PHANTOMS OF HOME CARE AND VICTIMS OF DESIGNED NEGLECT: A QUALITATIVE STUDY OF HOME CARE NURSE AND SOCIAL WORKER PERCEPTIONS, DECISIONS, AND COPING WITH PERSONS WITH ALZHEIMER'S DISEASE

by

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A dissertation proposal submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Philosophy,
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APPROVAL PAGE

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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Abstract

PHANTOMS OF HOME CARE AND VICTIMS OF DESIGNED NEGLECT: A QUALITATIVE STUDY OF HOME CARE NURSE AND SOCIAL WORKER PERCEPTIONS, DECISIONS, AND COPING WITH PERSONS WITH ALZHEIMER'S DISEASE

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Alzheimer's disease is a major cause of illness and death in the United States, imposing significant social, economic, and psychological burdens on clients and their caregivers. Over 5 million, primarily older, Americans were estimated to have Alzheimer's disease in 2007, with most living at home, cared for by family members or friends (Alzheimer's Association, 2007a, 2007b).

A literature review indicates that there are psychosocial, rather than medical, interventions which currently benefit the Alzheimer's population. Despite these findings, the Medicare home health benefit provides virtually no psychosocial care to this population. The literature review also indicates that there has been no research on how home care social workers and nurses perceive, cope with, and make decisions about this population and the consequent impact on their care needs.

The dissertation addresses this research gap, interviewing thirty-three home care nurses and thirty-nine home care social workers. The overall finding is that the Medicare home health policy, as mediated by home health agencies, nurses, and social workers, significantly influences the care of persons with Alzheimer's disease and their caregivers. Both home care nurses and social workers assert the lack of coverage results in a system with many unmet client and caregiver needs, high costs, and limited quality. As a result,

nurses characterized persons with Alzheimer's disease as "phantoms" while social workers characterized them as "victims of designed neglect".

Overall social workers and nurses conformed to policy, with social workers more *conformist* than nurses. Both social workers and nurses agreed that the more conformist their practice, the more limited the care and greater the unmet client need. Nurses and social workers were virtually equal as *innovators*, seeking creative, legitimate means to provide greater care, and *rebels*, invoking illegitimate means to achieve their goals. These coping strategies validated, in part, pre-existing theory of Merton (1938, 1957). Home care nurses expressed greater job satisfaction, ability to effectively deliver care, and ability to use professional training than social workers.

The dissertation recommends research, policy, practice, and advocacy actions to create more cost-effective Medicare home health coverage of the needs of persons with Alzheimer's disease and their caregivers.

ACKNOWLEDGEMENTS

This study occurred only because of the cooperation of thirty-nine home care nurses and thirty-three home care social workers. They deserve great thanks. Through their words, we learned that the Medicare home care benefit creates not one, but four sets of victims: the professional caregivers (i.e., nurses and social workers), persons with Alzheimer's disease, informal caregivers (i.e., friends, family, and significant others), and the community at large. Hopefully their insights will lead to action to improve available cost-effective Medicare home health for all.

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CHAPTER ONE: INTRODUCTION

Problem Formulation

Alzheimer's disease is a major and increasing cause of illness and death in the United States, imposing significant social, economic, and psychological burdens on patients and their caregivers. The disease progresses with the aging process. Symptoms include a gradual and steady decline in being oriented, a decrease in memory and ability to participate in everyday activities, and personality changes. In the twentieth century, Alzheimer's disease became the most frequently identified type of dementia in the United States and Western society (Cohen, 1998; Whitehouse, 2001). Over 5 million persons were estimated to have Alzheimer's disease in 2007, including 4.9 million over age 65 and between 200,000 and 500,000 under age 65 with early onset Alzheimer's disease and other dementias (Alzheimer's Association, 2007a, 2007b; U.S. department of Health & Human Services, 2008). An estimated 4.5 million Americans, most over age 65 years old, had the disease in 2006 (Alzheimer's Association, 2006; Dementia, 2003; Herbert, Scherr, Bienias, Bennett, & Evans, 2003; Sadick & Wilcock, 2003; Wimo, Winbald, Aguero-Torres, & von Strauss, 2003).

The number is projected to increase to 14-16 million by 2050 at an annual cost of $300 billion, with the international projections at 18 million currently and upward of 80 million persons by 2050 (Whitehouse, 2008; World Health Organization, 2008). Alzheimer's disease is the fourth leading cause of death for Americans aged 65 and older, exceeded only by cardiovascular disease, cerebrovascular disease, and cancer. It is the third most costly disease in the United States, with an estimated annual cost of $100

billion (Centers for Disease Control and Prevention, 2006; McConnell, 2004; Rice, et al., 2001; Sadick & Wilcock, 2003).

Alzheimer's disease is especially frustrating and burdensome to professionals and caregivers alike because there is no known effective medical or pharmacological cure or treatment. Despite extensive medical research on Alzheimer's disease (Albert, 2001; Santaguida, et al. 2004; Stahl & Firth, 2001), studies indicate no medical cure (Gauthier, 2002; Whitehouse, 2001) and little effective medical and pharmacological treatment (Dementia, 2003; Evans, Wilcock, & Birks, 2004; Peterson, 2004; Santaguida, et al., 2004). However, some research indicates that non-pharmacological interventions are effective at improving patient and caregiver symptom management and quality of life (Cohen-Mansfield, 2001; Mittelman, 2004; Rosack, 2006; Schulz, et al., 2003; Small, et al., 1997).

Managing the symptoms of Alzheimer's imposes significant patient and caregiver burdens. Alzheimer's disease patients display a combination of cognitive, behavioral, and functional symptoms. The symptoms vary by individual disease stage and over time (Small, et al., 1997). Cognitive symptoms include memory impairment, speech and language comprehension problems, and impaired judgment. Behavioral symptoms may include personality changes, irritability, anxiety, depression, delusions, hallucinations, aggression, and wandering. Functional symptoms include difficulty with eating, dressing, bathing, toileting, walking, grooming, getting in/out of bed, meal preparation, shopping, moving within and outside the house, money management, and using the telephone or computer.

Caregiver burden also is a major issue for caregivers of persons with Alzheimer's disease and other chronic conditions (Dartmouth Atlas Project, 2006; Kennet, Burgio, & Schulz, 2000; Levine, 2000; Levine, 2003; Levine & Murray, 2004; O'Brien, 2004; Robert Wood Johnson Foundation, 1996, 2001). An estimated 70% of Alzheimer's patients live at home, where approximately 75% of care is provided by family members and/or significant others, with increasing numbers being men caring for their elderly parents (Leland, 2008; McConnell & Riggs, 1999). Most caregivers report increased financial burden from supporting the household and paying out-of-pocket health care costs, estimated nationally at between $15,000 and $18,000 a year. Caregivers' informal care reflects the dominance of personal and family responsibility in Alzheimer's care, as with much American health care. Employers, government, and private insurers provide limited coverage to assist patients and caregivers dealing with the burdens of home-based care (Fried, 2004; Levine, 2000, 2003; Levine & Murray, 2004; McConnell, 2004; McConnell & Riggs, 1999; MetLife Foundation, 2006; Morrow-Hall, Tang, Kim, Lee, & Sherraden, 2005; Society for Human Resource Management, 2003; Robert Wood Johnson Foundation, 1996, 2001). Gibson & Houser (2007) estimate the economic value of family caregiving at $350 billion. Reinhard, Brooks-Danso, Kelly, & Mason (2008) assert that, given the current health care system, as America's elderly population continues to increase, families and other informal caregivers will remain their primary support.

Caregivers often experience increased stress, depression, substance abuse, loss of sleep, health and mental health problems, and increased personal isolation (National Alliance for Caregiving, 2004; Sadick & Wilcock, 2003). Caregiver decline, including

burnout, may contribute to patient health decline and increase the likelihood and speed of patient institutionalization (McConnell & Riggs, 1999; Reinhard, et al., 2008; Schulz, et al., 2004). Placement may not significantly reduce caregiver burden because of the existing negative impacts of caregiving and an ongoing sense of responsibility, loss, and guilt (Mittelman, Roth, Haley, & Zarit, 2004).

Non-pharmacological and social interventions have varying effectiveness in improving patient and caregiver quality of life and symptom management (Cohen-Mansfield, 2001; Schulz, et al., 2003; Sloane, et al., 2002). Social networks, support groups, counseling services, and environmental assessment, modification, and skills-building interventions generate the most evidence of positive outcomes, though there is some evidence of benefits from recreational therapies, respite care, and other psychosocial interventions (Bennett, Schneider, Tang, Arnold, & Wilson, 2006;Cohen-Mansfield, 2001, 2004; Gitlin, Liebman, & Winter, 2003; Gitlin, et al., 2003a, 2003b; Mittelman, 2002, 2004; Mittelman, et al., 1993, 1995; Schulz, et al., 2003). Some research supports the assertion that psychosocial and non-pharmacological interventions may reduce costs of medically-based home, community, or institutional care (Abt Associates, 1998; Brumley, Enguidanos, & Cherin, 2003; Chappell, Havens, Hollander, Miller, & McWilliam, 2004; Gage, et al., 2000; Leon, Cheng & Neuman, 1998; Newcomer, Miller, Clay, & Fox, 1999; Watt, Browne, Gafni, Roberts, & Byrne, 1999).

Despite empirical support for the benefits of home and community-based social services and an estimated 13-17% 2007 annual profit margin, the nearly $15 billion annual Medicare home health program does not cover such interventions (Fried, 2004; McConnell & Riggs, 1999; Medicare Payment Advisory Commission, 2006a, 2006b

2008a, 2008b). The Medicare home health benefit is the major home benefit in America's medical model health care policy (Buhler-Wilkinson, 2002, 2003; Hacker, 1997, 2002; Skocpol, 1997; Starr, 1984, 2004; Vladeck, 1997). Likewise, the *medical model* assumes patient conditions are acute and can be treated and cured using medical technology, treatments, and drugs (Conrad, 2001; Dubos, 1959; Starr, 1984). The *medical model* dominates research on the definition, diagnosis, cause, prevention, treatment, and cure of Alzheimer's, focusing primarily on pharmacological interventions (Cohen, 1998; Gubrium, 2000; Whitehouse, 2001).

Medical Model

The *medical model* also creates a restrictive Medicare home health benefit. Thus, Medicare requires that an eligible home health patient be homebound; in need of skilled, part-time or intermittent skilled nursing care or physical therapy; and have a condition with a finite and definite end point prescribed by a physician-certified plan of care (Health Care Financing Administration, 1999). If eligible, the patient may receive additional skilled nursing, physical therapy, speech therapy, occupational therapy, home health aides, or social work services. However, there is no coverage for respite care, support groups, counseling services, home modifications, personal care services or any services for caregivers, unless they separately meet the eligibility requirements. In fact, Medicare did not recognize Alzheimer's disease as an approved home health primary diagnosis until 2001 (Smarr & Carson, 2006). Even now, the only explicit home health Alzheimer's disease coverage designated by Medicare is limited home health nursing teaching and training, and not all home health nurses may be aware of the coverage (Cabin, 2006b; Smarr & Carson, 2006).

As a result of the dominance of the medical model, Medicare regulations do not permit social workers to initially assess clients or develop the plan of care. Instead, nurses, or in some instances physical therapists, must conduct initial assessments and develop the client's plan of care for physician certification. Covered social work services are limited to assessing the client, only upon a nurse or physical therapist referral; assisting the client to obtain community resources, though social workers may not assist the client or family in completing Medicaid or other applications; and making two to three counseling visits to the client's family member or caregiver, only if designed to remove a clear and direct impediment to client treatment or rate of recovery (Centers for Medicare & Medicaid Services [CMS], 2006a). As a result, social work historically represents only one to two percent of all national Medicare home health visits (Medicare Payment Advisory Commission, 2003, 2004a, 2004b). A recent Medicare Payment Advisory Commission report indicated that home health social work visits represented only 0.3 of the 31.6 visits per 60-day episode in 1998 and had dropped to 0.1 of the 22.0 visits per 60-day episode in 2007 (Home Health Line, 2009). However, there is even less use of social work services in Medicaid home health because social work is not a required service under federal Medicaid legislation (National Association for Home Care & Hospice, 2006).

Research also indicates that social workers, nurses, home health aides and family members recognize that limited social work services, among other limitations, result in significant unmet client and family needs during home care and post-discharge (Egan & Kadushin, 1999, 2001, 2004, 2005; Kadushin & Egan, 2003, 2008; Hokenstad, Hart, Gould, Halper, & Levine, 2005, 2006; Lee, 2002; Lee & Rock, 2005; Levine, Albert,

Hokenstad, Halper, Hart, & Gould, 2006). Other research indicates that Medicare eligibility, coverage, and reimbursement requirements pressure nurses and social workers in healthcare to provide fewer services, less time to direct patient care, and shorter lengths of stay; and to be cost-conscious, particularly since Medicare adopted managed care model prospective payment systems (Berger, 1996, 2005; Kadushin & Egan, 2003; Mizrahi, 1993, 2001; Weinberg, 2003). However, there are no studies of how home care nurses and social workers perceive and cope with Medicare requirements and how the requirements affect care decisions about Alzheimer's disease persons (Cabin, 2005, 2006a, 2006b, 2006c). Such research seems essential to prudent policy design, given that the nurses and social workers directly service and experience both the needs of persons with Alzheimer's disease and the success of care interventions.

