said, okay. So I went over to Elder Services, and they gave me the information, and number to call in Boston. So I got the ball rolling, and they said she has to be MassHealth eligible, you have to buy down, or pay down, her bank account, and that wasn't difficult to do by this time! Just stop the reverse mortgage payments, so we had to stop that down.

Wilma's mother became Medicaid eligible in 2007. The Caregiver Homes program paid Wilma a stipend of \$49 a day. Because the money is not considered wages, she did not have to pay taxes on that amount, nor did she receive any employment benefits such as health insurance, retirement pension, or workman's compensation. Eventually Wilma's mother became eligible for hospice and palliative care services and Meals on Wheels. This was how Wilma became eligible for hospice in the community:

She must have had a TIA [transient ischemic attack] at the daycare, and they said come and get her, we're worried about her. And I picked her up and she wouldn't speak to me or anything, and the scary part was, we're driving home, and she reached over and took my hand, and I thought, oh, this must be the end. And coincidentally, we were going to a program down here, pictures, artists, for Alzheimer's, and so I took her there because I knew there was going to be someone from Alzheimer's [Services] there to look at her, and said, she's probably had a TIA, and she'll probably be fine tomorrow, but call Hospice. So I did. And that was it.

A part of the hospice benefit included a 5-day respite Wilma could take every 3 months. She told me how important this benefit was to her and Doug. This would allow the two of them some time together apart from Wilma's mother and her 24-hour caregiving responsibilities. These respites allowed time for Wilma and Doug to be together, which helped solidify their relationship with each other and with Kate. During my 6 months of interviews, Wilma received two respites. On both occasions after being away, she appeared less tired, even though she still reported having difficulty sleeping both while she was away and after she returned. The availability and utilization of formalized care in the community appears to complement informal caregiving, as it did in all three cases in my study (Gaugler et al., 2005a, 2005b).

Nursing Home Placement

AD and related dementia diseases are progressive, and in late stages require skilled nursing care. Because these diseases take their own course, there are many variables, but it is logical to assume that in the later stages it becomes more difficult for a family caregiver to provide the necessary care, because of the eventual physical manifestations of the disease process. Since high caregiver stress is one precipitating trigger leading to a nursing home placement, we can deduce that better family caregiver supports in the community could delay this potential outcome. The New York University caregiver study demonstrates that interventions that support the family caregiver can delay costly nursing home placements for spouses with

dementia by more than a year (Mittelman et al., 1996, 2006). These delays signal not only a potential savings, but also an important component of community dementia care.

Family caregivers provide the assistance that allows people with dementia to remain in the community; this should be reason enough to provide interventions that support the family caregiver. This human capital—the caregivers' work—is as important as any accommodation we could make in the community at-large.

As the need for care increases, family caregivers need more assistance and support to provide adequate care in the home. If additional care is not available, a nursing home placement becomes a likely alternative.

For Greg and Susan that alternative became a reality on November 1, 2007; they both remember that day vividly because it was the day Jill entered a residential care unit. Even when a nursing home placement is the absolute right thing to do, as it was for Jill, the family's loss is palpable. Though 3 years had passed since Jill was placed, it still felt tender when we talked about it. Here is how Susan told the story:

The next couple of nights were really tough, for whatever reason, probably just from [Dad] thinking about it, would be my guess. He called me at 10 one morning at school and he said, 'Susan, I can't take it anymore,' and so I said, 'Go ahead, I'll be there for you, Dad.' And I arranged to leave work. We took her over at 4 o'clock with her suitcase and at 5 o'clock we walked out. And it was tough. It was tough. She didn't know why she was staying.

In Margie's case, the issue was no less difficult. She had just started broaching the subject of nursing home placement with Terri during the last month of my study. Margie described her first real discussion on the topic with Terri:

It was on a Friday that we went to the facility, and then on the following Monday my doctor had arranged for Terri to see her doctor . . . and the idea was that we would all get together over this. So we did that. And when we got home that night, Terri said to me

when we were in bed, ‘would you snuggle with me a bit?’ And I said ‘yes, gladly.’ And she said, ‘I just want you to know that I really love you, and that you’re a beautiful person, and that I’ve always loved you, and I just want you to know that I think that if I go into the nursing home I’m not coming back out.

Then, as quickly as the discussions about Terri’s nursing home placement began, they tapered off; they were just too difficult. Margie explained:

And it was because her stress about talking about the nursing home, and feeling like she wanted to do something so that she wouldn’t be a burden on me. It’s that part’s been really good. I also started to see a psychologist, and I only saw her once, and I talked to her about this situation where I was feeling really burned out, and went to my doctor and talked to her about it, and the issue of putting Terri in a nursing home came up, and I said to my doctor, ‘I can’t do it, it’s just not in me, I can’t even have the conversation with her.’

Margie’s doctor was the one who first discussed the possibility of moving Terri to a nursing home because Margie’s cancer has returned. I asked Margie why the doctor brought up the subject of a nursing home placement, and she answered:

Because my health and stress levels and the fact that I was getting pneumonia and I was getting sick, and my dad died this summer, and I was totally exhausted, and with the bladder cancer, which is very sensitive to immune system functioning, she said, ‘You’re not going to get a chance, look at your history—so, anything that you’re thinking about can affect you, you’re going to be okay, I hope you are, but not at the rate you’re going.’ Then we talked about going to see [the nursing home] and I talked with a [paid] caregiver about going over and looking at the nursing home and we decided to take Terri with us, and we picked a Friday and we went over, and Terri was okay, and she was thinking that ‘if I have to go in because Margie needs surgery, then I could probably put up with this place.’ And the doctor was thinking more like, ‘let’s get her in there and then she isn’t leaving, because you need to get ready for surgery.’

Therefore, Margie makes a plan to take Terri to a nursing facility for a temporary placement so Margie can get strong enough to have her cancer surgery. This is what happened the morning Terri was expected to move into nursing care:

First thing in the morning Terri asked me, ‘Will you help me get in the wheelchair so I can start packing?’ And I started crying, and I just cried for the next three or four days. I had to cancel all my clients; I couldn’t stand to see anyone. And so by Thursday she was

ready to call and go in, and I said, 'no, don't do it.' So Thursday I called my doctor and said, 'I have to talk to you.' And I went over and we talked for about an hour, and I said, 'You know, this is someone I've loved for over 30 years.' I can't go look at a place and say, 'Okay, you're going in,' when it's a humongous thing. And not only that, but it's not just changes for her. It's changes for me. And we have a system going here—it's not enough for me, but it's still part of my daily routine.

Terri did not move to the nursing home on the day designated. Instead, Margie borrowed money from a friend. The loan paid for care during the night which meant the aide would get up with Terri on those nights so Margie could rest. A few weeks later, Margie was willing to discuss a nursing home placement again. This was what Margie told me about Terri's possible placement during our last interview:

So I started feeling a bit better. So I thought 'okay, she'll go in, I'll go see her,' and then Terri's daughter came down last weekend and we talked about it more, and I said, 'So let's just set a date. We'll go in November 1.' And [Terri's daughter] said, 'Yeah, that sounds cool.' And Monday came around and Terri was really quiet. And I said, 'Honey, what's going on?' And she said, 'I'm losing my house, I'm losing my children, they're going to come down here and stay with you and they're not going to be over there. And I don't really know why.' So we have to look at this in a different way, because in the meantime I had met with the psychologist, and I had said something to her about I don't know if I'm torturing Terri by not moving on this and not being clear, and she said 'yes, you have to do it.'

I asked Margie to expound on what she was going through. It was clear how difficult a struggle this decision was for her:

And in this process, one of the things I've realized is that this is where the whole notion of a partnership between a caregiver and the person they're caring for becomes so important. Because even in this decision—I mean, Terri loves me, she doesn't want me to be sick—but would you want to be abandoned? And it's like, we put this new idea on the table, and we talk about it, but we don't really know where it's going to go yet. I mean I know there are certain things that could happen that could force it to go one way or the other, but I'm engaged in a process with her and we're both wrestling with it. And I know that we're both hurting over it. And it's kind of like I can really see where there was a point in the discussion where she could see that if she did this that she was doing it as an act of love for me.

This was my last interview with Margie. Toward the end of our talk, Terri had started tapping on the other side of the wall. It sounded like Morse code—tap, tap tap. Margie yelled directly into the wall, “I’ll be there in a minute,” as she tapped back on the office wall in response. Next came a tap, tap, tap in response from Terri.

For Wilma, the decision to place her mother in a nursing facility came after a physical injury made it impossible for her to continue lifting her mother. Her decision was clear and concise; this was how she described how she made the choice:

I began hurting myself lifting my mother. . . I finally woke up and realized I needed to take care of myself and mother could go to the nursing home and be well cared for by many helpers. I went to an Alzheimer’s seminar and the speaker said that 40 percent of caregivers die before their care-recipients. I never verified that figure but it was eye opening . . . I never thought it would be me who gave in to the injuries. It’s like giving up, and I hate to quit! But I know I did the right thing, and I have no regrets.

Margie, Greg, and Wilma—the primary caregivers in my case studies—were dedicated to keeping their family members in residence in the community as long as physically and emotionally possible. We will never know if the provision of family caregiver support and services could have delayed the nursing home placements of their care-recipients, but we do know that at the very least such supports might have reduced the level of physical and emotional stress these caregivers experienced.