Palliative Care Model

The *medical model* contrasts with the *palliative care model*, which is part of a more *holistic model* of care. Palliative care is most frequently associated with terminal conditions, end-of-life, and hospice care. Palliative care assumes treatment is not curative and focuses instead on patient, caregiver, and family psychosocial and spiritual needs, symptom management, and quality of life (Center for Medicare Education, 2001; National Hospice and Palliative Care Organization, 2004a; World Health Organization, 2004). Some physicians and other professionals advocate combined use of medical and palliative care as an effective lifelong basis for care regardless of proximity to death, especially for chronic illness, which appears most appropriate for home care-based treatment of persons with Alzheimer's disease (Jerant, Azari, Nesbitt, & Meyers, 2004; Small, et al., 1997). This combined approach, also referred to as the bio-psychosocial

model, integrates the quality of life focus of palliative care in a way that appears most appropriate for home care-based treatment of persons with Alzheimer’s disease.

The Hospice Medicare Benefit (HMB) is an exemplar of the palliative care model, although it is restricted to terminally ill persons. The HMB provides Medicare-required respite care, pastoral care, and volunteer services and the six Medicare Home Health Benefit services to persons physician-certified with a prognosis of six months or less to live (Medicare Payment Advisory Commission, 2006b). Volunteers are required by Medicare hospice, accounting for an estimated 13% of all clinical hours in 2003 (National Hospice and Palliative Care Organization, 2003a). Hospices also provide a variety of other covered palliative care services including, but not limited to, music, art., pet, aroma, and other therapies.

Social work is more extensive in hospice care, representing an estimated 9% of all full-time-equivalent hospice employees (FTEs) and 10% of all hospice visits compared to approximately 2% of home health FTEs and 1to 2% of all Medicare home health visits (National Hospice and Palliative Care Organization, 2003b; National Association for Home Care, 2003). The Centers for Medicare and Medicaid Services (2006b) also has a specific set of national guidelines recognizing Alzheimer’s disease and related disorders as a basis for HMB-covered terminal care. As a result, Alzheimer’s disease and related disorders is the second highest non-cancer primary diagnosis for the HMB, representing 8.3% of all HMB primary diagnoses in 2002 (National Hospice and Palliative Care Organization, 2003b).

The current conception and nature of the practice, policy, and research problems involving Alzheimer’s disease is informed by its historical development.

Historical Background

Overview

Alzheimer's disease was not recognized as a distinct medical disease until 1907 and its status as a distinct disease is still debated (Beard, 2004; Berrios, 1996; Cohen, 1998; Holstein, 1997). The major rise in Alzheimer's disease identification and public awareness occurred primarily in the United States and Western Europe beginning in the 1970s and 1980s. The rise of Alzheimer's disease as the definition inclusive of all types of dementia is attributed to a social movement that involved medical researchers, pharmaceutical companies, family support groups, and the growth of anti-ageism in America (Beard, 2004, Cohen, 1998; Fox, 1989, 2000; Gubrium, 1986, 1987, 2000).The culmination of this movement was the founding of the Alzheimer's Association in 1980, resulting in hundreds of millions in government funding in the last two decades, primarily for biomedical research for effective medical treatment and a cure (Ballenger, 2006; Beard, 2004).

The increased prominence of Alzheimer's disease as a social problem reflects these stakeholders' ability to convince both government and the public that their definition of the problem deserves recognition and funding. The definition of Alzheimer's as a medically-caused and medically-curable disease persists despite no evidence of a cure, limited evidence of progress in pharmacological treatments and diagnostic technology, and a continuing debate about whether Alzheimer's is a unique disease (Santaguida, et al., 2004; ten Have & Purtilo, 2004; Whitehouse, 2001).

The Discovery

Prior to 1906, the term “Alzheimer’s disease” did not exist in many medical circles or existed without a consensus definition (Ballenger, 2006). According to Berrios (1996), “… the psychiatry of the late nineteenth century is still a remote country: concepts such as dementia, neurone, neurofibril, and plaque were still in process of construction and meant different things to different people” (pp. 195-196).

Alois Alzheimer, a German neuropathologist, first wrote about what later was called Alzheimer’s disease in 1906. At the time, he was director of the research laboratories at a new psychiatric clinic in Munich headed by his mentor, Dr. Emil Kraepelin, a leader in German psychiatry who was author of a widely-read psychiatry text. In his autopsy of one 51-year-old woman, Alzheimer found “atrophy and lesions in the area of the cerebral cortex and an unusual clumping and distortion of cortical neurofibrils” (Holstein, 1997, p. 1). These are now known to be brain tangles and plaques which progressively attach to and destroy cells in certain parts of the brain. They result in the cognitive and behavioral symptoms and problems labeled by the modern-day diagnosis and description of Alzheimer’s disease. In 1906, Alzheimer identified the woman as having memory loss and disorientation followed by depression and hallucinations, ultimately followed by dementia and death in five years. Alzheimer did not believe he had found a new disease, separate from senile dementia, because “… the neuropathological changes could not always be demonstrated” (ten Have & Purtilo, 2004, p.2).

However, Kraepelin came to a different conclusion, asserting in the eighth edition of his textbook in 1910 that a review of four cases led him to declare Alzheimer’s a new

disease. Though Kraepelin's conclusion is still debated, his prominence facilitated the recognition of a new, separate disease based on Alzheimer's work. In reaching his conclusion, Kraepelin emphasized the unique clinical symptoms and pre-senile course of the disease rather than the medical focus on pathological changes in the brain.

The Disappearance

Kraepelin's designation did not gain wide popularity within the medical or the broader public community. There is no consensus for what Cohen (1998) describes as "… the disappearance of Alzheimer's disease" and "its failure to capture the language of senility treatment and treatment for half a century…." (p.80). Cohen (1998) identifies two possible explanations for the "disappearance" of Alzheimer's disease until the late 1960s. Both explanations emphasize that the social construction of Alzheimer's disease varies by historic period, depending on the dominance of particular views, values, and beliefs. For example, Kraepelin's focus on the pre-senile stage and symptoms over brain pathology conflicted with the dominant medical views of the time and did not provide a basis conducive to lab or clinic research.

In addition, the development of vascular or arteriosclerotic dementia "… became the dominant concept in senile dementia research and clinical practice for much of the twentieth century" (Cohen, 1998, p.80). Cohen further observes that the vascular dementia growth was tied to its compatibility with medical and pharmacological research, producing new classes of vasodilatory drugs for dementia well into the 1970s in the United States and later in Europe, Asia, and elsewhere.

The Reappearance

Alzheimer's disease reappeared as a medical diagnosis and social problem in the 1960s, and by 1980, it dominated public and medical discourse about dementia. Ten Have and Purtilo (2004) observe that it was not until the 1970s that a "pragmatic consensus" emerged that recognized Alzheimer's disease as "a special category of the clinical syndrome of dementia, a constellation of psychological and behavioral phenomena" (p.3). Cohen asserts that the re-emergence was caused in large part by the growth of the middle and upper class "young old" who pushed for a definition of "normal" aging which was positive and healthy compared to a pathological and unhealthy dementia or senility. As Cohen (1998) observes, the plaques and tangles of Alzheimer's became "a medical idiom for dementia and a lay idiom for senility" (p.82) and characterized what he calls "Alzheimer's hell". Cohen identifies the American Association for Retired Persons as one promoter of this distinction. Others identify academic, medical, and business interests' desire to capture the graying marketplace by promoting successful, positive, and productive aging and an increased focus on use of pharmacology, surgery, aggressive medical treatment, and lifestyle behaviors (Cole, 1992; Cole & Thompson, 2001-2002; Kaufman, Shim, & Russ, 2004; Moody, 2005).

At the same time a confluence of physicians, medical researchers and family support groups solidified the uniqueness and separateness of Alzheimer's disease as a social problem distinct from normal healthy aging. Multiple authors (Beard, 2004; Fox, 1989; Gubrium, 1987) state that the creation of the Alzheimer's Association in 1980 was the result of a social movement and continues as a social movement organization. They assert that the Association perpetuates its Alzheimer's prophecy; regularly reinforcing

their perceptions of the reality of Alzheimer's as pathological senility by publicizing the devastating impact on caregivers and need for government and pharmaceutical companies to fund biomedical research.

The Association was founded by care providers and scientists to provide "cause and cure research" and to increase public awareness (Beard, 2004, p.799; p. 804). It has spent over $150 million since 1982 on biomedical research that has produced only minimal results. Beard (2004) observes that the Association perceived Alzheimer's disease as the dominant and pervasive brain disorder causing dementia. Thus, Beard (2004) asserts, the Association became so focused on making Alzheimer's disease the single orientation of dementia research that in 1988 it changed from its original name of the Alzheimer's disease and Related Disorders Association, Inc. The scientists involved in the Association's creation were from the National Institutes of Health and National Institute on Aging (NIA), both of which continue to spend billions annually on a nationwide network of biomedical research centers, again with minimal results. The NIA Alzheimer's initiative began in 1975 with its first director and ardent advocate of positive aging, Dr. Robert Butler (Alzheimer's Disease Education & Referral Center, 2005; Butler, 1975). Whitehouse (2008) recounts the escalating NIA spending on Alzheimer's disease medical research. In 1979, he observes, the NIA spent only $4 million on Alzheimer's disease medical research. By 1985, NIA had created 10 Alzheimer's Disease Research Centers nationally and by 2008 there were nearly 30. By 1991, NIA was spending $155 million on Alzheimer's disease medical research. In 2007, the annual spending was at $673 million (Whitehouse, 2008).

CHAPTER TWO: THE SOCIAL CONSTRUCTION OF ALZHEIMER'S DISEASE

Introduction

This chapter will present the analytic frameworks that provide the backdrop for understanding the current context in which nurses and social workers are available to serve persons with Alzheimer's disease in the community. It is followed by a review of the empirical and authority-based literature to determine the nature of research on the definition of Alzheimer's disease; intervention research and public policy regarding Alzheimer's disease; and unaddressed research questions. The literature review ends with the selection of an unaddressed research question and a preliminary discussion of a research methodology and design for the selected question.

Analytic Frameworks

The biomedical or medical model and the holistic or bio-psychological model are the two dominant frameworks used to conceptualize approaches to health problems. These models take different approaches to the detection, definition, causation, treatment, study and research about Alzheimer's. They establish outcome measures and success criteria regarding illness and specifically Alzheimer's disease and dementia.

The medical model asserts that illness is a biologically-caused disease which makes a normally well person sick (Friedson, 1988; Parsons, 1951). The model emerged with germ theory in the nineteenth and twentieth centuries and increasingly asserts that skilled interventions by medical professionals and use of medical technology and pharmacology can cure a disease or limit its progression (Avorn, 2004; Conrad, 2001; Dubos, 1959; Starr, 1984, 2004). The medical model increasingly has dominated American physical and mental health policy (American Psychiatric Association, 2000;

Anspach, 1997; Hacker, 2002; Kutchins & Kirk, 1997; Marmor, 2000; Oberlander, 2003; Rosenberg, 1987; Rothman, 2002, 2003; Starr 1984, 2004; Stevens, 1998, 1999; Trattner, 1999).

Medical model advocates assert that their approach creates positive outcomes, allowing life enhancement and prolongation and successful acute care medical interventions to treat disease or trauma (Anspach, 1997; Parsons, 1951; Starr, 1984, 2004). For the aging population, proponents assert, the medical model results in a more positive or successful life experience, which is referred to in the literature variously as *successful aging* (Rowe & Kahn ,1998) , *positive aging* (Gergen & Gergen, 2001-2002), and *productive aging* (Morrow-Howell, Hinterlong, & Sherraden, 2001). On the other hand, critics assert that the medical model reinforces an extreme anti-aging attitude in Western society. The result is a proliferation of medical interventions and unproven commercial remedies to avoid aging symptoms and de-emphasis of symptom management and psychosocial needs (Cole, 1992; Cole & Thompson, 2001-2002; Kaufman, Shim, & Russ, 2004; Moody, 2005).

Some critics contend that the various successful and positive models that focus on healthy lifestyles to avoid chronic illness result in stigmatizing the chronically ill and disabled people (Cole, 1992; Cole & Thompson, 2001-2002). Medical and pharmacological treatments for healthy people receive funding and attention while symptom management and quality of life improvements for the chronically ill and disabled to experience a more broadly conceived *successful aging* are devalued (Kahana, et al., 2005). These improvements include use of support groups, counseling,

computerized and other technology, recreational therapies, and environmental modifications (Kahana, et al., 2005; Borawski, Kinney, & Kahana, 1996; Rodwin, 1997).

Other critics label such extreme application of the medical model as bio-medicalization. They claim that medical technology and pharmaceuticals create a decision-making process focused on life-extending capacity. This creates ethical dilemmas and reduces the emphasis on quality of life as people age (Clarke, Shim, Mamo, Fosket & Fishman, 2003; The President's Council on Bioethics, 2003). Some specifically critique the bio-medicalization of aging for focusing on cure, life enhancement, and life prolongation, making the natural aging process irrelevant (Callahan, 1987; Estes & Binney, 1989). Kaufman, et al.(2004) note the rising age of patients using cardiac procedures (bypass, angioplasty, stent, and implants), kidney dialysis, kidney transplants and other medical interventions as examples of life extension procedures that have become "routine" clinical practice. From their perspective, bio-medicalization ignores patient and family needs, symptoms, and quality of life. Others assert that bio-medicalization depicts patients as sick and deviant and not worthy of medical attention. As a result, treatment focuses on the well caregivers and normal society whose health is threatened by the Alzheimer's or dementia patient (Basting, 2001; Coenen, 1991; Davis, 2004; Gergen, 1991; Kitwood, 1997; Lyman, 1989; Woods, 1999).

Social Constructions and Treatment Models

There is literature which presents both Alzheimer's disease (Ballenger, 2000) and dementia (Lyman, 1989) as specific social constructions informed by the medical model. This perspective is consistent with a broader assertion that physical and mental disease definitions are socially constructed for various purposes, including creation and

maintenance of a specific social order, power structure, and social control (Berger & Luckmann, 1967; Bordieu, 2000; Foucault, 1984, 2000; Goffman, 1959, 1961; Szasz, 1964). In this case, control rests with the medical establishment.

Many medical scholars have noted that Alzheimer's disease was recognized as a unique disease in 1907, but was not accepted until powerful forces created its public acceptance(ten Have & Purtilo, 2004; Whitehouse, 2001). In America, these included the medical establishment, government, pharmaceutical companies, and professional advocacy groups such as the Alzheimer's Association (Cohen, 1998; Fox, 1989, 2000; Gubrium, 2000; Whitehouse, 2001). Over time, these interest groups continued to reinforce Alzheimer's as a biologically-based disease requiring pharmacological and medical technology, research, and treatment (Cohen, 1998; Fox, 2000; Gubrium, 2000). In contrast, in many non-Western societies, Alzheimer's disease is either not a defined disease or rarely recognized as a discrete diagnosis. Cohen (1998) asserts that Alzheimer's disease is rarely identified as a disease in India or Africa because experts have not convinced the public that the disease definition is useful for treating seniors with cognitive impairment. Thus, seniors are viewed as having normal declining cognitive abilities of aging without the label of a separate disease. Topinkova and Callahan (1999) observe that Czech society's focus on aging as a natural process generates little recognition of Alzheimer's as a unique disease requiring medical intervention. Whitehouse (2001) asserts that African Americans tend to conceive of and treat their elderly with age-related cognitive impairments within their communities as part of the normal aging process without explicit focus on whether the dementia is of the Alzheimer's or another type.

Medical model critics support a holistic model, also referred to as the bio-psychosocial model of illness. This model assumes that illness has biologic, psychological, sociocultural, and historic aspects, all of which are relevant to assessing the definition, causation, and treatment of disease (Borrell-Carrio, Suchmann, & Epstein, 2004; Conrad, 2001; Dubos, 1959; Engel, 1997; Good, 1994; Kleinman, 1986, 1988; Mattingly & Garro, 2000; Terris, 1992). Similarly, they assert that "… conceptions of 'normal' and 'pathological' aging, like all scientific knowledge, are not objective, natural or given" but "… are constituted in particular social and political contexts" (Kaufman, et al., 2004, p. 736).

The palliative care treatment model is consistent with the holistic conception of illness and serves as an alternative to the medicalized definition and treatment of Alzheimer's disease (Borrell-Carrio, et al., 2004; Cohen, 1998; Whitehouse, 2001; Whitehouse, Maurer, & Ballenger, 2000). Palliative care is primarily identified with terminal disease, end-of-life and hospice care, with interventions focused on patient, family, and caregiver psychosocial and spiritual needs, symptom management, and quality of life, instead of cure or permanent rehabilitation (Mor, Greer, & Kastenbaum, 1988; World Health Organization, 2004). Interventions include use of medical professionals, such as nurses, dieticians, physicians, and speech, occupational and physical therapists; and social service personnel, such as social workers, volunteers, home health aides and personal care workers, recreational and other therapists, and clergy. It also incorporates supportive services, including transportation, meals, home repairs and maintenance, and respite.

Palliative care is used for dementia care in Scotland (Mitchell, 1999), Sweden (Malmberg, 1999), and France (Cantegreil-Kallen, Turbelin, Angel, Flahault, & Rigaud, 2006) where government finances dementia group homes, day care for dementia patients, and physician-coordinated care and support services. Literature also indicates use of palliative care with other chronic diseases, such as congestive heart failure, chronic obstructive pulmonary disease, and Parkinson's disease, which also has no cure and limited pharmacologic treatment success. (Agency for Healthcare Research and Quality, 2003; Clark & Heller, 2003; Giutana, Parrish, & Adams, 2002).

Some physicians and other health care professionals advocate use of palliative care in conjunction with curative treatments (American Academy of Hospice and Palliative Medicine, 2003; Brumley & Hillary, 2002; Brumley, et al., 2003; Center to Advance Palliative Care, 2001; Cherry, et al., 2004; Pioneer Programs in Palliative Care: Nine Case Studies, 2000; Small, et al., 1997; Smits, Furletti, & Vladeck, 2004; United Hospital Fund, 2004a, 2004b). This approach promotes palliative care as the guiding philosophy for treating illnesses throughout the aging process, regardless of proximity to death (Jerant, et. al, 2004). Such care utilizes multiple interventions, including: medical interventions as part of early and ongoing therapies by an interdisciplinary team; use of social workers, volunteers, and pastoral care; family and patient conferences; and coordination of home and community-based care with institutional care.

Some private groups and public-private collaborations advocate the use of palliative care through community networks (Hopper, 2003, 2004; United Hospital Fund, 2004b). Other palliative care advocates use coordinated housing, health, and social services to allow seniors to age in place in their homes and communities. These programs

include case management, respite services, individual and group psychiatry, counseling, escorts, housekeeping, and personal care service (Pine & Pine, 2002; United Hospital Fund, 2004c; Vladeck, 2003, 2004).

CHAPTER THREE: LITERATURE REVIEW

Introduction

The literature review began in 2003 when I was a MSW student at the University of Michigan School of Social Work (UMSSW). The initial review was part of an aging course paper for Professor Berit Ingersoll-Dayton. I selected the topic based on my twenty years' experience as a home care and hospice management professional. During that time I found it ironic that while most home care patients had some form of dementia, if not specifically Alzheimer's disease, Medicare virtually prohibited giving them psychosocial care. In fact, a dementia or Alzheimer's primary or secondary diagnosis might lead to ineligibility as Medicare viewed the condition as long-term and custodial. Home care had to be limited to acute care, thus making the dementia patient eligible only for care of a separate qualifying physical problem requiring short term intermittent or part-time nursing care. I wondered if this seemingly senseless policy was based on research.

I expanded the initial 2003 UMSSW literature review in Spring 2004 as a research assistant for Professor Ingersoll-Dayton. She was preparing a grant proposal to the national Alzheimer's Association to test an intervention for improving quality of life (QOL) for Alzheimer's disease patients and their spousal caregivers. I concluded from the expanded literature review that there was a dissonance between intervention research and Medicare home health policy. More specifically, the literature review indicated both statistically and clinically significant evidence that psychosocial interventions improved Alzheimer disease patient and caregiver quality of life. In addition, there were some studies which measured and found positive results of these interventions also reducing

care costs. Despite such evidence, Medicare home health policy does not cover such interventions.

I pursued the topic when I entered the doctoral program in social welfare at Hunter College School of Social Work/City University of New York in September 2004. As a result I selected the topic "Is there a relationship between Alzheimer's disease intervention research and Medicare home health policy?" for my problem formulation and literature review paper in Professor Harriet Goodman's knowledge-building course. I continued to pursue and refine my work through the doctoral program through the second exam and doctoral dissertation proposal.

The literature review includes both empirical and other literature regarding the nature and significance of Dementia and Alzheimer's disease; patient and caregiver burden; public policy; program policy; and practice interventions. The review ends with the selection of an unaddressed research question as the basis of the dissertation proposal.

The primary literature review is based on a search which yielded 70,968 articles. Use of the keyword "Alzheimer's disease" generated 61,135 articles and use of the keyword "Home Health Care" generated 9,833 articles in the Cinahl, Social Work Abstracts, PUBMED, Sociological Abstracts, PsychINFO, and the Cochrane Database of Systematic Reviews. An additional 36 aging and social work journals were individually reviewed for the last ten years or more, using primarily the same keywords, though many were included in the database searches. Books, websites, and other sources also were reviewed. A literature review update was conducted both in 2007 and 2008 adding over 1,500 additional articles and publications.

The Nature, Cause, and Prevalence of Dementia and Alzheimer's disease

The nature, cause, prevalence, and relationship between dementia and Alzheimer's disease are complicated and unresolved. Debate continues as to whether Alzheimer's is a unique and separate disease (ten Have and Purtilo, 2004; Whitehouse, 2001). Diagnostic criteria that distinguish Alzheimer's and dementia remain unclear (Erkinjuntti, Ostbye, Steenhuis, & Hachinski,, 1997). New medical model aging-related diseases raise even more questions about the uniqueness of Alzheimer's disease (Whitehouse, 2001). These include mild cognitive impairment (Morris, et al., 2001), aging-associated memory impairment (Crook, et al., 1986), and aging-related cognitive decline (Levy, et al., 1994), among others. Debate also continues about whether Alzheimer's disease is a physical disease, a mental disorder, or both, although the medical model-physical disease argument dominates research, funding, and treatment (Lebowitz & Evans, 2004).

Alzheimer's is identified as both the major type and a cause of dementia (Whitehouse, 1993). Dementia is identified as both the broad diagnostic category encompassing Alzheimer's and as a symptom of Alzheimer's and other diagnoses with features of cognitive impairment, such as cerebrovascular disease, Multiple Sclerosis, Parkinson's disease, and AIDS (Rockwood, 2002; Whitehouse, 1993). There is no definitive cause, no known cure, and little effective pharmacological treatment either for Alzheimer's or for dementia (Alzheimer's Association, 2004; American Geriatrics Society, 2004; Cohen, 1998; Gauthier, 2002; Whitehouse, 1993, 2001).

The dominant medical model identifies cognitive impairment, or dementia, as a syndrome caused by a cluster of diseases which have a chronic, progressive brain

dysfunction resulting in decline in memory and at least one other cognitive function, such as language, visual-spatial, and other intellectual abilities (American Geriatrics Society, 2004; Gauthier 2002: Whitehouse, 1993). Dementia usually displays a gradual and steady decline in being oriented, with decrease in memory and other cognitive abilities, a decrease in the ability to participate in everyday activities, and personality changes. Alzheimer's displays similar symptoms, but is distinguished from dementia by pathology of unique brain tangles and plaques which progressively deteriorate with the aging process (Cohen, 1998; Petrovich, et al., 2001; Whitehouse, 2003).

Dementia and Alzheimer's disease are recognized as having a significant current and projected prevalence and cost, despite lack of consensus on their definition and relationship. Alzheimer's represents an estimated 50%-70% of all dementia cases in America (Small, et al., 1997). Approximately 4 million Americans suffered from Alzheimer's disease in 2000 and 4.5 million in 2006 (MetLife Foundation, 2006). This amounts to 12.5% of the American aged 65 and older population in 2000, with projections at 16 million or 16.5% by 2050 (Federal Interagency Forum on Aging Related Statistics, 2004; Sadick & Wilcock, 2003). Over 5 million persons were estimated to have Alzheimer's disease in 2007, including 4.9 million over age 65 and between 200,000 and 500,000 under age 65 with early onset Alzheimer's disease and other dementias (Alzheimer's Association, 2007a, 2007b). Alzheimer's disease is the fourth leading cause of death of persons 65 and older in the United States and since 1999 the Alzheimer's death rate has increased by 7 to 9 percent annually, with women being about 30% more likely to die from the disease than men (Centers for Disease Control, 2006; Gorina, Hoyert, Lentzner, & Goulding, 2005).

The prevalence of Alzheimer's disease progresses with age, with an estimated 10% of all persons over age 65 and 50% of all persons over aged 85 having the condition (MetLife Foundation, 2006; MetLife Mature Market Institute/National Alliance for Caregiving, 2006). Alzheimer's disease is the fourth leading cause of death for Americans aged 65 and older exceeded only by cardiovascular disease, cerebrovascular disease, and cancer. It is the third most costly disease in the United States, with an estimated annual cost of $100 billion (Centers for Disease Control and Prevention, 2006; McConnell, 2004; Rice, et al., 2001; Sadick & Wilcock, 2003).The World Health Organization estimates there were 25 million persons worldwide with dementia in 2002, with 46% living in Asia, 30% in Europe, and 12% in North America. They project over 30 million worldwide by 2020 (Wimo, et al., 2003).