Providing long-term care supports in the community for family caregivers as they provide care for their family members is the promise of *Olmstead*.

Dedication of Caregivers Regarding Dignity of Care-Recipient

Each caregiver interviewed during the course of my study demonstrated what could only be interpreted as a sense of dedication or strong commitment to uphold the dignity of his or her care-recipient. This dedication stood out in the language and in the tone of caregiver statements

gathered during interviews and from the stories penned in journals. It was observed during the time I spent with caregivers and their care-recipients. I recognized this in the form of compassionate support that caregivers expressed in many ways throughout the study—in the kind and gentle way they provided care, in the tenderness of their communication, and sometimes in their tempered frustration.

This is one of the most moving aspects of family caregiving: despite the difficulties and relentless stress, the caregivers persist with their duties, often showing almost superhuman levels of compassion. Margie, for example, never stopped providing the care and support Terri needed in a way that preserved her dignity:

I know that one of the things [Terri] is struggling with right now is that there's times when she can't talk. And I think the thought of being someplace where you can't see and you can't walk and you can't talk and you don't have someone to reach out to—I know that's part of the advanced stage of Parkinson's, and I know that that's important to the not too distant future, the aspiration is going to start happening, she's going to get pneumonia, and there's going to be a point, it could be three or six months where that's going to happen anyway. I don't know if I can let her go like that. If this is the end stage of her disease coming up, I don't want her to go before she has to.

Greg, who survived nine invasions during his World War II service, showed a similar compassion and dedication to his wife. Tears streamed down his cheeks as he described to me with pride how beautiful his wife looked when she played the piano. The event took place during an activity period she had attended with the other residents. One resident had a portable keyboard she was not using so the attendant placed it on the table in front of Jill and Jill started to play. Greg had no inkling she had remembered how to play, but it made him happy. This was the story Greg had saved his tears for—not for his considerable financial burden, or the difficulties associated with caring for Jill—but his tears fell when he talked about his wife's beauty and dignity, even 13 years after her AD diagnosis. He still was proud of her.

Wilma was equally dedicated to her mother. Without malice or real complaint, she described her usual daytime routine:

We'd start at 5 in the morning to get her up [to get ready for daycare], and she was sleeping upstairs and I'd get her up, and give her a bath, and this was in the bathtub, and 'No, I can get out of the bath,' but she couldn't get out of the bath, and so I'd haul her up, and dry her, and then we'd have to do the hair, and the makeup, and stockings, and earrings, and the whole nine yards! . . . and it would take between the two of us—because I'd let her do most of the stuff because you want them to be as independent as possible—and it would just take forever.

Wilma had cared for her mother for 4 years until the day came when it was no longer physically possible for her to continue. Greg cared for his wife Jill at home for nine years, and two and a half years later, she continues to reside in nursing care, which he is paying for out-of-pocket. Margie has been providing care and support for Terri, whose Parkinson's continues to progress, for more than a decade. Wilma captures a moment of reflecting about her mother in the last journal entry she made for this study:

Mother said for many years she never wanted to be a burden to any of us. She had apparently said the same thing to my cousins, because they've told me about it. She'll probably live to 100 or beyond because she has not a care in the world. Her stress is gone from one minute to another. Is that what is good about Alzheimer's? So a person can regress into childhood and beyond? One day we were sitting outside on the front porch and my mother told me, 'Daddy built this for me to sit out on in the summer and I never did until now.'

Maybe Wilma had discovered some unseen benefit from her experiences as her mother's caregiver. The two of them—Kate and Wilma—sitting together on that front porch, a mother and her daughter with nothing else to do but cherish the present.

Need for Respite Care Services

Every family caregiver in my study mentioned the need to take a break from the stress of caregiving. If we considered family caregiving as employment, we would never expect an

employee to handle a similar job so socially isolating, physically burdensome, emotionally difficult, and economically taxing for 24 hours a day, 7 days a week, without a break.

Greg took advantage of a social daycare program during the day to run errands. Whether or not having a weekend respite or the occasional time away from caring for Jill may have provided Greg with enough support to reduce his stress we will never know.

Wilma's hospice respite benefit was a critical support to her family. Every caregiver needs some time off from caregiving to replenish. Wilma said she would start planning her respite weeks in advance. Having a plan for how she would spend her five-night respite gave her and Doug something to look forward to. This was how they coped with the stress.

Margie, on the other hand, found it almost impossible to get away. She received so little time off from her caregiving responsibilities that when her father died suddenly she had to scramble to schedule enough help so that she could attend his funeral. Even though Terri received Medicaid services, Margie had to pay caregivers to cover for her so she could obtain a few nights of uninterrupted sleep a week.

The family caregivers in my study demonstrated a need to actually "take a break" from their caregiving role in the community for a night or weekend. If affordable respite care was made available in the community, it could provide an incentive for family caregivers to care longer while giving some much-needed relief.

Need for Long-Term Care Services and Supports

Since the Community Living Assistance Supports and Services (CLASS) component has been eliminated from the Patient Protection and Affordable Care Act (2010), there is no new federal program on the immediate horizon to provide long-term care services and supports in the

community. This was a significant loss to families who thought help was on the way. Without a network of long-term care services, care support will continue to be fragmented and families will continue to serve as their own case managers. Currently, family caregivers must identify and access the services in the community; if they are not able to navigate a host of obstacles they go without.

The caregivers in my study accessed services scattered around the community housed in different agencies; there never was a single point of entry. Wilma's case demonstrates what happens when people turn to the fragmented system of supports that is now available to family caregivers in the community: they are on their own to cobble together services from a hodgepodge of uncoordinated, overlapping service providers. The system is inefficient and wasteful. To be clear: Wilma needed the help. An LPN by trade, she had accessed more formalized community care than the caregivers in my other case studies; still, the primary day and nighttime responsibilities rested on her shoulders.

An experienced case manager, a professional with 20 years of case management experience, said this about Wilma:

Wilma's complex web of services is not the status quo. Though it is possible to receive all of the supports you mention, it is uncommon due to the fragmented system of navigating the maze of the various organizations that one needs to piece together . . . and then these services are only available if you have Medicaid. In addition, people are not educated soon enough to do their Medicaid planning. Therefore, the vast majority of people usually only get a fraction of what they qualify for (Faith, 2010).

In the community the primary family caregiver must organize all care from the first symptoms until diagnosis, through midstage when a person with dementia cannot be left alone all the way until end stage when the Medicare hospice benefit begins, if accessed.

Without more formal support, family caregivers will always be the “last resort” when a care worker does not show. More than once during the course of this study, Kate’s prearranged formal caregiver became sick or unavailable, and the agency did not have another formal caregiver available to send in her place.

By default, Wilma would have to step in. She was always reliable, ensuring her mother had care: it was never optional. The same held true for Margie, who was trying to work a full-time job as well as overseeing Terri’s full-time care. Greg had already retired when he started caring for his wife; it was not exactly the retirement he had planned, but he wanted his wife with him for as long as possible.

New Insights

Exploratory research should try to capture new discoveries (Stebbins, 2001). To that end, I have included the unique or nuanced findings of my case studies in this section. These themes are not consistent across all three of my case studies or they would have been included in the previous section. Yet, good exploratory research should leave no stone unturned.

Marriage

For married couples, income and assets are considered jointly when paying for long-term care. Financing care for the spouse who needs assistance can eliminate family savings. (This subject is intertwined with another issue of concern to most family caregivers: how they will finance their loved one’s care—see the following section.) Asset limitations and income qualifications for publicly funded programs apply to the spousal unit, not just to the spouse with the disease. In Margie and Terri’s case, for example, Margie’s income and assets never entered the equation when Terri qualified for Medicaid, because they were not legally married.

When I asked Margie why she and Terri did not marry after gay marriage became legal in Massachusetts, Margie confided in me that Terri had already qualified for Medicaid as a single person, and she did not want to lose her eligibility in the program. Margie worried that if they married, Terri would become ineligible for the home care she was receiving. This couple needed the Medicaid program to support Terri in the community, so they never married.

The issue of marriage came up during one pre-study interview. It was a second marriage. The woman explained that her husband was diagnosed with Alzheimer's only a few years after they had been married. After they started to settle into that fact, at the request of her kids, the second wife went to see her lawyer. In the meeting, the lawyer offered one suggestion, which was to get a divorce. Both she and her husband had children from previous marriages, and previous spouses, so their financial decision-making affected many people. She stressed clearly that she loved her husband; in fact, she was fiercely committed to caring for him as long as she could. But rather than risking the financial resources from a previous marriage to pay for her current husband's care, she was deciding if divorcing the man she loved should become part of her long-term AD care plan.

The issue of marriage could be an interesting topic for future research, whether in relation to couples deciding *not* to marry, because of a chronic disease as in Margie and Terri's case, or in relation to divorce because of financial concerns related to chronic disease and the financing of long-term care.

Out-of-Pocket Costs

AD is incurable, it has a progression that can last anywhere from 2 to 20 years, and families will of course worry about how to finance the long-term care they will need. What differed among the families in my study was what kinds of public programs they were able to access. Greg paid out of pocket for more than 13 years for his wife's dementia care. Terri qualified for Medicaid early on and was enrolled in MassHealth; Wilma was able to enroll Kate in MassHealth when she needed to access more care in the community.