A 2006 MetLife Foundation survey of 1,006 Americans age 18 years and older found that 20% of the persons feared getting Alzheimer's disease, an amount only exceeded by fear of cancer, and that persons aged 55 and older feared getting Alzheimer's disease more than any other disease, including cancer, heart disease, stroke and diabetes (MetLife Foundation, 2006). The same survey found that 35% of respondents have a family member or friend with Alzheimer's disease and 63% worry they will have to care for someone with Alzheimer's disease.

Although there is no known definitive cause for Alzheimer's disease, research has identified several risk factors. These include age, family history, Down's syndrome, and a normal variant of the gene apolipoprotein E (APOE-E4) which encourages the depositing of the harmful protein (American Geriatrics Society, 2004; Whitehouse, 1993). Other possible identified risk factors include genes, head trauma, lower educational level, and

depression. Research also indicates that vascular risk factors such as type 2 diabetes, hypertension, obesity, high cholesterol, dietary fat intake and related co-morbidities, such as stroke, may significantly influence the rate of Alzheimer's development and progression (Haan & Wallace, 2004). Some recent studies assert that having Type 2 diabetes increases the risk of Alzheimer's disease (Alzheimer's Association, 2006a).

An estimated 70% of all Alzheimer's patients live at home where families provide 75% of their care (Fried, 2004; McConnell & Riggs, 1999). Another report estimates that 25% of the patients with heart disease, diabetes, or cancer as their primary diagnosis also have Alzheimer's disease, dementia, or other mental confusion (National Alliance for Caregiving, 2004). A study based on Medicare claims data indicates that persons with dementia as a co-morbidity and certain demographic characteristics generated more than three times the expenditures and more than three times the odds of hospitalization as persons without dementia (Bynum, Rabins, Weller, Niefeld, Anderson, & Wu, 2004).

Estimates are that 95% of all Medicare beneficiaries with dementia have one or more other chronic conditions (Bynum, et al., 2004). At any time an estimated one-third of all persons with dementia are institutionalized in long term care facilities (Rockwood, 2002) and 60% of all nursing home patients have Alzheimer's disease or dementia (Fried, 2004). Institutional care usually reflects severe progression of Alzheimer's with severe cognitive and functional disability. Nursing home patients with severe Alzheimer's disease are estimated to cost 2.25 times more than community dwelling persons with mild or moderate Alzheimer's (Hu, Huang, & Cartwright, 1986; McConnell & Riggs, 1999).

Alzheimer's disease annual cost estimates range between $33 billion and $100 billion in America, ranking third only behind heart disease and cancer (Sadick and

Wilcock, 2003; Ernst, et. al, 1997; National Institute on Aging, 1996). Estimates vary depending on the definition used and factors included (Sloane, et al., 2002). Sadick & Wilson (2003), using 1998 dollar values data, estimate an annual average cost of at least $50,000, with at least one-third or more ($15,000-$18,000) being out-of-pocket expense. Their cost estimates include "….direct medical costs such as medications, physician visits, hospitalization, and nursing home costs; direct nonmedical costs such as daycare and other social services; and indirect costs such as the time caregivers spend with patients and associated loss of productivity in the workplace" (p.S76). Alzheimer's disease is one of many diseases creating health care risks for employed caregivers and productivity losses for employers. Productivity losses to employers are estimated at $34 billion annually, with only 25% of employers offering an elder care benefit (Burton, Chen, Conti, Pransky, & Edington, 2004; MetLife Mature Market Institute/National Alliance for Caregiving, 2006; Society for Human Resources Management, 2003).

There also is a significant direct cost to federal and state governments. Most of the estimated 30% of dementia patients who do not reside at home reside in nursing homes where over 50% of costs are paid by Medicaid (Fried, 2004; Kaiser Family Foundation, 2007; McConnell & Riggs, 1999). A recent federal study using 1999 National Long Term Care Study and other data found stress among caregivers of chronically disabled elders "is a strong predictor of [nursing home] entry over follow-up periods of up to two years" (U S Department of Health and Human Services, 2007, p. iii).

Patient and Caregiver Burden

Caregivers and patients assume the largest portion of Alzheimer's costs (Levine, 2000; McConnell & Riggs, 1999; National Alliance for Caregiving, 2004; Robert Wood

Johnson, 2001; Small et al., 1997). Institutional care and physician services are primarily covered by government and private insurance coverage, however, there is limited insurance funding for home and community-based care of dementia and Alzheimer's disease patients and their caregivers (Greene & Feinberg, 1999; Levine, 2000, 2003; McConnell & Riggs, 1999; Robert, 2003)

Patients and caregivers experience multiple burdens coping with the cognitive, behavioral, and functional symptoms of Alzheimer's disease (Small, et al., 1997). Cognitive problems include memory impairment, aphasia (limitation in ability to speak or comprehend language), apraxia (a voluntary movement disorder), disorientation, visuospatial dysfunction, and impaired judgment. Behavioral problems include personality changes, irritability, anxiety, depression, delusions, hallucinations, aggression, and wandering. Functional problems include difficulty performing or an inability to perform activities of daily living(ADL), such as eating, dressing, bathing, toileting, walking, grooming, and getting in/out of bed, or instrumental activities of daily living (IADL), such as meal preparation, shopping, moving within and outside the house, money management, using the telephone or computer, and taking medication(Dunkle, 2001).

Caregivers also cope with the burden of adjusting to patient changes in diet and exercise, ability to drive, loss of personal identity, sleep disturbance, inclination to engage in sex or intimacy, urinary incontinence, and restlessness. Often the result is increased stress, depression, substance abuse, loss of sleep, increased personal isolation, identity loss, increased physical and mental health problems, and a perceived decline in quality of life (Eisdorfer, et al., 2003; Sadik and Wilcock, 2003; Sands, Ferreira, Stewart,

Brod, & Yaffe, 2004; Schulz, et al., 2003; Wisniewski, et al., 2003). A recent U S Department of Health and Human Services (2007) study found that caregiving-related physical strain, financial hardship, and recipient behavior problems among caregivers of chronically disabled elders predict high levels of caregiver stress.

Research indicates that most Alzheimer’s disease caregivers are female family members (spouses or adult children), who provide an estimated 75% of the predominantly at-home care, though there is an increasing number of male caregivers reported (Leland, 2008). In addition, an estimated 33% are Medicare beneficiaries themselves and use Medicare more than their peers. Over 12% of the Medicare caregivers become physically ill or injured as a direct result of their caregiving and experience depression at a rate three times the norm for peers. Most caregivers are not wealthy (90% have annual household incomes under $75,000 and 20% are under $15,000); however, 70% contribute part of their personal income or savings to their family member’s care. An estimated 33% have children or grandchildren under age 18 living with them and have less time to spend and more conflicts with them and other family members. Many quit their jobs or work fewer hours because of caregiving demands, resulting in less income at a time when caregiving costs are increasing (Levine, 2000, 2003; McConnell & Riggs, 1999; National Alliance for Caregiving, 2004; Robert Wood Johnson Foundation, 2001). While research indicates an increasing number of effective caregiver interventions exist, these interventions are not integrated and paid for under Medicare home health or any other Medicare benefits, though some funded projects exist through the Older Americans Act and other grant-based programs (Scharlach, 2008; Zarit & Femia 2008).

Public Policy and the Domination of the Medical Model

Despite its psychosocial correlates, the medical model dominates public policy for Alzheimer's disease and dementia patients and caregivers. The result is government funding, primarily of pharmacological and medical technology research and institutional care (Ballenger, 2006). The policy dominates despite evidence that: most patients and their caregivers live at home with extensive burdens; some non-pharmacological, palliative interventions reduce patient and caregiver burdens and improve quality of life; and some home and community-based palliative care programs may reduce individual and payer costs (Abt Associates, 1998; Chappell, et al., 2004; Leon, Cheng, and Neuman, 1998; Newcomer, et al., 1999; Yordi, et al., 1997).

The public policy is part of the medical model dominance of American health care policy, including physician direction of medical care, medical technology and pharmacology as the principal medical interventions, and the corporatization of medical care in hospitals and health care systems (American Psychological Association, 2000; Rothman, 1990; Starr, 1984, 2004; Szasz, 1964). An estimated 80 % of all national health, 75% of Medicare, and 80% of Medicaid expenditures are for physician services, prescription drugs, and hospitals and nursing home care (Health Care Financing Review, 2002).

The medical model persists despite evidence of its limitations. The medical model was designed primarily for acute, institutional care, though it has been extended to home and community-based care (Evans, Bauer, & Marmor, 1994; Thompson, 1996). The medical model is costly (Anderson & Knickman, 2001; Cassel, Rudberg, & Olshansky, 1992; Watt, et al., 1999). The medical model often results in limited care, unmet needs,

and financial hardship, particularly for persons requiring long term care as the American population becomes increasingly aged and chronic (Feder, Komisar, & Niefeld, 2000; Luft & Greenlick, 1996; Ostry, 1994). Some critics assert that the medical model is a costly approach to chronicity, does not address the bio-psychological issues of chronic care, and is particularly deficient in addressing symptom management and pathology of chronic conditions for which there is no known cure or predictable resolution (Bickenback, 1993; Watt, et al., 1999).

Medicare and Medicaid are based on the *medical model* (Anspach, 1997; Fried, 2004; Marmor, 2000; Morrow-Howell, et al., 2005; Oberlander, 2003; Vladeck, 1997). Medicare and Medicaid coverage for all care settings is based on physician certified diagnostic conditions, categories or groups (Medicare Payment Advisory Commission, 2003, 2004a). Private insurers use similar reimbursement models. Government and private mental health coverage is primarily for psychiatrist-certified institutional and physician office-based care by physicians and psychologists. Most mental health coverage is based increasingly on diagnostic, medical model categories from the American Psychological Association's Diagnostic and Statistical Manual of Mental Disorders. Gaps in home and community-based mental health coverage have been identified (U. S. Department of Health and Human Services, 2000).

Medicare Coverage and Alzheimer's disease and Dementia

Fried (2004) notes that Medicare coverage for Alzheimer's disease patient is primarily for physician office visits, hospital and nursing home care, and a variety of diagnostic tests such as blood studies, positron emission tomography (PET) scans, computerized tomography (CT) scans, magnetic resonance imaging (MRI), and others.

Medicare pays 80% of its fee schedule amount for Alzheimer's patient outpatient diagnostic or medical management and 50% for psychotherapy or other therapeutic mental health visits to psychiatrists, clinical psychologists, and social workers. Family counseling is not covered. Mental health visits may be denied if Medicare determines dementia patients are too impaired to benefit from psychotherapy.

Medicare covers limited inpatient and outpatient rehabilitation services for Alzheimer's and dementia patients, including speech, occupational, and physical therapy. However, coverage may be denied if the patient does not improve significantly in a timely manner or cannot establish a safe and effective self-maintenance program. Medicare nursing home care is limited by the requirement that it must be within thirty days of a hospital discharge, have at least a three-day prior hospitalization, and require skilled care for the same condition as the hospitalization. Medicare coverage is limited to 100 days, making private insurance, private pay, and Medicaid the primary payers for nursing home care.

Medicare, Medicaid, and private insurers provide limited home and community-based coverage for palliative and psychosocial interventions found beneficial to Alzheimer's disease patients and caregivers. Government waiver programs and private and government demonstration programs provide some additional limited coverage, usually to limited numbers of participants from targeted populations, often for limited time periods. Most of these programs have been funded through Medicaid waivers in Sections 1915 (b) and (c) of the Social Security Act and experimental, pilot, or demonstration projects under section 1115 of the Social Security Act. These provisions allow states to alter the required coverage, reimbursement, or payment requirements to

test feasibility of program modification. In such demonstration and waiver programs, Alzheimer's or dementia patients and caregivers may be a targeted population, though most programs are for low-income, racial minority, specific disability, rural, veterans, children, and specific elderly populations. Use of case management, and other expanded home and community-based services, often occurs in such studies (Wiener, Tilly, & Alecxih, 2002).

Medicare provides a limited home health benefit. The benefit is the primary home-based government benefit for the elderly, created and maintained to decrease hospital and nursing home costs (Mottram, Pitkala, & Lees, 2002; Vladeck, 1997). Annual expenditures were estimated at $12.5 billion for nearly 2.6 million beneficiaries in 2005 (Medicare Payment Advisory Commission, 2006b). Cares is based on an acute care medical model, requiring that eligible patients be homebound; in need of skilled, part-time or intermittent skilled nursing care or physical therapy; and have a condition with a finite and definite end point, all as prescribed by a physician-certified plan of care (Health Care Financing Administration, 1999). If the requirements are met, the patient may receive additional skilled nursing, physical therapy, speech therapy, occupational therapy, home health aides, or social work services. Physical therapy and skilled nursing represent an estimated 72% of national home health visits (Medicare Payment Advisory Commission, 2003, 2004a).