Because MassHealth offers long-term care support and services at no out-of-pocket cost to the recipient, Margie and Wilma will pay less in out-of-pocket care costs than Greg will pay. The current regulations mean that a family like Greg's will most likely pay substantially more for long-term dementia care than either Wilma's or Margie's family. Greg describes his financial situation as quite dire. He has paid legal fees to have his financial options spelled out and he still has spent almost \$400,000 in fees to nursing homes. He could purchase a more expensive house, but every transaction also has associated costs. Once Greg has only \$109,000 left in assets, he can have all his monetary transactions evaluated (for the 5-year look back) to see if his wife can qualify for MassHealth. Why should Greg pay so much out of pocket when many families find ways to protect their assets?

Margie and Wilma received good information about financial planning early on. Financial planning makes a difference in what is incurred in out-of-pocket care costs.

Accessibility Barriers in the Community

It was in August when I arrived at Margie's house for our interview and noticed right away that the house was very quiet. Terri was still in bed, which was unusual because it was 5

p.m. and she had no other caregiver in the house. Instead of meeting in Margie's office, I was ushered into the living room. Margie offered me a seat on her couch before going back to the bedroom to check on Terri; she continued to do this periodically throughout the interview.

Margie started to cry the moment I asked her how things were going. I grabbed a tissue from a box on the table. Margie said she had been feeling good about the additional support they were receiving and had a little extra energy to do something special for Terri, so she decided to take Terri out to a play. Instead of a real ramp, Margie had rigged a metal ramp from her front porch into the driveway. This was the ramp Margie used when transporting Terri in and out of the house after she could no longer walk.

It had been one of those perfect summer Cape Cod nights, Margie explained:

I was going down the ramp, and I was going down backwards in case [the wheelchair] got away. I didn't want her to fall out, and then it got under my shoes. I was wearing sandals and there was something about the angle, but I fell out of my shoes and started going backwards, and the wheelchair started rolling over me and then it rolled off the ramp . . . I tried so hard to keep her from falling . . . And Terri went facedown in the dirt.

Margie was crying. A few neighbors had come over to help Terri get back into her wheelchair.

Margie had planned to build a real ramp one of these days. Because Medicaid does not pay for home modifications, she was trying to save enough money to build a better ramp; but any additional money she had was used to pay for extra care.

Wilma experienced a similar problem with her mother, who had become wheelchair bound. During the first few months of my interviews, Wilma and Doug helped Kate, with progressing difficulty, get safely in and out of the house to attend an early morning daycare program. However, by April, Wilma was having trouble lifting her mother, so she rented a portable metal ramp so she could take her out safely by wheelchair. The flimsiness of the metal

ramp, and the lack of side rails, made this temporary ramp relatively unsafe, but without a permanent alternative, she still wheeled her mother down the ramp four mornings a week. Finally, after a near accident, Wilma hired a carpenter to build a wooden ramp, which ultimately allowed Wilma to get her mother safely in and out of the house. Fortunately for Wilma, the outreach worker at the local COA helped her to secure a local grant to reimburse her for the ramp.

Without a funding stream for home modifications, it is virtually impossible for a Medicaid care-recipient living in the community with less than \$2,000 in assets to be able to afford to build a wheelchair ramp.

Caregiver Support Groups

The caregivers in my study turned to community supports to varying degrees. Greg regularly attended a caregiver support group. This helped keep him connected to other caregivers, it validated his difficulties with AD caregiving, and it provided some education, thereby helping to alleviate some of his stress. It also helped him to formulate a backup plan for when he could no longer be his wife's primary caregiver.

Wilma also attended a caregiver support group at the local COA. She said she had picked up some very useful information from other caregivers. The group also allows her an opportunity to talk about her experiences as a caregiver to other caregivers who understand what she is going through. She believes everyone could benefit from attending a group. Interestingly enough Margie, a therapist, did not have the additional time or extra in-home respite support to attend a caregiver support group.

Gender

The differences between Greg, a male spousal caregiver, and Margie and Wilma were subtler than I had originally imagined they would be. Studies show that the majority of male family caregivers are spouses and that the majority of all family caregivers are female (NAC & AARP, 2009). In our interviews, Greg talked about the household chores:

Well, you know, some husbands are not capable of doing much around the house: cooking, housekeeping, ironing—all these things. Some guys, my brother is the same way, but I've always helped Jill out. I do my washing whenever I need it, and housecleaning, probably not as good as when Janet was here—the dusting gets ahead of me—but I'm managing.

Then Greg went on to talk about his neighbor, who has a wife with dementia:

You know what he [his neighbor] told me the other day? He said [referring to his wife with dementia], 'She's become incontinent.' Whoa, that'll be it. That'll be the breaking point. Can you imagine having to clean up the bed in the morning? And not just in the morning, all day! And you don't know when it's going to happen. That would be horrible. This friend of mine told me that when his wife became incontinent that's when he had to put her in the nursing home. Because you just can't handle that. You can't.

The incontinence seems to be a bigger deal for Greg than for Margie or Wilma. Another difference that surfaced was how these caregivers talked about their physical and emotional strains. Greg barely discussed the fact that he had developed high blood pressure and his health was declining when he was providing 24/7 care for his wife. Margie and Wilma were much more talkative and forthcoming about the negative health impacts they were experiencing.

Understanding the peculiarities of gender differences between male and female caregivers in relationship to their day-to-day caregiving tasks would be an area for future research.

Discussion

After a complete examination of my findings, various themes emerged from family caregiver narratives. Many of these themes are consistent with the current literature on family

caregivers; however, some issues that emerged from my caregiver narratives seem to be of greater importance to my study participants than the current literature would suggest. For example, the sleep deprivation of my family caregivers was almost intolerable in their daily lives; lack of sleep was easily identifiable as one of their premier stressors and yet, although it is mentioned, this topic is rarely of prominent importance within the current literature.

The contribution of more qualitative methods is to draw out wider thematic meanings of experiences or social phenomena. After contrasting and comparing my study's caregiver narratives for themes, I then synthesized my findings within my research questions and the current literature. This analysis is discussed in Chapter 5.

Chapter 5: Discussion of Findings

Introduction

This chapter begins with a general discussion of my findings. The second section synthesizes my study findings within the specific framework of my research questions. Included will be a review of applicable long-term care policies, the *Olmstead* decision as it relates to family caregiving, and current literature concerning family caregiving. The findings of my exploration of the culture of family caregiving in the context of the community expand our current knowledge of informal family caregiving and offer suggestions for policy to better support families in this situation.

Discussion of Findings

Unmet Needs of Caregivers

The family caregivers in my study consistently reported a high degree of unmet needs while they cared for family members in the community. Unlike other diseases in which the person has retained cognitive functioning, a progressive dementia eventually requires the care-recipient to have 24-hour care. For people whose dementia has progressed, they cannot safely be left alone; this fact makes caring for a person with dementia more onerous than caring for a person with other kinds of illnesses.

For primary caregivers in the community, the level of unmet needs results from various situations: it could be something as simple as trying to have a private phone conversation in the household without interruption, or something as difficult as trying to schedule a needed surgery while simultaneously providing care to a family member with dementia. Without some type of formalized respite care network in the community, many primary family caregivers are both the

front line and the last line of defense in the provision of community care. The care they provide is essential to their family member with dementia. Yet, the caregivers, as evidenced by reports of the caregivers in my study, are unable to address their own needs.

Consider the health risks of Margie, who suffered from chronic stress, lack of sleep, and recurring bladder cancer. Current research has shown that family caregivers had a lowered immune response for years after they stopped caregiving (Kiecolt-Glaser, 2009). Variations of her story were common. Greg had high blood pressure; Wilma had back and muscle injuries. These issues surfaced repeatedly throughout my study.

Home Is the Place

Caregivers and care-recipients in my study valued living with their families, and family caregivers endured tremendous hardship to keep their care-recipient in the community for as long as feasibly possible. Despite evidence of significant financial, social, physical, and emotional burden, all three primary caregivers in my study reported that they valued keeping their family members in the community for as long as possible. The desire to delay the institutional placement of their family member with dementia was evidenced by the high degree of stress each caregiver endured before a placement was obtained.

The high cost of nursing home care has created a natural incentive for families who are paying out of pocket (as well as for publicly funded long-term care programs) to keep care-recipients in the community for as long as safely possible. This was true for Greg's family, who paid \$8240 a month privately for nursing care.

What is equally interesting is the fact that both Wilma's mother and Margie's partner were Medicaid-qualified, which meant that both care-recipients could have been placed in

nursing care at no additional expense to their primary caregivers. Margie and Wilma endured significant caregiver burdens as they attempted to delay institutionalization for their family members with dementia.

Affordable Community Care

The cost of long-term care provision strains both government and family budgets. Because the majority of Americans do not have long-term care insurance, many people will first pay out of pocket for care, until they deplete their savings, and then qualify for Medicaid. The financial burden of caregiving weighs heavily on families: after 12 years of caregiving, Greg will have little left to pay for his own care if he ever needs it. In addition, the stress Greg experienced as a caregiver was also very high, which may have increased his risk of needing long-term care in his future. Is this how we want our family caregivers in Massachusetts to end up—financially destitute and sick?