Medicare did not recognize Alzheimer's disease as an approved home health primary diagnosis until 2001 (Smarr & Carson, 2006) (3). Even now, the only explicit home health Alzheimer's disease coverage designated by Medicare is limited home health nursing teaching and training, and many home health nurses are not aware of the

coverage (Cabin, 2006b; Smarr & Carson). Additional, expanded medical coverage guidelines for Alzheimer's disease might allow for expanded home health aide, nursing, social work and physical, speech and occupational therapy services with the medical model limitation of coverage of the six services.

Medicare regulations do not permit social workers to initially assess the client or develop the plan of care. Nurses, and in some instances physical therapists, must initially assess the client and develop the plan of care for physician certification. Covered social work services are limited to assessing the client, upon a nurse or physical therapist referral; assisting the client to obtain community resources, though social workers may not assist the client or family in completing Medicaid or other applications; and two to three counseling visits to the client's family member or caregiver, only if designed to remove a clear and direct impediment to client treatment or rate of recovery (Centers for Medicare & Medicaid Services [CMS], 2006a). As a result, social work historically represents only 1-2% of all national Medicare home health visits (Medicare Payment Advisory Commission, 2003, 2004a, 2004b). Some researchers contend that utilization has decreased with a new prospective payment system, despite evidence of need and increased coverage flexibility (Kadushin & Egan, 2001, 2004; Lee, 2002; Lee & Gutheil, 2003). The Medicaid home health benefit provides even less social work service than Medicare because social work is not a required service under federal Medicaid legislation (National Association for Home Care & Hospice, 2006).

The Medicare home health benefit also discourages other palliative care interventions. The benefit does not cover in-home companion, homemaker, live-in, and other personal care services; respite care; support groups and counseling; personal

assistive devices and environmental assessments and modifications; and other non-pharmacological interventions and therapies (Cherry, 1999; Greene & Feinberg, 1999; Lee & Gutheil,1993; McConnell & Riggs, 1999; Robert, 2003; Smyth, 1995).

Alzheimer's disease and dementia are not significant primary or principal secondary diagnoses in Medicare home health, despite their high prevalence rates in the elderly population. Some professionals advocate more Medicare in-home mental health services for the elderly, including dementia and Alzheimer's disease (Albert, Marks, Barnett, & Gurland, 1997; Kohn, Goldsmith, Sedgwick, & Markowitz, 2004). The top six home health primary diagnoses (diabetes, essential hypertension, heart failure, chronic skin ulcers, acute cerebrovascular disease, and osteoarthritis) represent over 30% of all cases (Health Care Financing Review, 2002). Many early stage Alzheimer's persons may not qualify for Medicare home health because they are able to walk to outside places unescorted and thus are not considered homebound by Medicare. Similarly, mild or moderate stage persons often are able to walk outside their home and, therefore, may not be homebound under Medicare requirements, even though they are prone to getting lost (Centers for Medicare and Medicaid Services, 2006c; Mahoney, Volicer, & Hurley, 2001). Others may be disqualified because they are deemed not to require skilled nursing or physical therapy or because their condition is viewed as chronic, without a finite and definite end point (*Duggan, et al. v. Bowen,* 1988; Fried, 2004).

Medicare does not evaluate new services for home health coverage, despite continuing debate about the efficacy and cost of home health services (Centre on Aging, 1999; Chappell, et al., 2004; Fraser, 2003; The Home Care Research Initiative, 2001a, 2001b; Weissert, 1985, 1991; Weissert, Cready, & Pawelak, 1988; Weissert, Lesnick,

Musliner, & Foley, 1997). Coverage and eligibility requirements have not changed since Medicare was created nearly forty years ago, despite evidence of an increasingly chronic aging population and increasing costs (Vladeck, 1997). Medicare did not implement a national assessment instrument for reimbursement and mandatory outcome measures until 2000 (Medicare Payment Advisory Commission, 2003, 2004a). Some professionals assert that the measures inappropriately focus on improvements in narrow clinical indicators, such as wound healing and reductions in falls, instead of outcomes for the patient's condition (Elias, Ferry, & Treland, 2000; Martin, 2000; Outcome Concept Systems, 2004).

Medicaid and most private insurers mirror Medicare. The Medicaid home health benefit is more limited than Medicare, though New York and a few other states have expanded Medicaid home health programs (Kellogg & Brickner, 2000; Tully, 1996). Most Medicaid programs do not cover in-home companion, homemaker, live-in, environmental assessment and modification, personal assistive devices, support groups and counseling, and other non-pharmacological therapies and interventions, unless they have Medicaid waiver programs. Some state Medicaid programs provide limited funding for assisted living, respite care, or adult day care.

A federal report (Jackson & Burwell, 1990) analyzed Medicare and Medicaid home and community-based care programs, finding them based primarily on *medical model* physical disability criteria. The report specifically recommended the government "… specify criteria that would include persons who require human supervision due to cognitive impairment problems, most notably Alzheimer's disease, which could result in behavior harmful to the disabled person and others" (p. 2). Criteria have not been

developed and there has not been a pilot or demonstration project to test proposed criteria.

The Medicare Hospice Benefit

In contrast to the home health medical model, the Medicare Hospice Benefit is based on dealing with non-curable, chronic diseases. As a result, Medicare hospice focuses on quality of life improvement, not medical cure or condition improvement, as its outcomes. The Medicare hospice benefit provides primarily home-based end-of-life care based on the *palliative care treatment model*, demonstrating cost reduction and improvements in patient and caregiver symptom management. Palliative care assumes that treatment is not curative and focuses treatment on patient, caregiver, and family psychosocial and spiritual needs, symptom management, and quality of life (World Health Organization, 2004; Forbes, 2002; National Hospice and Palliative Care Organization, 2004a).

The Hospice Medicare Benefit (HMB) was legislated in 1982 and states may opt into a parallel Medicaid Hospice benefit. Patients must have an initial and ongoing physician-certified prognosis of six months or less to live and care is managed through a physician-led interdisciplinary team. Hospice patients relinquish all other Medicare and Medicaid coverage and the pursuit of curative, medical care. Hospice care includes physician involvement and direct medical care by nurses and physicians within the context of palliative care. Medicare-required services include respite care, pastoral care, and volunteer services as well as the six Medicare home health services, though art, music, massage, aroma, pet, and a variety of other palliative care therapies often are provided (Center for Medicare Education, 2001).

Volunteers are required by Medicare hospice, accounting for an estimated 13% of all clinical hours in 2003 (National Hospice and Palliative Care Organization, 2003a). Hospice social workers represent an estimated 9% of all full-time-equivalent employees (FTEs) and 10% of all hospice visits compared to approximately 2% of home health FTEs and 1-2% of all Medicare home health visits (National Hospice and Palliative Care Organization, 2003; National Association for Home Care, 2003). The Centers for Medicare and Medicaid Services (2006b) also has a specific set of national guidelines recognizing Alzheimer's disease and related disorders as a basis for HMB-covered terminal care. As a result, Alzheimer's disease and related disorders is the second highest non-cancer primary diagnosis for the HMB, representing 8.3% of all HMB primary diagnoses in 2002 (National Hospice and Palliative Care Organization, 2003b).

The Hospice Medicare Benefit was based on results from a 28-site demonstration project indicating simultaneous improvement of patient and caregiver symptom management and quality of life and reduced Medicare end-of-life care expenditures (Gage, et al., 2000; Kidder, 1992; Mor and Kidder, 1985; Mor, et al., 1988) The benefit uses a managed care, risk-sharing model focusing on simultaneous cost reduction while improving quality of life (Luft and Greenlick, 1996). Hospices are paid a per diem rate based on the patient's assessed status in one of four levels of care, regardless of the nature or amount of daily care delivered. Studies indicate that the Hospice Medicare and Medicaid Benefits may significantly reduce government expenditures (National Hospice and Palliative Care Organization, 2003; Pyenson, Connor, Fitch, & Kinzbruner, 2004) and improve quality of life (National Hospice and Palliative Care Organization, 2004b, 2004c). There also is evidence that enhanced home-

based hospice programs may save private insurers costs and improve patient and caregiver outcomes (Brumley, et al., 2003; Brumley & Hillary, 2002; Gage, et al., 2000).

The Bio-Psychosocial Care Alternative

Other programs demonstrate varying effectiveness of home and community-based psychosocial and palliative care interventions in improving patient or caregiver symptom management for persons who are not terminally ill, usually in combination with medical services. In 1997, the Program of All-Inclusive Care for the Elderly (PACE) moved from demonstration status to a permanent Medicare program. Multiple studies found that PACE enabled participants to remain in the community while improving symptom management and quality of life at a lower cost than traditional Medicare and Medicaid (Chatterji, Burstein, Kidder, & White, 1998; Eng, Pedulla, Eleazer, McCann, & Fox, 1997; Temkin-Greener, Meiners, & Gruenberg, 2001; Temkin-Greener & Mukamel, 2002; White, 1998; Wieland, et al., 2000).

PACE integrates Medicare and Medicaid financing of acute and long-term care for the elderly. Participants opt out of regular Medicare and Medicaid coverage as in Medicare hospice care. An estimated 60-65% of PACE participants have some level of cognitive loss and dementia (Hansen, 2005). The program provides adult day care augmented by home care and meals at home managed by an interdisciplinary team. The team includes a primary care physician, nurse, social worker, recreational therapist, physical and occupational therapists, and home health aides, sometimes supplemented by a pharmacist, nutritionist, psychiatrist, transportation coordinator, or other professionals. Services include personal care and chore services, transportation services, recreational

therapy, prescription drugs, psychiatric care, and others in addition to the six Medicare home health services (Gross, Temkin-Greener, Kunitz, & Mukamel, 2004).

Medicare Social Health Maintenance Organizations (SHMOs) demonstrations have existed for twenty years with mixed evidence of improving patient symptom management and cost reduction (Wooldridge, et al., 2001). SHMOs provide case managed care, nursing home care, and a package of in-home supportive services which include personal care, homemaker services, home-delivered meals, adult day care, respite for caregivers, telephone emergency response services, and transportation .

The eight-site, five-year federal Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) found statistically significant reductions in unmet needs of Alzheimer's patient and caregiver improvements, without a reduction in informal caregiving and a tendency toward reduced costs using a limited community care service benefit (Newcomer, Arnsberger & Zhang, 1997; Newcomer, Miller, Clay & Fox, 1999; Yordi, et al., 1997). Improvements included decreases in patient and caregiver depression, caregiver burden, and hospital and nursing home placements. The demonstration is case-managed, providing the six Medicare home health services and many non-covered services, including education and support services to caregivers and patients; adult day care; homemaker, housekeeping, chore, companion, and personal care services; home repairs and maintenance; home-delivered meals; non-emergency transportation service; adaptive and assistive equipment; safety modifications to the home; and home care-related medical supplies.

Other government and private programs provide palliative care and psychosocial interventions, focusing on service delivery and descriptive statistics without evaluation of

symptom management and quality of life improvement and cost reduction outcomes. Over $100 million has been spent in 12 years delivering in-home and adult day care respite services to an estimated 10,000 families through the federal Alzheimer's Disease Grants to the States program (Montgomery, Karner, & Kosloski, 2002a; Montgomery, et al., 2002b; Starns, 2002). The federal National Family Caregiver Support Program has spent over $100 million a year in combined federal and state funds since passage in 2002 for respite care, support groups, education, and individual counseling for elderly patients, patients under 18 years of age, and their family caregivers (Family Caregiver Alliance, 2002, 2004; Feinberg & Newman, 2004; Silberberg, 2001).

Other examples of government programs delivering palliative care and supportive services without measuring quality of life or cost impacts include: Medicaid personal care waivers which pay informal caregivers (Linsk, Keigher, Simon-Rusinowitz, & England, 1992; Stone & Keigher, 1994); a four-state Medicaid consumer-directed cash and counseling demonstration providing cash, counseling, education, and support to older adults (Rozario, 2000); the Veteran's Administration's housebound aid and attendance allowance program of cash allowances to low-income disabled veterans for informal caregiving (Grana & Yamashira, 1987; Rozario, 2002); the Veteran's Health Administration's program of respite, counseling, and support group services (Morrow-Howell, Tang, Kim, Lee, & Sherraden, 2005); and federal programs allowing child and dependent tax credits for informal caregiving (Internal Revenue Service, 2001). A variety of collaborative programs between state government, Alzheimer's Association chapters, and community groups provide care coordination and psychosocial interventions with limited quality of life and cost impact evaluation (Bass, Clark,

Looman, McCarthy, & Eckert, 2003; Caro & Morris, 2003; Coon, et al., 2004; Douglass & Fox, 1999).