Under the qualifying rules for Medicaid in Massachusetts, not until Greg's assets are depleted to less than \$109,000 and his income drops to below \$2,739 a month will he become eligible for Medicaid reimbursement and be able to stop paying out of pocket for his wife's nursing home care. Greg is a World War II veteran who did not have access to any entitlements. He paid his own way, only to now have his own option for community care become limited by a lack of available financing. We do not know how much of his remaining \$109,000 will be left by the time he needs care, but we do know that if he falls into the 40 percent of Americans over 65 who will need 3 or more years of nursing home care (Komisar, 2009), he will not have enough savings left to pay for it.

Family Caregiver Supports and Services

We know that families are dependent on informal caregivers in the community. If we are to continue our reliance on community-based family caregivers like Wilma and Margie, we need to provide caregiver supports and services. By not addressing the stressors that so profoundly affect the informal family caregiver, we run the risk of adding to the escalating costs of long-term care.

The average cost of 1 year of nursing home care in Massachusetts is roughly \$91,250 (MetLife, 2009). This amount is greater than the savings of more than 70 percent of Americans over the age of 65 (Feder, Komisar, & Friedland, 2007; Lyons, Schneider, & Desmond, 2005). The financial implications of dementia care, to both state and federal long-term care programs and individual families, are nothing less than daunting. Providing family caregivers with a respite or break from caregiving can have many positive effects, such as fostering stronger relationships between family members and alleviating stress. To provide these services and supports we need some type of community-based structure or network.

The Promise of *Olmstead*

Given what we know about the high stress of at-home dementia caregiving as well as the demonstrated efficacy of family caregiver interventions in delaying institutionalization, supporting family caregivers is akin to supporting the mandate set forth in the *Olmstead* decision. (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Mittelman, Haley, Clay, &

Institutionalized not because of their own declining health but because of the failing circumstances of their caregivers— physical, financial, social, and emotional. The documented

lives of the informal caregivers in my study demonstrate the enormous burdens family caregivers endure while caring for a family member with AD or dementia (Burns et al., 2003; Mittelman et al., 2006; Vitaliano, Young, & Russo, 1991). Greg reported he could not face another day as a primary caregiver; the emotional strain and habitual sleeplessness he had endured as his wife's caregiver was a major factor in his decision to place his wife in nursing care. Wilma suffered a physical injury from lifting her mother; this increased physical burden influenced her nursing home placement decision. Additionally, as Margie grapples with Terri's placement decision, her own failing health, sleeplessness and the recurrence of her cancer factor into her decision.

Discussion of Research Questions

In this section, I synthesize my study findings within the context of my research questions, addressing each question in terms of long-term care policies and how they relate to provision of community care and the *Olmstead* decision.

Research Question 1

What are the "caregiver burdens" for each participant in my study? Specifically, what are the economic burdens of care for the family caregivers in my study caring for their family member with AD or dementia? Are there out-of-pocket costs or loss-of-income/employment costs associated with family caregiving?

My research supports findings in the literature (see Gaugler, Kane, Kane, Clay, & Newcomer, 2005a; George & Gwyther, 1986; Vitaliano et al., 1991; Zarit & Orr, 1985) on the stress and burden of caregiving. The two caregivers who were providing at-home care consistently looked tired. They reported that they did not sleep or eat well or exercise regularly, and they were ill with physical complaints at various times throughout the 6-month study. Two

had physical injuries from lifting their care-recipients and one told me she had started drinking alcohol more frequently and in larger amounts than normal. One caregiver had been treated for depression. The third caregiver in my study was still in the process of recovering from caring for his wife; at the time of our interviews, it had been almost 3 years since she had entered a nursing home, and he was still suffering from insomnia. He had tried various medications, but still could not sleep through the night. Isolation and lack of social connection hampered all three caregiving families. Greg was just beginning to reinvent his social life, by going out to lunch with some of his former friends. He was trying to imagine his life beyond his wife's illness. Margie had very little time for social connections, nor did Wilma.

I do not know if Margie's immune system will find a way to recover, or if her bladder cancer will return and she will ultimately be relieved of her caregiving responsibilities for another cancer surgery. Not one caregiver will emerge from his or her caregiving experiences unscathed. The loyalty and admiration the caregivers exhibited for their care-recipients were demonstrated consistently throughout the study. All three kept their family member in the community as long as possible, and in doing so, each family caregiver in my study experienced significant "caregiver burdens."

The difficulties particular to dementia care, as enumerated in the previous chapter, are what made caregiving for a family member with AD more onerous and burdensome than caregiving for a family member without AD. My findings were consistent with the current literature focused specifically on family caregivers caring for a family member with AD, which found the behavioral aspects of AD, coupled with the progressive neurologic decline, meant care-recipients required 24-hour care, making AD caregiving more burdensome than caregiving

for people with other diseases (MetLife, 2006). My ethnographic data demonstrates the important and significant role that informal family caregivers provide in the management and delivery of care in the community. These family caregivers take on many different roles in the delivery of care. They act as nurses, doctors, social workers, case managers, home-health aides, and homemakers in their role as family caregivers in the community, but their existence within the systemic framework of community- and home-based services goes unacknowledged. good

The economic burden of care persisted after a care recipient was moved to a nursing home. The spousal caregiver in my study corroborated burden: after 9 years, Greg reached his breaking point. Greg was up most nights taking Jill to the bathroom and most nights he was unable to get back to sleep. Jill needed Greg's help dressing and bathing, including help with toileting. Then, Greg reached his breaking point. His economic stress continued as his savings were depleted by the expense of nursing home care. Nevertheless, his physical and emotional health recovered when Jill went into nursing care.

The loss of income experienced by the other two family caregivers in my study was also significant. Through analysis of collected data displaying yearly income as reported for tax purposes, I was able to confirm actual loss of income by a comparison of income before a study participant became a family caregiver with income earned during the time she was caregiving. (If my study had spanned a longer period, I would have continued measuring incomes after family caregivers no longer provided 24-hour care.)

For one participant in particular, the economic burden attributable to her duties as a family caregiver was much more diffused and difficult to quantify. Many factors may contribute to an individual's professional attainment, but in this case Margie modified her professional life

for 13 years to accommodate the needs of her care-recipient. Could she have continued her career path toward national prominence as a psychotherapist? Based on the information from my interviews, to accommodate caregiving her partner Margie attended to clients in a small home office in an economically challenged town with a dwindling year-round population. Sacrificing opportunities for personal achievement in order to fulfill caregiving duties is a problem that women, of all educational and professional levels, continue to struggle with. It is also an area in which society continues to provide inadequate supports—supports that could lessen this struggle.

Typically, the cost of informal care is calculated by using the replacement cost for care, which sets the estimated cost at what the job of homemaker or health care attendant would be paid. For Margie this method of estimating costs does not accurately depict the economic losses associated with her caregiving. But the fact that caregivers like Margie—or like former Supreme Court Justice Sandra Day O’Connor, who was known to bring her husband with AD to work—make professional choices based on their ability to provide care and support to a spouse or partner with dementia, means that this is another social cost in need of consideration.

Because the average AD caregiver is working age and predominately female, there are costs associated with unpaid leave, reduced hours of employment, lower Social Security contributions, lack of advancement, future health costs, and the fact that the stress of caregiving may impact the caregiver’s risk for needing long-term care in the future. This is why Weiner, a policy expert, stated that gender is a topic that cannot be ignored. “In virtually every way, long-term care is a women’s issue. Because of greater longevity, long-term care is primarily needed by elderly women, and women are overwhelmingly the main providers of both formal and informal care” (Weiner, 2003, p. 19).

In addition, out-of-pocket costs can be significant and pose barriers to the provision of care. For example, two of the study care-recipients were Medicaid qualified and had been for many years before their participation in my study. At the time of my study, for a care-recipient in Massachusetts to qualify for Medicaid he or she must show less than \$2,000 dollars in assets as well as a monthly qualifying income; yet Medicaid does not pay for home modifications, which might include installation of grab bars, wheelchair-accessible doorways and thresholds, or ramps. This lack of Medicaid coverage means that care recipients who have little to no savings must rely on the family caregiver—who may or may not be working outside of the home because of the time constraints of family caregiving—to pay for modifications to the home that will help keep the care recipient safe.

Research Question 2

What are the current community- or home-based services that the family caregivers and care-recipients in my study relied on? Are these services adequate?

Simply put, the services currently offered on Cape Cod are not adequate to meet the needs of family caregivers who are caring for a family member with dementia in the community. All three caregivers in my study did turn to some type of formal care in the community, and although what was available to them was undoubtedly helpful, they could have used so much more help. The following is a description of services utilized by case.