Program Policy: *The Impact of Medicare Funding on Home Care Nursing and Home Care Social Work*

Introduction

Upon completion of the initial literature review, a second, more detailed literature review was conducted to examine the literature on public and program policy specific to Medicare home health care, home care nurses, and home care social workers. This electronic bibliographic search utilized, Academic Search Premier and Cinahl databases using the keywords "home health and nurses", "home health nurses" and "home health prospective payment system", and "home health prospective payment system" yielded only 483 articles, with only a limited number addressing the fiscal requirements issue. The literature review also included a combined electronic and manual bibliographic search of 2,502 articles from 1997-2005, the post home health PPS era, in the four major home health professional publications (*Caring Magazine, Home Health Care Management & Practice, Home Healthcare Nurse,* and *The Remington Report*); the *American Journal of Nursing*, *Journal of Community Health Nursing*, & *Nursing Economics*; *Home Health Care Services Quarterly*; and the bimonthly magazine, *Success in Home Care*.

Fiscal requirements have always been a factor influencing Medicare home health agencies, though relatively little research has explored the relationship between fiscal requirements and care decisions (Benjamin, 1993;Buhler-Wilkerson, 2002, 2003; *Duggan, et al. v. Bowen,* 1988; National Association for Home Care and Hospice, 2005; Vladeck,1997). The requirements involve a combination of eligibility, coverage, and

reimbursement decisions embodied in federal regulations, program memorandums, laws, and interpretations of Medicare's contract fiscal intermediaries. Medicare home health was a cost-based, fee-for-service system for thirty-one years, from 1965-1996. Medicare changed the home health reimbursement system three times from 1996-2000. Each change was designed to decrease home health utilization and costs and lead to a managed care model, prospective payment system (PPS) in October 2000 mirroring the Medicare inpatient hospital prospective payment system implemented in 1984 (Cabin, 2006a; Gundling, 2000; St. Pierre, 2000).

The Interim Payment System (IPS), legislated in the Balanced Budget Act of 1997, and its successor in October 2000, home health PPS, created significant new fiscal requirements which impacted Medicare home health practice and service delivery (Medicare Payment Advisory Commission, 2004). The number of Medicare-certified home health agencies decreased by more than 2,700 agencies, or 26%, from 1997-2004, and Medicare home health expenditures decreased by more than $7 billion, or 43%, from 1997-2002, to its current annual $15 billion level (National Association for Home Care and Hospice, 2008). The number of Medicare beneficiaries receiving home health services decreased by 29%, from 3.5 million to 2.5 million, from 1997 to 2003; average home health patient length of stay decreased by 61 %, from 106 days pre-PPS to 41 days post-PPS at the end of 2002; and the number of beneficiary visits per episode decreased by 42 %, from 36 visits pre-PPS to 21 visits post-PPS at the end of 2002 (Medicare Prospective Payment Commission, 2005).

The Medicare home health prospective payment system (PPS) intensified the relationship between fiscal requirements, practice, and care delivery by linking

reimbursement to Medicare's first mandatory national home health assessment instrument. The seventy (70) item instrument is the Outcome and Assessment Information Set (OASIS), which is used for reimbursement and outcome measures (Medicare Payment Advisory Commission, 2003, 2004). An OASIS form is used for each patient's initial admission to a sixty-day care episode, renewal for subsequent sixty-day episode, transfer, and discharge. Twenty-three (23) of the OASIS items are used to score the patient into one of over eighty (80) Home Health Resource Groups (HHRGs), which are the basis for agency reimbursement during the sixty day period. With the advent of OASIS, home health care represents the only Medicare program using a standardized national assessment instrument to assess patients, determine reimbursement, and measure outcomes, ten of which are posted on a public website (Home Health Compare, 2004).

There have been limited analyses of the impact of home health PPS on agency management, practice, and patient care. None of the research is Alzheimer's disease or dementia- specific and none focused specifically on fiscal requirements as a variable impacting care and practice decisions. One study measured changes in 16 OASIS measures, comparing functional status at admission and discharge (Keepnews, Capitman, & Rosati, 2004). Another measured pre-PPS and early PPS period improvement rates for functioning and dyspnea, community discharge, and hospitalization and emergent care (Schenkler, Powell, & Goodrich, 2004)).

Three studies assert that OASIS inappropriately focuses only on improvements in narrow clinical indicators, such as wound healing and reductions in falls, instead of outcomes for the patient's condition (Elias, Ferry, & Treland, 2000; Martin, 2000;

Outcome Concept Systems, 2004). Among the possible patient condition outcomes would be improvement dealing with underlying conditions such as Alzheimer's disease, Parkinson's disease, and Multiple Sclerosis which often account for falls among the elderly. Such a focus might place more emphasis on psychosocial assessment and interventions which deal with such conditions instead of interventions focusing on acute physical symptoms caused by the condition.

Two studies have questioned the validity and reliability of the OASIS measures (Madigan and Fortinsky, 2000) and initial pre-PPS and early-PPS outcome study results raise significant questions about declines in patient improvement rates related to surgical wound healing, urinary incontinence, and all four OASIS cognitive and all four emotional/behavioral outcomes, and cost increases (Schlenker, Powell, and Goodrich, 2005). Madigan (2001) found that 37% of Medicare beneficiaries discharged from home health with a wound or skin ulcer were discharged before the wound was healed. A study of all Virginia Medicare home health patients from 2000-2001 found a significant increase in the percentage of pressure ulcers that deteriorated in the six-month period after PPS compared to the six-month period post-PPS (Eaton, 2005). These studies did not specifically focus on Alzheimer's disease or dementia patients.

Home Care Social Work

There is a general recognition of Medicare prospective payment systems and managed care impacting health care and home health care social workers, though none is Alzheimer's disease or dementia-specific. In 1994, the National Association of Social Workers (NASW) and the Society for Social Work Administrators in Health Care (SSWAHC) commissioned a national survey with 340 hospital social work directors to

assess the nature of hospital changes, their effects on social work departments and strategies used to deal with change (Berger, 1996). The study affirmed anecdotal reports from both groups that the Medicare inpatient hospital reimbursement system resulted in cost-cutting, an emphasis on shorter lengths of stay, and elimination, decentralization, or merger of hospital social work with other departments. A follow-up survey study was conducted to obtain hospital social work directors' view of changes over an eight-year period (Berger, 2005). The findings were that the cost-reduction and early discharge emphasis continued, social work services had shifted from direct patient care to facilitating discharge, and various strategies were being used to adjust to these changes.

Mizrahi (2001) analyzed the responses to the six open-ended questions in the initial NASW/SSWAHC and found that hospital social workers generally had positive attitudes to change and creative adaptations to social work roles. Mizrahi (1993) published a managed care and managed competition primer article for health care social workers, explaining terminology and the current state of the marketplace.

There is limited research on the relationship between fiscal requirements and home health social work practice. A survey of home care social workers found that 63% of respondents reported a decrease in home health visits after the introduction of the Medicare home health prospective payment system (Kadushin and Egan, 2003). The 2001 National Home Health Social Worker Survey, conducted on behalf of the American Network of Home Health Social Workers, found that social workers were doing more intake and pre-discharge and office consultation activities and participating in ethical forums (Malinowski, 2002).

A 2001 roundtable of experts and an invited audience acknowledged that Medicare home health PPS was further limiting the already limited role of home health social work practice and recommended greater integration of social workers in the home health team (Lee & Rock, 2005). Lee (2002) similarly found that two focus groups with ten (10) home health nurses and eight (8) home health social workers also recommended increased social worker integration into the home health care team to help increase social services to patients. Lee (2005) is researching the relationship between patient outcomes and social work services for elderly disabled home health patients, using OASIS data and interviews. Fiscal requirements are not identified as a variable in the research.

Other studies on home health social worker practice and fiscal requirements are limited, do not focus on Alzheimer's disease or dementia, and are based primarily on national mailed survey responses. The research indicates that social workers feel they often experience ethical conflicts in care decisions where they must choose between financial pressures to limit care and unmet patient needs. Egan and Kadushin (2005) surveyed 117 home health social workers, and found their practice activities focused on transferring patients from Medicare and private insurance coverage in their agency to informal caregivers and community resources. The results indicated that some patients had cognitive impairments, inadequate available family follow-up care, and unmet psychosocial needs at discharge. The survey did not link the care decisions directly to fiscal requirements.

Egan and Kadushin (2004) also surveyed 228 home health social workers' job satisfaction, finding that social workers perceived that their administrators could help resolve ethical conflicts between agency financial priorities and patient access to services,

thus increasing social worker job dissatisfaction. A 1998 national survey of 364 home health social workers (Kadushin and Egan, 2001) and a survey of home health social workers in Tennessee and Wisconsin (Egan and Kadushin, 1999) surveyed four pre-defined ethical conflicts: assessment of patient mental competence, patient self-determination, access to services, and patient advocacy. The survey found three conflicts (patient self-determination, patient mental competence, and patient advocacy) as moderately frequent and difficult to resolve. These surveys also were not specific to home health patients with Alzheimer's disease or dementia and did not interview or survey social workers regarding the influence of fiscal requirements and PPS on practice pressures and decisions.

The research on home health social workers is further limited by the fact that social workers provide limited services and have limited authority in patient care decisions in all government and private payer home health programs (Benjamin, 1993; Kane, 1995; Smith, 1999). Home health nurses, not social workers, are the pivotal decision makers in Medicare home health. Social work visits have never represented more than 2% of all national Medicare home health visits. In 2003, social workers represented approximately 2% of all Medicare-certified home health agency full-time equivalent (FTE) positions, with there being 23 home care nurse FTEs for every one home care social worker FTE (National Association for Home Care & Hospice, 2005).

In contrast, in 2003 nurses represented approximately 52% of home health agency FTEs (National Association for Home Care and Hospice, 2005). Home health nursing visits historically have always represented over 40% of Medicare home health visits and, in 2002, represented over 50% of all national home health visits (Health Care Financing

Review, 2002; National Association for Home Care and Hospice, 2005; Medicare Payment Advisory Commission, 2005). Further evidence of the pivotal role of nursing is that the need for intermittent or skilled nursing or physical therapy is an eligibility requirement for Medicare home health (Health Care Financing Administration, 1999). Furthermore, nurses do home health intakes, OASIS, and other patient assessments. For example, nurses prepare the recommended plan of care which is reviewed and certified by physicians (Health Care Financing Administration, 1999).

Nursing

There is considerable literature on the impact on nurses of changes in the Medicare inpatient hospital reimbursement system and managed care insurance industry, beginning in the 1980s, and indirectly on home care. Diagnosis-related groups (DRGs) were the basis for a new Medicare inpatient hospital prospective payment system. The DRGs and managed care allowed hospitals to move from a cost-based reimbursement to a profit system. Hospitals received pre-set payments based on diagnosis, regardless of actual length of stay and costs. If their actual costs exceeded the pre-set payment, they took a loss; if the actual costs were less than the pre-set payment, they made a profit. Reinhardt (1996) and Gray (1991), among others, observed that these reimbursement systems drove hospitals to cut costs and shorten lengths-of-stay. Weinberg (2003) presents the pressures on nurses created by restructuring of Beth Israel Hospital in Boston into the merged Beth Israel-Deaconess hospital system. The restructuring was prompted by fiscal pressures from the DRG and managed care system. Gordon (1997) similarly recounts the pressures on nurses to increase productivity, decrease patient bedside time, and discharge earlier in her participant-observation study of three nurses at Beth Israel

Hospital in Boston. The pressures on nurses were exacerbated by the nursing shortage, which has persisted since the 1980s.

The inpatient change to DRG and managed care had "a ripple effect throughout all healthcare settings" and on their nurses (Institute of Medicine, 2004, p. 38). The resulting earlier discharges of more acute hospital patients resulted in pressures on nursing homes, rehabilitation facilities, and home care agencies. In turn, between 1984 and 2000 Medicare implemented prospective payment systems for nursing homes, rehabilitation facilities, physicians, and home care agencies (Medicare Payment Advisory Commission, 2006). Thus, all major health care provision settings could make a profit and utilized a combination of cost cutting and shortened lengths of stay to maximize profit opportunities. The Medicare Payment Advisory Commission (MedPac) (2006) reported that 2004 Medicare profit margins for skilled nursing facilities were 13.5%; home health agencies, 16%; long-term care hospitals, 9%; and inpatient rehabilitation facilities, 16.3 %. The Medicare inpatient hospital profit margins have declined steadily from a high of 17.8% in 1997 to -0.3% in 2004. However, overall hospital profit margins, including all payer sources and all hospital inpatient and outpatient services, were 4.4%.The National Association for Home Care and Hospice (2006) contests the MedPac home health agency profit margins.

Home Care Nursing

The impact of Medicare eligibility, coverage, and reimbursement changes has affected all areas of nursing from institutional to community-based care. In discussing the dilemma of nursing from the 1990s until now, Gordon (2005) asserts "… no hospital, no area or group of nursing, no country --- indeed no nurse --- has been left behind" (p.312).