In Margie and Terri's case, they used Medicaid's Personal Care Attendant (PCA) Options program, Meals on Wheels, and the Massachusetts Home Care Program administered by Elder Services of Cape Cod. Greg was able to access a social adult daycare program for Jill, a caregiver support group at the local Council on Aging, and the Massachusetts Home Care

Program from Elder Services of Cape Cod. Wilma took advantage of free dementia education and phone consultation from Alzheimer's Services of Cape Cod and the Islands; she also was able to connect into Medicaid's Caregiver Homes program, the Massachusetts Home Care Program from Elder Services of Cape Cod, Meals on Wheels, and a caregiver support group at the local Council on Aging. Wilma's mother, Kate, attended the social day program at the local COA as well as meeting the qualifications for Hospice and Palliative Care of Cape Cod, a Medicare benefit.

Arbitrary nature of access. What was so unwieldy was the almost arbitrary nature by which caregivers gained access to formalized care in the community. For example, Wilma found out about the Caregiver Homes Medicaid program first from a hospital social worker in the Boston area after a hospitalization and then from Elder Services of Cape Cod. Margie learned of Medicaid's PCA Options program through a friend who worked in the health care field. Greg, who did not qualify for Medicaid, paid on a sliding scale for the homemaker services he accessed through the Elder Services Home Care Program.

Studies have shown that the early use of community-based services can help families delay institutionalization (Gaugler et al., 2005a; 2005b). Nonetheless, family caregivers are usually left to fend for themselves when looking for services. Without a case manager to help him access paid services, Greg's only formal help, besides the visiting homemaker, was a social daycare program his wife attended three days a week. This he managed for 9 years with the help of his daughter.

Lack of coordinated care. Programs in the community were accessed from different agencies that allowed for multiple entry points into various programs and services. This created

inefficiencies and duplications, causing the care to be fragmented and lacking in overall coordination. For example, Wilma worked with a number of services and professionals—a care manager from Elder Services, a social worker and a nurse from Hospice and Palliative Care of Cape Cod, a social worker and a nurse from Caregiver Homes, and an outreach worker from her local COA. This produced multiple monthly visits by two different nurses and multiple visits by two different social workers. Wilma did not need two nurses or two social workers coming to the home but she certainly needed more home health aides. Despite this duplication, she had unmet needs and it was still up to her to manage and schedule her mother's care so she had help dispersed throughout the week. Because each agency had specific scheduling limitations, Wilma sometimes did not have help when she needed it. If, for example, the home health aide from Elder Services cancelled one day, Wilma was on her own; the services set their schedules in advance, so she could not call a different organization for help on short notice. Also, when Wilma's care-recipient needed more care it was her responsibility to petition for help, even with all those care professionals making monthly visits. If additional care was not available, she went without it. Wilma always operated as the care manager, and she was responsible for organizing and providing the default care.

The idea of more consumer-driven care is the concept behind Medicaid's PCA Options program. This was the program Margie helped Terri enroll in, which allowed Margie more flexibility to tailor the care Terri needed around her work schedule. It gave Margie enough help to continue working during the day, which then allowed Margie to provide the care Terri needed in the evening and early morning. The difficulty was that the PCA reimbursement rate was lower than the going hourly rate. This left Margie to make up the difference between the \$12.50 an

hour she was authorized to spend and the \$15 an hour it cost for care. The 58 hours of care provided by the Options program was a substantial benefit, providing enough support so that Margie could continue working. Because Margie was still working, making over \$50 an hour, she could not access the Caregiver Homes Medicaid program that granted Wilma a roughly \$49-a-day stipend for the caregiving services she was providing. (Wilma was no longer considered a paid worker, so she did not pay taxes on or have deductions for Social Security or Medicaid taken from her stipend, nor would she be eligible for Disability or Worker's Compensation.) The other difference between the two Medicaid programs was that Margie could use her money to pay for some respite care if needed, while for Wilma it was expected that another informal family caregiver would provide respite if she needed it. For Wilma, the Hospice and Palliative Care of Cape Cod respite benefit was crucial to her continuing to care for her mother in the community. This benefit gave her 5 days away every 3 months, which she looked forward to and used every time it was offered to her.

The manager at Elder Services of Cape Cod defines her job as a “manager of services” rather than a “case manager.” With a client base of 120 people receiving services in the community, the best she can do is manage the current services provided, leaving a very important need unaddressed: the management of high-stress caregiving cases (Rodgers interview, 2010).

Respite care is a critical support for family caregivers. Research has shown that family caregivers like the ones in my study, who could be referred to as “high-stress caregivers” because they are caring for family members with dementia, were far more likely to have utilized more formalized care such as adult daycare, respite, or home services (Cho, Zarit, & Chiriboga,

2009). As an example, Greg, one of the caregivers in my study, mentioned the stress he experienced from the constant repetition of stories his wife told repeatedly without cease for 9 years. We cannot know whether a periodic respite from caring for his wife would have enabled Greg to care for her longer at home, but experience tells us that better caregiver supports do allow families to extend the time they are able to care for their loved ones with dementia at home. Because we do not frame family caregiving within the context of other kinds of work or employment, we do not appreciate the need for a break—whether a weekend off or a longer vacation—from the stress of caregiving. It would hardly be reasonable to expect an employee to work a stressful job for 9 years without a break.

The principles embodied within the Massachusetts *Olmstead* plan. Family caregivers often have no time off until the day comes when “they can’t take it another day,” a phrase spoken numerous times during many of my initial interviews with family caregivers that had placed a family member in a nursing facility. This is not the vision set forth in either the *Olmstead* decision or the principles of the Americans with Disabilities Act (ADA, 1990). The principles of the ADA and the *Olmstead* decision have been made operational within the Massachusetts “Community First” Plan. Alignment with the principles embodied within the Massachusetts plan would mean that long-term care policies would consider the needs of both the care-recipient and the caregiver as vital members of our communities. Family caregivers provide a natural link between needed community services and their care-recipients and they need to be brought into the policy equation and supported in their role as caregivers.

Research Question 3

If a study participant has utilized a nursing home placement for his or her care-recipient, what were the reasons for placement? Did the “caregiver’s burden” influence the need for placement?

During one of my initial interviews with family caregivers, a caregiver told me, in reference to nursing home placement, “You just know when it’s time. The day comes when you can’t do it for another day.”

My study began with only one care-recipient in nursing care, and 7 months later, two of the three families had their care-recipients in nursing home placements. The third family caregiver began struggling with the idea of placement during the last 2 months of my study and 2 months after the completion of my interviews, she decided on a nursing home placement for her partner. My observation of these two families struggling with this issue during their participation in my study without any real guidance or counseling was profoundly moving. The decision to institutionalize a family member was the most difficult choice these family caregivers had ever made, and they made the decision with little outside support.

High caregiver stress has been correlated with the decision to institutionalize a care-recipient (Spillman & Long, 2007, 2009). Another explanation is the “wear and tear hypothesis,” which interprets the duration of care as a contributing factor to caregiver burden, and a factor in the decision to institutionalize a care-recipient that spans the entire caregiving experience (Gaugler et al., 2005). Both of these issues seemed to influence the decision to institutionalize, but there are many other factors that come into play, including the absence of an available family

caregiver to provide backup care, inadequate financial resources, and a general lack of coordinated and affordable care in the community.

In Wilma's case, after she had been caring for her mother for 4 years, health issues forced her to use emergency nursing care for her mother; in other words, she could no longer physically provide care. When this health emergency occurred, Wilma lost her \$49-a-day stipend from the Caregiver Homes program; also, she lost the meager contribution of her mother's Social Security toward living expenses when her mother went into the nursing home. Still, the mortgage needed to be paid in spite of the unhealed abdominal injury she had incurred from lifting her mother.

Additionally, although she was being paid for a specific job—the full-time care of her mother—she was not classified as an employee of the Caregiver Homes program, leaving her ineligible for Workmen's Compensation benefits for the injury sustained while performing that job. Such is the invisibility of the caregiver of a person with dementia in the community.

The truth is that nursing home care may be inevitable for many people with dementia, but for many who could remain safely in the community with a caregiver we need to implement evidence-based caregiver interventions that demonstrate a reduction in caregiver stress as well as delays in institutional placements of care-recipients. This policy shift will enhance and strengthen the naturally occurring partnership between informal and formal care in the community for families caring for a relative with dementia.

Research Question 4

Do current state and national long-term care policies address the needs of people with AD or dementia living in the community? Does a bias exist within current long-term care policy toward the provision of formalized long-term care in institutions?

Currently, both a national and state AD plan is being formulated and hopefully in the near future will be implemented to meet the specific long-term care needs of people with AD or dementia, or to provide support services to their caregivers. Unfortunately, for the family caregivers in my study these plans were only being discussed during their time as primary family caregivers in the community. More generally, the financing of long-term care in the United States is grossly inequitable from one family to the next. Families who need long-term care enter into the equation with variable degrees of wealth. Some have the financial means to pay for care, a small percentage has long-term care insurance, and a majority of Americans could not pay for 1 year in a nursing facility. The three families in my study were representative of this range of resources: two care-recipients were Medicaid qualified and one was not, which meant that care-recipient's family paid privately for her care.

Currently, whether you start out impoverished at the time you need long-term care, or whether you become impoverished, the outcome is the same: care-recipients must meet poverty guidelines in order to receive assistance in the form of Medicaid. Given the length of the disease progression, the expense of long-term care, and the likelihood that a care-recipient with AD or dementia will need nursing care, it is not hard to see why Medicaid is the largest funder of long-term care. The cost of nursing care is made clear in Greg's case, where he has paid an average of almost \$9000 a month for the past three years for Jill's nursing care. Obviously, her \$40 a day daycare at the local COA was a substantially lower monthly cost of \$800 a month for five days per week of care. According to Greg, his attorney has made him aware of the fact that most likely he will reach the financial threshold for Jill to qualify for Medicaid during her nursing home stay.

Nearly half of all nursing home patients in the United States are Medicaid-qualified, meaning that, according to federal guidelines (with states having some flexibility since the program is jointly funded), each beneficiary generally has less than \$2,000 in assets and meets income limitations within federal poverty guidelines.

As discussed previously, only a very small percentage of the adult population in the United States had private long-term care insurance (Feder et al., 2007). Americans relied on Medicaid for a majority of the financing of long-term care, a fifth relied on Medicare, and almost another fifth spent out of pocket. Given that Medicaid is the largest payer of long-term care, where does Medicaid spend the bulk of those dollars?

Only 20 percent of the total long-term care budget was spent on the 8.8 million Americans who resided in the community, while more than 50 percent was devoted to the 1.5 million who resided in nursing homes in 2005 (Feder et al., 2007). These numbers indicate the higher cost of institutional care compared to home care services in the community. Moreover, while institutionalized care is an important option for AD caregivers and care-recipients, it should not be the only option. Watts (2009) stated: “There is a well known bias in Medicaid policy that steers people with long-term needs into an institutional setting while most beneficiaries would prefer living in their own homes or community while receiving services” (p. 1). Wilma and Margie pieced together care in the community for as long as possible, which required both caregivers to provide hours of direct care to their family members with dementia at considerable financial, social, emotional and physical costs. Jill and Terri were both Medicaid-qualified during this time, which meant that a nursing home placement would have

instantaneously relieved their family caregivers of their direct care responsibilities and reduced many of the burdens associated with the care they provided.

The Alzheimer's Association and NAC (2004) study compared elderly people dwelling in the community with elderly people who become institutionalized. The findings showed that women without spouses or children were less likely to remain in the community, as were people with little financial means. These are common determinants influencing whether a care-recipient will receive care in the community or in an institution. Quality of life, the affordability of community care versus institutional care, or the severity of the disability have little impact on whether or not a care-recipient with long-term care needs remains in the community. The two main factors remain consistent: (1) finances and (2) whether or not there is a family member willing to provide care.

Given the cognitive decline associated with AD or dementia, the lens of the Americans with Disabilities Act that requires that "individuals with disabilities receive public services in the most integrated setting appropriate to their needs," a disconnect exists between current long-term care policies and the intent of the 1999 Supreme Court *Olmstead* decision. *Olmstead* ruled in 1999 that unnecessary institutionalization of individuals with cognitive disabilities was a form of discrimination. The scope of *Olmstead* is very broad, both in its application and in its interpretation of disability. The Court required that community-based services be made available by the state, but ADA regulations do not require states to "fundamentally alter" existing programs. Rather, states were required by the Court to make "reasonable progress." In the case of people disabled by AD and dementia, do the programs that exist currently constitute "reasonable progress"?

If cuts in the 2010 Massachusetts budget were any indication of progress, I would say the answer to that question is no. The legislature cut funding for both the Medicaid Personal Care Attendant Program and the Elder Affairs Home Care Program. All three families participated in the Massachusetts Home Care program as reported by family caregivers. Imagine what a reduction in this program would do to families like Wilma's or Margie's? Budget cuts signal that community care in Massachusetts is not making the progress it should (Massachusetts Budget and Policy Center, 2010). Especially since we know that we can care for three people in the community for what it costs to care for one person in a nursing home (AARP, 2009). In Greg's case the cost savings between community care and nursing home care is well substantiated. Yet, we have not committed to a greater allocation of funds to community care, nor developed a partnership between informal caregivers and more formal care.

Research Question 5

What alterations in more formalized care services or in additional support services could alleviate "caregiver burden" particular to people with AD or dementia living in the community?

My cases illustrate what we know from the literature: "Family caregivers—untrained, under supported and unseen—constitute a 'shadow workforce' acting as geriatric case managers, medical record keepers, paramedics and patient advocates to fill dangerous gaps in a system that is uncoordinated, fragmented and often depersonalized" (Bookman & Harrington, 2007, p. 1005). All family caregivers in my study never received formal dementia caregiver training and all were in charge of coordinating and organizing the care for their care recipients in the community, as well as filling any gaps in care. Caregiver counseling interventions were not offered or readily available to caregiver study participants in the community.

The problem is not insurmountable: we know how to reduce caregiver burden. We simply have not implemented the programs that we know would work. Greg received very little support besides his monthly attendance at his local caregiver support group, which he stated was extremely beneficial. The groundbreaking NYU caregiver study demonstrated that six in-person counseling sessions and a counselor available by telephone could reduce caregiver depression and positively impact caregiver burden while at the same time delaying nursing home placements by more than a year (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman et al., 2006). Supporting dementia caregivers could have a profound impact on the delivery of informal care, could improve the lives of family caregivers, and could possibly allow them to care for their care-recipients longer in the community.

Another significant multi-national study, Resources for Enhancing Alzheimer's Caregiver Health (REACH), demonstrated the positive impact of even a very brief, easily replicated, and relatively inexpensive intervention for family caregivers; although both caregiver and care-recipient benefit from such interventions, our current policies do not provide for these programs (Burns et al., 2003; Nichols et al., 2008, 2011). When a care-recipient has qualified for hospice care, a caregiver becomes eligible for respite care. Wilma benefited from the hospice respite program because Kate was far enough along in her disease progression to qualify for this Medicare benefit. Unfortunately, because of the need to be hospice-qualified to receive the respite benefit, this program is provided very late in the disease progression. A care-recipient is qualified for hospice after a doctor has certified the care-recipient is in the end-stage of AD or a related dementia disease with possibly 6 months or less to live (though a patient can be recertified and remain a hospice patient well beyond the 6-month certification period). We

already provide a respite program to family caregivers as part of the Hospice Medicare benefit. So Medicare knows families need respite care.

The question is: How can we balance current health care spending to include more long-term community-based services and supports? The formal care received in the community by the care recipients in my study was fragmented and contained large gaps in the provision of care. Family caregivers were operating as case managers and direct care workers with little or no respite services until the care recipient was near the end of her life (hospice-qualified) or was placed in nursing care. Even though Wilma and Margie had access to care managers, nurses, and social workers, no emergency plan was ever formulated in case of a caregiver emergency. Margie hesitated to call 911 when she thought she might be having a cardiac event or heart attack because she did not have an emergency plan in place for Terri. Luckily for Margie, it was only pneumonia.

Chapter 6: Policy Recommendations and Conclusion

Introduction

“Power is everywhere . . . because it comes from everywhere” (Foucault, 2001, p. 96). So wrote Paul-Michel Foucault, a French philosopher and sociologist born in 1926. This idea challenged the notion that power moves only from the top to the bottom of a hierarchy, until eventually reaching the base. If Foucault’s theory is correct and power has the inherent capacity to move up and down, forward and backward within any group of people, then within any society the capacity for change is ever present. A shift in the culture of family caregiving could be initiated by past and current informal family caregivers who individually may command very little authoritative power in their day-to-day lives filled with lifting, toileting, and bathing, but if ever mobilized could become a powerful political coalition. Various grassroots movements have emerged from the base of our hierarchal system, and by creating momentum have influenced the cultural center of an issue. Family caregivers constitute a very broad base of American culture and by their sheer numbers, if ever organized, could influence public policy in this area.

At the very least, as family caregivers become more visible within the context of public policy, they may become more of a consideration to policymakers (Stone, 2002). Some 10 million family caregivers currently provide care to a family member with dementia in the United States; and as our population ages the prevalence rates of AD and dementia will increase, along with the need for both formal and informal caregivers.

From the micro to the macro, I have studied and observed informal family caregiving in my literature review and in my research in the context of the home and community. The firsthand observations compiled from my case studies coupled with my own personal caregiving

experience and professional consultations with 500 families living on Cape Cod and the Islands have informed my ideas about potential policies that could influence family caregivers. I have formulated the following policy recommendations.

Policy Recommendations

Community Care Corps

Create a Community Care Corps, which would be a volunteer force of trained dementia companions to assist families registered through the Massachusetts Home Care Program with companion or “custodial” care.

The Community Care Corps would be a volunteer force of trained dementia care volunteers, organized potentially as a pilot program through Elder Services of Cape Cod and the Islands, which is one of Massachusetts’s 27 Aging Services Access Points (ASAP). This program would use federal and local grant funding to train, conduct Criminal Offender Record Information (CORI) searches, and provide a workforce of volunteer dementia companions to families providing care for a loved one with AD or dementia-related illness in the community, as modeled after the Benjamin Rose Institute’s volunteer program (2009). The Community Care Corp could replicate the Hospice and Palliative Care of Cape Cod’s Volunteer Program, but it would be available for people in the community with AD or a dementia-related disease. This program provides companion care to people receiving hospice care at home. Wilma’s mother, Kate, received a volunteer from this hospice program; I had a chance to sit with her on the night of Wilma and Doug’s anniversary. Vicky was an important part of Wilma’s team—trained, knowledgeable, and dedicated to both caregiver and care-recipient. Because Wilma and Doug had a volunteer to call, they were able to go out to celebrate their anniversary. This volunteer

program could be connected to “aging in place” programs such as Beacon Hill Village in Boston or Nauset Neighbors on Cape Cod, which are part of a village network that attempts to supply a menu of services to seniors living at home and in their communities. A pilot program could be funded by local grants and the volunteer care delivered by seniors could be made sustainable by utilizing the number of aging baby boomers retiring to Cape Cod.