MacMillan-Scattergood,(1986) asserts that the DRG system created pressures on home health nurses by discharging patients quicker with higher acuity needs, but without adding resources to home health agencies. The Institute of Medicine (2004) observed that length of stay reductions “transfer the risk of adverse events from the hospital setting to the home, where such events may be less readily detected and result in more serious consequences for the patient” (Institute of Medicine, 2004, p. 39). The Medicare home health IPS and PPS systems, in turn, pressured home health nurses to restrict patient care even further than the existing short-stay, acute-care-based home health stay.

Gordon (2005) asserts that the end result was that “nursing care would ultimately be outsourced to family and friends who would be asked to provide professional-level services to a loved one in the home” (p.238). Gordon’s observation relates to the Medicare home health setting which historically has remained focused on intermittent, acute care, not chronic care for Alzheimer’s disease or any other disease (Buhler-Wilkerson, 2003; Cabin, 2006a, 2006b). Thus, home health nurses were operating in a system where home health agencies had financial incentives to restrict further care that already was only intermittent and acute, let alone consider symptom management and medical care for chronic patients.

Likewise, Gordon (2005) emphasizes the impact on nurses and patients of further restriction of existing short-term acute home care in several interviews. A former hospital nurse who left inpatient care in 1995 for home care due to the pressures of the DRG system found a brief reprieve from those pressures in home health. The nurse thought she would “have more control over your time with patients”, but soon found in home health pressure for nurse “productivity per day” increasing from 5 to 7.5 patients per day

(Gordon, 2005, p. 316). After recounting a case involving a patient with post-mastectomy complications and no family or outside support, the nurse observed that “when home care nurses are delivering those kinds of care to seven patients a day they’re under tremendous stress because the system is telling them they’re providing too much care ….. We call it drive-by nursing” (Gordon, 2005, p. 317).

A clinical nurse specialist interviewed by Gordon (2005) observed, “The financial squeeze is on every agency or facility you work for. From the point of view of the individual nurse, you do not have a sense of efficacy anywhere you work.” (p.317). She continued, asserting “And it’s hard to be a home care nurse and have to send them [the patients] back to the hospital or, even worse, have them ill and home and saying, ‘I will never go back to the hospital’ “ (p.317).

Other than these anecdotal accounts, the literature provides few studies on the relationship between home health fiscal requirements and home health nurse practice decisions, let alone practice decisions for the Alzheimer’s disease or dementia patients. Liken(2001) discusses the difficult task of ill-prepared home care nurses discussing Alzheimer’s disease patient need for supportive services and institutional place with family caregivers. However, most articles discuss home health and hospice nurse clinical practice management, such as wound care management; descriptions of home health PPS; or billing, outcome measurement, OASIS, or HHRG requirements.

Humphrey (2002a; 2002b) conducted a 2002 survey of 34 clinicians and clinical managers at several home health agencies and conventions and phone interviews with follow-up discussions with several agency leaders and five consultants. Humphrey’s goal was to analyze home health nurse perceptions of post-PPS changes in clinical practice,

the intake process, productivity, clinical models of care, and future issues and trends. She found home health nurses believed PPS had positive impacts on all areas, thus validating that the reimbursement system change affected home health nursing practice. The questions, results, and analysis focused on practical adaptations, strategies, and professional guidance. There was no discussion of nurse decision-making dilemmas, nor specifically on the influence of fiscal requirements on assessment, care planning, or care delivery; no inclusion of quotes or themes from interviews; no specification of the number of persons interviewed; and no questions specific to the identification and care of Alzheimer's disease or dementia patients, let alone how fiscal requirements influenced either activity. Humphrey herself stressed, "This is not a scientific study, but the results of interviews that describe the current state of practice under PPS" (Humphrey, 2002b, p. 742).Humphrey (2002b) did not elaborate as to why she believed her study was not scientific, perhaps because the study did not use random selection, tests of statistical significance, or a randomized controlled test. Though the study does not "prove" that PPS is effective, it offers a keen insight into its potential to operate as a framework accommodating psychosocial interventions.

In an effort to further address the research gap, I conducted a pilot study interviewing seven home care nurses from six different home health agencies between December 2005 and February 2006 (Cabin (2006a, 2006b). The pilot study was an unpublished classroom practicum study addressing the question of: "How do Medicare fiscal requirements impact home care nurse care decisions regarding persons with Alzheimer's disease in Medicare-certified home health agencies?"

The pilot study found that fiscal issues such as Medicare reimbursement, coverage, and eligibility were dominant factors guiding nurse admission and care decisions. Nurses varied in their responses to fiscal requirements from strict adherence (nurse mechanics) to seeking maximum flexibility/challenging requirements (nurse caregivers), with most nurses balancing strict adherence and providing additional client care (nurse mediators); nurses felt Alzheimer's disease patients' symptom management and patient and caregiver psychosocial needs were ignored, creating what several nurses described as a "phantom-like" character to the patient; and Alzheimer's disease patients were discharged from home care with significant unmet needs, often returning for readmission in a costly process which did not manage or treat the disease and its symptoms. The "phantom-like" character of the person with Alzheimer's disease was described by the nurses as their knowing the disease was present, but repressing or ignoring its existence due to a focus on the acute medical need qualifying the patient's care. The underlying "disease" receded into the dark. However, the nurses observed, much like a phantom, the underlying "disease", as they described it, was always there, lurking and hidden and periodically surfacing to haunt the nurses' inability to give more medical and psychosocial care to the underlying disease and quality of life issues of the patient and caregiver.

Recent research on home care clinicians indirectly provides insights on the impact of fiscal requirements. Hokenstad, Hart, Gould, Halper, and Levine (2005) conducted 5 focus groups with 46 home care clinicians (i.e., nurses; social workers; and physical, speech, and occupational services) regarding their interactions with 99 family caregivers of discharged stroke and brain injury patients at three different New York City-based

Medicare-certified home health agencies. The major findings were that clinician services often depend on caregiver participation, but caregivers do not have formal status or consideration. In addition, clinicians balance competing priorities in a short time frame; clinicians recognize that families have unmet emotional and training needs which the home health benefit does not address. They experience conflicting roles as patient advocates and service gatekeepers. Notably, they consider that social work services are essential for access to community resources, but observe that they are reserved only for the most difficult cases.

A related study, a panel survey and interviews of the 99 caregivers in these cases, found that family caregivers provided 75% of all care. Between one-third and one-half reported being inadequately prepared for the patient's discharge; and, at all stages of home health agency care, they felt significant isolation, anxiety, and depression (Levine, Albert, Hokenstad, Halper, Hart, & Gould, 2006).

Medical and Psychosocial Interventions for Alzheimer's Patients

Introduction

There are studies of pharmacological and non-pharmacological interventions for the diagnosis, prevention, and treatment of Alzheimer's disease and dementia. They vary in method and design from randomized controlled trials (RCTs) and other non-randomized quantitative studies to individual and multiple case studies, observational studies, focus groups and other qualitative approaches. Studies address a multitude of different interventions, with varying definitions and components. Some studies measure a single intervention; others measure multiple interventions. Researchers use different definitions, types, and stages of Alzheimer's disease and dementia, with varying research

methods, settings, populations, sample sizes, outcome measures, and tests of statistical, clinical, and practice significance (Belle, et al., 2003; Clare, Woods, Moniz-Cook, Orrell, & Spector, 2004; Cohen-Mansfield, 2001, 2002; Czaja & Schulz, 2003; Czaja, Schulz, Lee, & Belle, 2004; Gitlin, Liebman, & Winter, 2003; Lee & Cameron, 2004; Santaguida, et al., 2004; Schulz, et al., 2003; Thompson & Spilsbury, 2003). These variations may raise questions about research validity and reliability and use of interventions in practice (Weiss, 1998).

Pharmacological Interventions

As stated earlier, most research funding for Alzheimer's disease and dementia involes pharmacological interventions based on the medical model (Ballenger, 2006). These interventions explore cause, diagnosis, and treatment through clinical trials, pharmacology and medical technology. (Santaguida, et. al, 2004). Currently-available pharmacological interventions have limited, short-term impact on dementia and Alzheimer's disease despite hundreds of millions of dollars of federal government and private pharmaceutical research (Albert, 2001; Alzheimer's Association, 2004; Gauthier, 2002;Gwyther, 2001; NIMH, 2007; Peterson, 2004; Santaguida, et al, 2004; Small, et. al, 1997; Stahl & Firth, 2001; Tobin, 1995). Most pharmacological intervention research is based either on randomized controlled trials (RCTs) of specific drugs or systematic reviews of multiple RCTs. These are the so-called "gold standard" studies which are at the top, or level one, of the oft-cited, quantitatively-oriented levels of hierarchical evidence used in much evidence-based medical and other practice fields (Sackett, 1993; Sharma, 1997). They are typically required by the U. S. Food and Drug Administration,

National Health Service in Great Britain, and both the Campbell Collaboration (2007) and Cochrane Systematic Reviews (2007).

The American Geriatrics Society (AGS) and Food and Drug Administration (FDA) recommend only a few cholinesterase inhibitors with close monitoring. These drugs demonstrated some delayed cognitive decline progression in mild to moderate and moderately severe Alzheimer's disease (American Geriatrics Society, 2004; Santaguida, et al., 2004).The federal Agency for Healthcare Research and Quality (AHRQ) found cholinergic inhibitors as the only recommended medications, having evidence of limited positive impact in cognitive decline progression, however no statistically significant evidence of delay of dementia onset. The AHRQ review included studies from eight databases including 249 studies and clinical trials examining whether pharmacotherapy improves cognitive symptoms and outcomes for dementia (Santaguida, et al., 2004). Lingler, Martire, & Schulz (2006) reached a similar conclusion in a systematic review and meta-analysis of seventeen studies of cholinesterase inhibitors involving 4,744 subjects. In 2006, the National Institute for Health and Clinical Excellence (NICE), the body that decides which treatments are supplied by the National Health Service in England and Wales, cited research evidence in recommending that cholinesterase inhibitors specifically not be used for early or late stage Alzheimer's disease (Day, 2006a).

Cochrane systematic reviews, which require randomized controlled trials as a pre-requisite for their study reviews, examined the three most prescribed cholinergic inhibitors (donepezil, galantamine, & rivastigmine) and memantine and found their efficacy "relatively modest" (Evans, Wilcock, & Birks, 2004, p. 351). Lingler, Martire,

and Schulz (2005) performed a meta-analysis of the impact of cholinesterase inhibitors on Alzheimer's disease caregiver burden, using four clinical trials in a burden analysis and six trials in a time-use analysis. They found the inhibitors had "a small beneficial effect on burden and active time use among caregivers of persons with AD" (p. 983) with no statistical significance at p=.05. Cochrane systematic reviews have not found any efficacy for other pharmacological Alzheimer's treatments including selegiline, piracetam vitamin E, Ginkgo biloba, anti-inflammatory drugs and hormone replacement therapy (Evans, et al., 2004). A recent National Institutes of Health (NIH) funded study found Ginkgo biloba is not beneficial in preventing dementia in the elderly (National Institutes on Aging, 2008).

In 2006, a 42-site, double-blind, placebo-controlled trial, monitoring patients for up to nine months, found that the three most common "atypical anti-psychotics" class of drugs used to control agitation and aggression in Alzheimer's disease patients are no more effective than placebos for most patients (Schneider, et. al, 2006). The study also found the medications put most patients at risk of serious side effects, including confusion, sleepiness, and Parkinson's disease-like symptoms. Results from phase one of National Institute of Mental Health clinical trials found that it is unclear as to whether atypical anti-psychotic drugs benefit Alzheimer's disease patients (NIMH, 2007).

Various Alzheimer's assessment instruments and methods exist, but use remains cautionary and limited. These include : physical and neurological exam, taking of family history, functional status assessment, laboratory tests (CBC, TSH, B12,serium calcium, liver & renal function tests, electrolytes), and neuroimaging (detecting structural brain

lesions), though clinically significant structural lesions only occur in 5% of Alzheimer's disease patients (American Geriatrics Society, 2004).

Non-pharmacological Interventions

Research indicates that non-pharmacological interventions vary in effectiveness in improving symptom management and quality of life for dementia and Alzheimer's disease patients and their caregivers (Boettchner, Kemeny, Boerman, 2004; Borawski, Kinney, & Kahana, 1996; Cohen-Mansfield, 2001, 2004; Gitlin, 2003; Iliffe, Wilcock, & Haworth, 2006; Kahana, et al.,1994; Kahana, et al., 2005; Mittelman, 2002, 2004; Mittelman, et. al., 2003, 2004a, 2004b; Schulz, et al., 2003). Among these interventions are support groups and counseling to assist patients and caregivers in dealing with identity issues, depression, and isolation. Respite care is a strategy to relieve caregiver stress from caretaking and environmental modifications are put in place to ease patient mobility limitations and need for caregiver assistance. Recreational therapies are available to enhance caregiver-patient interaction and limit patient physical atrophy. Other therapies may be used to improve self-image and personal identity. A summary of the major non-pharmacological intervention studies appears in a matrix in Appendix One.