The program could receive grant funding for start-up costs and attract retirees who can spare 3 hours a week for one visit per family. Senior volunteers could receive stipends at \$8 an hour. This is well below the current cost of \$24 an hour for a home companion with a minimum of three consecutive hours. The program costs are \$24 stipend for a 3-hour respite visit. This reduces the cost of respite substantially for families. This cost savings could create greater utilization of respite by more families or it could provide a number of high stress caregivers with respite for a greater amount of days.

Community Care Alzheimer’s Waiver

Create a Medicaid 1115 waiver program in Massachusetts, called the Community Care Alzheimer’s or Related Dementia Waiver, which would address the needs of Medicaid beneficiaries with AD or dementia-related diseases, as well as provide a respite program for their caregivers.

This 1115 Medicaid waiver would provide home- and community-based services to Medicaid participants who have AD or dementia-related disease. The waiver would increase the asset limit to \$10,000 to allow care-recipients to qualify for services in the community before they become impoverished, and keep the current \$2,022 income benefit, which is currently available within a currently available waiver called “1915c Frail Elder Waiver.” The higher asset

limit would also allow for more wiggle room as families transition through increasing services, and would allow some available money for out-of-pocket emergency care if needed. This waiver addresses the needs of dementia care-recipients as they move into the mid-stage of the disease, when 24-hour care becomes increasingly necessary to keep a care-recipient safe. This waiver program would provide access to companion care or local daycare services, as well as a caregiver respite program for care-recipients and their primary caregivers choosing to reside in the community. The language of this waiver would acknowledge the partnership between informal caregivers and more formalized care in the community. The respite program would be available to any primary caregiver whose caregiving responsibilities exceed 40 hours per week.

The *Olmstead* decision could be used as a catalyst for the provision of this program because this Community Care Alzheimer's and Dementia-Related Disease Waiver would be consistent with two principles in *Olmstead*. First:

Institutional placements of people with disabilities who can live in, and benefit from, community settings perpetuates the unwarranted assumptions that persons are so isolated are incapable or unworthy of participating in community life. (*Olmstead v. L.C.*, 1999, p. 2176, 2179, 2187).

And second:

Confinement in an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment. (*Olmstead v. L.C.*, 1999 p. 2176, 2179, 2187)

Currently, lower-socioeconomic-status community-dwelling elders with cognitive disabilities and long-term care needs are less likely to remain in the community because of economic factors (O'Brien, 2005; Summer, 2005). These barriers for care-recipients and family caregivers need to be broken down if *Olmstead* is ever going to be realized in Massachusetts.

This policy recommendation is consistent with my review of *Olmstead* and the 21 legal cases currently listed as applicable to *Olmstead*. *Olmstead* is agnostic in its application to various disabilities and many of these lawsuits do not differentiate between types of disabilities (McGuire, J. personal interview, Dec.8, 2010). The one lawsuit, filed by Michela Leocata, a plaintiff with dementia, was denied standing by a federal court when she attempted to remain in an assisted living facility as opposed to moving into a nursing home, claiming her needs for a less restricted environment under *Olmstead* were not being met. *Leocata* wanted to remain in the assisted living facility, but she could no longer afford the rent (*Leocata v. Wilson-Coker*, 2004). The claim was denied because *Leocata* was not Medicaid qualified at the time of her lawsuit. The 1999 *Olmstead* decision gives support to the notion that people with disabilities want to reside in the least restrictive environment available, be included in our communities, and increasing access earlier to publically funded long-term care supports could help keep people in the community longer by delaying costly nursing home placements. In Massachusetts the cost of a one-year delay could equal some portion of the \$75,000 average annual cost of nursing care.

Long-Term Dementia Care Community Support and Services Center

Create a local Long-Term Dementia Care Community Support and Services Center to provide a single point of access for services and supports in the local community for families dealing with AD or a dementia-related disease. This center would be the axis for long-term care supports and services in the local community. It could attract federal and state demonstration grants to implement evidence-based family caregiver intervention programs, including a model for care consultation and respite care program.

Caregivers and care-recipients need a single point of entry to obtain information about Alzheimer's disease and other dementia-related diseases as well as an access point to initiate long-term care supports and services. Currently, the local senior center, local health care facilities, local AD agencies, and Aging Service Access Points (ASAP) already provide numerous points of entry for members of the local community.

A single local access point, a center or hub where families and family caregivers could go to get the support and services they need in the community, would create a monumental shift in how people with dementia-related diseases, and their families, access support services. The center could utilize local organizations, handle training and intervention programs, and ensure services are available to anyone regardless of income or insurance qualifications. The Center staff would be represented by highly trained counselors that are readily available to handle difficult cases, train informal caregivers, and offer mental health counseling services to family caregivers and their family members with dementia-related diseases.

The work of the Center would also be to link families to other dementia and long-term care services such as the Safe Return Program, which registers people with dementia living in the community in case of wandering, and other referral resources. Center staff would be available for emergency response workers so they would have a contact in the local area. For example, Alzheimer's Services of Cape Cod and the Islands (ASCCI), the local Alzheimer's organization for Cape Cod and the Islands, already provides education and telephone counseling, and manages a small respite program for family caregivers.

This Center would expand support and services by having mental health counselors trained in dementia-specific information to do care consultation, education, and family

interventions, modeled after the NYU interventions, but licensed to accept insurance reimbursements. Free services would also be readily available for those families without the availability of an insurance reimbursement.

The Center would have a respite program modeled after the Alzheimer's Services of Cape Cod and the Islands respite program, which currently provides small grants (\$350–\$500) annually, or the respite program could be expanded to offer a longer respite of 5 days in emergency situations. Given what we know about the burdens of family caregiving and how these burdens impact the health of family caregivers, a periodic respite may provide many cost-saving benefits to both the caregiver and the care-recipient (Cheung, 1988; Cho, Zarit, & Chiriboga 2009; Conlin, Caranasos, & Davidson, 1992). The Center would make respite services a priority for families and growing this program would be a priority for Center staff. The goal would be to help every family caregiver utilize at least one respite per year. Connections with local agencies could also be leveraged for affordable respite care. Research grants could be explored to measure caregiver outcomes once interventions are implemented. A PhD-level clinician should conduct this work to insure validity and reliability of findings.

The Center's provision of these long-term care services and supports could potentially create a savings for families and governmental programs due to delayed placements. These benefits would be measured by calculating actual costs of families participating in intervention research. The Center will have a research unit to partner with regional government and a local college or university to study and measure the effectiveness of all family support and family service programs and evaluate the development of innovative programs.

This policy recommendation bridges the gap between formal and informal care in the community by providing both family respite services and critical supports for family caregivers and their families as a way to tie families into services earlier in the disease cycle. Building a local center or hub for family caregiving could be one big step toward developing strong private-public partnerships to help connect caregivers and their care-recipients with AD to both formal services and family supports in the community. Medicaid spending has estimated a cost of \$13,300 for community-based services and \$33,000 for institutional care (Ng et al., 2010). The generalized cost differential is roughly a 3-to-1 ratio; this suggests that Medicaid can provide services for three beneficiaries in the community for the cost of institutionalizing one person (Kaye, LaPlante, & Harrington, 2010).

Care Consultation Model

Implement evidence-based caregiver interventions in the community by offering family caregivers a care consultation model.

The care consultation interventions would be modeled after the structure used in the NYU caregiver study, which provides both in-person family and caregiver counseling along with telephone counseling for caregivers and people with AD or dementia regardless of the family members' ability to pay (Mittelman, Epstein, & Pierzchala, 2003; Mittelman, Haley, Clay, Roth, 2006). The difference between case management and care consultation is that the consultation model is about empowering the caregiver. The creation of a counseling intervention to reduce the stress associated with family dementia caregiving while providing the education necessary to handle the psychosocial aspects of dementia-related diseases and provide crisis interventions could radically change family caregiving in the community.

Because a cookie cutter model does not fit the individual nature of dementia symptoms, a one-size-fits-all approach does not work for caregivers. The care consultation model allows for an individualized approach to addressing family caregiver needs. This could be an expansion of what is currently a billable behavioral health service currently covered by most insurances. The out of pocket costs are usually a nominal (\$10-20) co-pay for clients in the community. The cost savings of 1.5 year institutional delay can be estimated at \$112,500 per family. Currently the numbers of people on Cape Cod estimated to have a dementia-related illness are 9,500. Obviously not every family can or should delay institutionalization, but if 1000 of those families delayed institutionalization by 6 months a \$37,500 average savings per family could be recognized. Additionally, the counseling intervention could be billable for high stress caregivers.

Expand Home Care Program

Change the income qualifications of the Home Care Program in Massachusetts to allow care-recipients with a diagnosis of AD or other dementia-related illness to participate in this program with an income cap of \$50,000.

The point of loosening the income restrictions for the Home Care Program would be to save both private and publicly funded long-term care costs in the future by offering affordable support for families caring for a family member with AD in the community. The cost-sharing structure would be altered to promote program participation while offering more affordable services to near middle income households. Such a change in income qualification and cost-sharing structure would provide an incentive for families to conserve money rather than spend down in order to qualify for Medicaid. Families could conserve their resources longer, to be used either at the end of the disease or, with enough help, to avoid expensive nursing home

placements if they choose to remain in the community with services, thereby also saving Medicaid dollars. Conservation of resources also preserves independence and dignity in the community. In the long run, this strategy has the potential to incur substantial savings for both the state and individuals.

Additionally, people in the Home Care Program would be connected to the Long-Term Care Family Support and Services Center; a referral process would get them officially enrolled. This referral process would help care managers connect people with the disease with the local community AD organization that provides caregiver interventions including training, education, support groups, and respite care programs.

More important, because home care is a state appropriation and not an entitlement, it is crucial that policymakers are made aware of the cost-savings measures associated with the provisions of this program. The Center, in partnership with the Home Care Program, could produce an advocacy arm to ensure local, state, and federal funding. Further, policymakers must be reminded that community care exists because it is consistent with the principles confirmed in the *Olmstead* decision and that funding, although theoretically “optional,” should not be cut. If care in the community is estimated to cost a third less than care in a facility, the additional program costs could be offset by the delay of expensive nursing home placements for both private and public payers. Since a co-payment is required, the co-pays could be increased to provide an additional funding stream for a greater utilization of clients. The savings realized by an expansion of this program could be delayed Medicaid qualifications for clients who need only a modicum of care to remain in the community as opposed to costly early institutional care.

Massachusetts AD Clearinghouse

Create a Massachusetts Office of Alzheimer's Disease and Related Dementias at the Executive Office of Elder Affairs.

The purpose of this office would be to create a network connecting the newly established National Alzheimer's Office within the U.S. Department of Health and Human Services to the state level. State government will connect with the local AD organization or the Long-Term Care Family Services and Support Center that will be the connecting point to families caring for loved ones with AD within the community. The state office would serve as the clearinghouse for all relevant AD information from federal to state and would complete the web of information pertinent to both caregivers and care-recipients. This state office would create a network or web of connection from the federal to the state to the local. On the local level, the focus would be on identifying every family that provides support to someone with dementia.

Conclusion

Alzheimer's disease was discovered in 1907, and although our knowledge base has expanded in the last 100 years, we still have much to learn, in terms of not only the physiology and biology of the disease process but of the familial, social, and economic impacts it has on our communities.

Margie, Greg, Susan, Wilma and Doug are the family caregivers who generously shared their stories through interviews, journals, and in-home observations. Their narratives and the information they provided allowed a glimpse into their lives as family caregivers; through their generosity, I gained access into what is usually a very intimate and private place.

Many costs of informal care are not easily discernable, although they exist. These costs need to be explored by future research. The cost of informal care is usually calculated using the replacement costs for care; however, since these caregiving jobs are relatively low paying, the cost estimation is inevitably quite low. For example, this method of estimating costs would not accurately depict Margie's economic loss associated with her caregiving. The economic costs associated with Wilma's caregiving are not so easily calculated either, due to the fact that when she was employed outside the home she was classified as an employee and was therefore eligible for Workmen's Compensation benefits as well as for unemployment benefits if she ever lost her job. The Medicaid program that compensated Wilma for caring for her mother, did not officially classify her as a worker. Such is the invisibility of the caregiver of a person with dementia in the community: the work done by family caregivers is not recognized nor acknowledged as work.

In light of what the subjects in my study have taught us about the perils and stresses of family caregivers, they have also allowed us to witness their fierce dedication and unwavering commitment toward keeping their family members with them in the community for as long as they were physically and emotionally able to do so. It is my contention that this commitment alone warrants a further exploration of the application of the 1999 *Olmstead* decision in the area of dementia caregiving in the community. Clearly, our current policies do not reflect the concerns expressed over and over again in their stories. It is the challenge of this generation to find new perspectives and innovative solutions for the expanding need for long-term care in our communities that include supports for family caregivers who provide the bulk of the daily care.

I am reminded of the first few lines from Adam Phillips's book *Equals* (2003, p. vii): "If the best thing we do is look after each other, then the worst thing we do is pretend to look after each other when in fact we are doing something else."

The author may have been writing about the psychoanalytic world, but policymakers, too, would do well to similarly pay attention to the importance of people actually looking after each other, as opposed to pretending to do so. If we want to support our families and our communities, these values must be reflected in our current policies, not just in our political rhetoric.

The 1999 *Olmstead* decision reinforced the right of people with cognitive impairments to remain in the community for as long as they could safely and reasonably do so with the necessary supports. We have now witnessed how three family caregivers provided the "necessary supports" so their family members with dementia could remain in their homes for as long as possible.

These family caregivers worked beyond their physical and emotional well being in support of their family members' continued residence in the community. Under the mandate set forth in the 1999 *Olmstead* decision, it seems reasonable to support our informal caregivers to the same extent we would aid and encourage any other necessary accommodations in the community. Supporting family caregivers could be the next logical next step in making the *Olmstead* promise a reality.

Caregiving efforts in the community mostly go unnoticed; the care is seemingly "invisible" because the real work of family caregiving takes place in our most intimate and private of places, our homes. For this reason we need more qualitative research on the topic of family caregiving. Ethnographic methods, allow the researcher to access the intimacy of the

home where caregiving occurs- this allows for firsthand observation of the phenomenon of caregiving.

The informal family caregivers of today, if better supported in their endeavors, could become part of the formal caregiving workforce of tomorrow. With the foresight to invest in our already existing human capital with caregiver training, respite services, and long-term care supports for families in our communities, we could welcome the aging of America as just another new frontier, rather than be fearful of our future. Whatever we do we will need to act soon: an aging demographic increases the number of Americans living with dementia who will need long term care (Arno, 2002; Hebert et al., 2003).

Respite care is a critical support for family caregivers and should be implemented within a structured network of care in the community. The creation of a local long-term care family services and supports center could begin to provide some much needed relief to caregivers in the form of available respite services along with education and counseling. It also creates a single point of entry for care consultation for every local family dealing with a dementia-related disease. Considering the arbitrary nature of access by which family caregivers identify current services and supports in the community, a single point of entry could reduce inefficiencies and duplications that cause care to be fragmented and lacking in overall coordination. It gives families who provide care a “center” spot in the local community. It has the potential to transition informal care providers to formal ones. Building a long-term care workforce out of experienced informal family caregivers could become the bridge by which informal caregivers simultaneously transition back into the workforce and satisfy our growing needs for additional health care workers.

I offer one final story that demonstrates the dedication of caregivers to uphold the dignity of those they love, and the support caregivers require and deserve in order to provide such a service. It was told to me by a man named Justin who was helping his mother Katherine take care of his father Allen, whose dementia was progressing rapidly (personal interview, December 2010). Allen had stopped sleeping at night so his family took shifts staying up with him. After three nights in a row no one had slept; exhausted, Justin and his mother had fallen asleep on the couch and awoke to find that Allen and his car were missing. In Justin's words,

We told the police the car had a full tank of gas and that dad was too confused to get very far. He'd get lost by the third or fourth turn. We were keenly worried that he might hurt someone by accident. He had almost no depth perception . . . he hadn't driven in years and the dexterity in his hands and feet was failing. In recent weeks he made more references to his childhood home [of Quincy, Mass.] and although it was extremely unlikely he might possibly be heading for a campground in the White Mountains of New Hampshire. But we were convinced there was no way he'd get through Boston, especially with the tunnels he had never driven through. (e-mail correspondence, Jan. 31, 2011)

The phone rang; Justin picked it up. A total stranger had found Allen walking down a quiet street in a New Hampshire neighborhood, 400 miles and 10 hours away from his home. She promised Justin she would play cards with his father until he arrived. As Justin later wrote to the woman who took his father in:

When [people] say, 'it's too bad he never made it to that campground' I tell them, 'Oh! But he did!' And I tell them exactly what you [the stranger] told me when I picked him up. You pointed to your lawn and said [to my father], 'This is the field, the one where you and your brother used to play softball with the other campers.' Then you pointed to your house and said, 'and this, this is the lodge, the one in the campground.' You looked right at me and said, 'He's there. He's been there all day. He believes this is the campground in the White Mountains where he was going. (e-mail correspondence, Jan. 31, 2011)

A few weeks later, Justin came to my office to tell me that Allen had passed away.

The family caregiver's desire to preserve the dignity of their loved one is exemplified in the gesture of the total stranger who helped Allen make it safely home from his final adventure. Having supports and services immediately available in the community is akin to having access to that kind stranger all the time.

In terms of difficulties, practicalities, and cost benefits, family caregiving makes no sense. Nevertheless, family caregivers accept their roles for a very important reason: they cherish life outside of institutions for the people they love, and they will try, at almost any cost, to provide care for as long as they can. If there is an argument to be made for supporting family caregivers and their family members with dementia in the community, surely this is it.

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