The research with the most positive and statistically-significant evidence for non-pharmacological interventions is based on experimental designs, namely randomized controlled trials (RCTs). Thus, the results of these studies have significant import for generalization in the form of the hierarchical model of evidence-based practice often looked upon favorably in governmental policy and practice. Other non-pharmacological intervention research consists primarily of quasi-experimental designs and qualitative studies. These non-experimental designs vary and are based on comparison groups; time-

series designs; interviews or observations of one or more patients or caregivers; focus groups of individual patients, caregivers, or both; and individual patient or caregiver accounts. Greenhalgh (2006) has observed that in studies assessing quality of care the combination of psychosocial and medical issues often make RCTs' utility limited, if not inappropriate. She asserts that RCTs require advance knowledge of criteria in order to form and test hypotheses about an intervention's impact whereas studies of quality issues focus on exploring and detecting patient or caregiver views of quality and care. Even some advocates of evidence-based medical practice assert the hierarchical model is limited and that patient value perceptions should be included in evidence evaluation, albeit it using a strictly quantitative formula (Brown, Brown, & Sharma, 2005).

Because the Cochrane Systematic Reviews (2007) and Campbell Collaboration (2007) generally set criteria that exclude most studies other than randomized controlled trials, their reviews of non-pharmacological interventions for physical and mental problems are limited and even fewer are specific to Dementia patients and caregivers. However, the breadth of design does not limit the value of the cumulative evidence of practice effectiveness of the non-pharmacological interventions. Researchers, as methodologically diverse as Epstein (2001), Cochrane Systematic Reviews (2007), Campbell Collaboration (2007), Thyer and Wodarski (2007), and Gambrill (2005, 2006), among others, recognize both the scientific and practice value of non-RCT design evidence, particularly where vulnerable populations, such as Alzheimer's disease and Dementia patients and caregivers, are subjects.

Despite methodological limitations of studies of many non-pharmacological interventions for Alzheimer's and dementia patients, these interventions have

considerable professional support. In 2006, the American Association for Geriatric Psychiatry (AAGP) issued a position statement which emphasized non-pharmacological interventions as a major part of their principles of care for patients with Alzheimer's disease (Rosack, 2006). The statement specified six clinical goals in the principles of care, four of which rely on non-pharmacological interventions, including improving quality of life, support of patient and caregiver dignity, symptom control, and provision of comfort at all stages of the disease. A 1997 consensus statement by the American Association of Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society concluded non-pharmacological interventions for behavioral problems associated with dementia can enhance patient quality of life by relieving depression, psychosis, and agitation, particularly in Alzheimer's disease. The statement also concluded that psychotherapeutic intervention often was appropriate for depressed caregivers (Small, et al, 1997).

Also in 2006, the National Institute for Health and Clinical Excellence (NICE) issued a report and guidelines emphasizing integrated social care for Dementia patients (Day, 2006b). The report and guidelines emphasized the need for a single point of assessment for all persons for a potential Dementia diagnosis and coordinated community-based and hospital medical and psychosocial care.

Cohen-Mansfield (2001) observed that prior to 1987, dementia-related inappropriate behaviors were "handled with psychotropic drugs, or physical restraints, or ignored" (p.361). Research and clinical observations questioned these practices and resulted in the Omnibus Budget Reconciliation Act of 1987 reducing the use of chemical and physical restraints in nursing homes (Hyer & Intrieri, 2006). The limits of

pharmacological interventions and the 1987 legislation have increased the study of non-pharmacological dementia interventions, particularly in long term care facilities (Hyer & Intrieri, 2006; Kaplan & Hoffman, 1998).

Cohen-Mansfield (2001) reviewed 83 studies of non-pharmacological interventions for inappropriate behaviors in persons with dementia, finding 91% reported a benefit and 53% demonstrated significant improvement from baseline to treatment. The patients were primarily in hospital or nursing home-type residential facilities. The inappropriate behaviors studied were: physically aggressive behaviors (i.e., hitting, kicking, biting); physically non-aggressive behaviors (pacing or inappropriate handling of objects); verbally non-agressive agitation (constant repetition of requests or sentences); and verbal aggression (cursing, screaming).

The eight intervention categories were sensory intervention to relax or stimulate (music, massage/touch, white noise, sensory stimulation); real or simulated social contact (pet visits, one-to-one interaction, and simulated presence therapy and videos); behavior therapy (cognitive, stimulus control, and differential reinforcement); staff training; activities (outdoor walks, structured activities, and physical activities); environmental interventions (wandering areas, natural or enhanced environments, and reduced stimulation environments); medical/nursing interventions (light or sleep therapy, pain management, hearing aids, and removal of restraints); and combination therapies (individualized and group treatments). Cohen-Mansfield (2004) found similar results as did Gerdner (2000) in an 11 study review of music, art, and recreational therapies.

The nearly decade long federally-funded, multi-site Resources for Enhancing Alzheimer's Caregiver Health (REACH) project came to similar conclusions. REACH

Phase I tested five interventions, finding "… a rich array of effective intervention strategies that can be used to enhance different outcomes for caregivers of persons with dementia" (Schulz, et al., 2003, p.518). These interventions included individual information and support strategies; group support and family systems therapy; psycho-educational and skill-based training approaches; home-based environmental interventions; and enhanced technology support systems. These interventions resulted in decreased patient and caregiver depression and sense of social isolation; improved relationships and patient self identity; and improved in-home patient mobility (Burgio, Stevens, Guy, Roth, & Haley, 2003; Gallagher-Thompson, et al.,2004; Gitlin, et al., 2003a, 2003b; Mahoney, Turlow, & Jones, 2003; Schulz, et al., 2003; Wisniewski, et al., 2003).

The REACH I findings resulted in extensive National Institute on Aging (NIA) funding of randomized controlled trails of multi-component approaches in REACH II. Belle, et al. (2006) reported statistically significant findings in improved caregiver quality of life across three different racial/ethnic groups for a multi-component RCT at five different REACH II sites. The study involved 212 Hispanic or Latino caregivers, 219 white or Caucasian, and 211 Black or African American and their care recipients with Alzheimer's disease or related disorders. Each racial/ethnic group was randomly-assigned to intervention and control groups. The intervention group received 12 in-home and telephone sessions over 6 months. The control group received only 2 brief check-in calls during the 6 months. Baseline and six-month measures of quality of life were conducted using valid and reliable scales to measure depression, burden, self-care, social support, and care recipient problem behaviors.

The study found statistically significant improvements in quality of life for intervention group caregivers compared to control group caregivers in all three racial/ethnic groups: Hispanic/Latino ($p<.001$); White/Caucasian ($p<.037$); and Black/African-American ($p<.003$). Overall, clinical depression was lower among all intervention group caregivers (12.6%) compared to control group caregivers (22.7%) at a statistically- significant level ($p = .001$). The intervention was considered so effective that the federal Substance Abuse and Mental Health Services Administration (SAMHSA) listed the intervention on its National Registry of Evidence-based Programs and Practices (NREPP, 2008a).

Burgio (2008) received funding from NIA, the Centers for Disease Control (CDC), and Kimberly-Clark Corporation for the multi-component REACH II in his Alabama REACH Translational Project from 2004-2007. The intervention included 4 hour-long home visits to families over 3-4 months to introduce treatment components. The first visit included a risk assessment. Three therapeutic phone calls were made between each visit. The four intervention components were tailored to individual patient and family situations and included: education about Alzheimer's disease, caregiving, and stress; a home safety check and health passport to assess and track health issues; behavior management/behavioral prescriptions; and signal breath management (i.e., stress management). Outcomes were measured at baseline and at four months using the Alabama Risk Assessment; the study enrollment form; scales for caregiver perceived health and depression; a scale for care recipient memory, behavior, and mood; a caregiver satisfaction survey; and caregiver focus groups with case managers.

The study found four positive caregiver and three care recipient changes based on the pre/post test comparisons. For caregivers, the findings were: improvement in overall health and depression levels; reduction in feelings of burden from caregiving; perceived improvements in care recipient problem behaviors; and fewer feelings of anger toward the care recipient. For care recipients, the findings were they were less likely to: be unsupervised; wander; and to have access to dangerous objects. While measures of statistical significance were not given, the Alabama REACH II findings resulted in a two-year Rosalyn Carter Institute and Johnson and Johnson cooperative agreement, commencing in September 2007, to make the REACH program a permanent part of Alabama CARES, a longstanding state program funded by the federal Administration on Aging (Burgio, 2008). The Alabama REACH II model also is being replicated in Georgia (Carter, 2008) and is a centerpiece for the CDC and Kimberly Clark Corporation's Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) public health framework for dealing with evidence-based programs for Alzheimer's disease caregiver health and well- being (Centers for Disease Control and Kimberly Clark Corporation, 2008). These interventions are premised on quasi-experimental evidence that increased caregiver health and well-being increase Alzheimer's disease care recipient health and well-being.

Environmental Skills-building, Counseling, and Support Groups: Support from Randomized Controlled Trials

In the present environment of the hierarchical model of evidence-based practice, program evaluations of interventions involving randomized controlled trials are especially salient for the proposed dissertation, especially those that included patients and caregivers in the home. Among the most important studies at this level of evidence are

studies dealing with environmental skills-building, counseling, and support groups for persons with Alzheimer's or Dementia and their caregivers.

Accordingly, Gitlin (2003) and Gitlin, et al. (2003a, 2003b) conducted multiple REACH I studies, demonstrating that environmental assessments, skills-building training, and home modifications increase patient mobility, decrease caregiver and patient stress, and improve both caregiver and patient quality of life. The results included improved activities of daily living (ADL) capability and reduced risks of falls and related injuries. The findings confirm earlier studies of residential modifications made in patient homes, long-term care facilities, assisted living facilities, and hospitals (Hall, Gerdner, Zwycart-Stauffacher, & Buckwalter, 1995; Kahana, et al., 1994, 2003; Kennet, et al., 2000; Lawton, 1982; Zeisel, et al., 2003). Gitlin's research is especially significant in this regard because the interventions are home-based whereas most other environmental design interventions for Alzheimer's disease and other dementia patients occur in long-term facilities (Hyer & Intrieri, 2006; Zeisel, Silverstein, Hyde, Levikoff, Lawton, & Holmes, 2003; Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005).

The intervention used by Gitlin (2003) and Gitlin, et al. (2003a, 2003b), with some variation, in most of their studies is the Environmental Skill-Building Program (ESP). ESP is designed to increase caregiver and patient quality of life by reducing burden (Gitlin, et al., 2003c). The program includes five ninety-minute home visits and one thirty- minute phone contact by an occupational therapist. The initial visit includes a review of goals and needs assessment based on eleven areas of typical caregiver patient management concerns. The second visit continues the education process on problem-solving and focuses on establishing an achievable and specific goal (i.e., reduce number

of falls; number of toileting accidents). Physical modifications are identified throughout the process and modifications, equipment, and assistive devices ordered accordingly from the equipment vendor. Subsequent visits and the telephone contact continue to reinforce education, discuss problem-solving on achievable and measurable goals, and assess and order equipment, modifications, and devices. The patient is involved in problem solving and education depending on their cognitive ability as assessed in baseline assessments and occupational therapist on-site judgment.

In another extensive randomized controlled trial, Gitlin, et al. (2006a) reported on a multi-component home environmental intervention designed to reduce functional difficulties in older adults. They tested this intervention using a randomized controlled trial assigning 319 persons age 70 years and older reporting difficulty with one or more ADLs between a control to a treatment and non-treatment groups. The treatment group was provided occupational and physical therapy sessions in home modifications and their use; balance and muscle strength training; and instructions in problem-solving strategies for personal energy conservation, safe performance, and fall recovery techniques. At twelve months, based on self-reporting by participants, researchers found the treatment group participants had less difficulty than control group participants in IADLs ($p = .04$) and ADLs ($p = .03$), with the most significant reductions in difficulty in bathing ($p = .02$) and toileting ($p = .049$). They also self-reported less fear of falling ($p =.001$), greater self-efficacy ($p = .03$), fewer home hazards ($p = .05$), and greater use of adaptive strategies ($p = .009$). Home hazards observations also were conducted on a pre- and post-test basis by the researchers. Statistical significance was measured at the 95% confidence interval.

Gitlin (2008) reported on randomized controlled trial results of a new intervention, the Tailored Activity Program (TAP). The TAP pilot study was funded by the National Institutes of Mental Health (NIMH) and included 60 dementia patients. The four-month TAP intervention for the intervention group included: six occupational therapy visits; assessment to identify spared abilities (i.e., those spared the negative impacts of dementia); tailored activities to enhance the spared abilities; and caregiver training. The participants were assessed at baseline and at four-month follow-up on the following behaviors: memory and problem-solving frequency; repeating questions; and following the caregiver around. Their caregivers were measured on two components: hours doing things for the care recipient and hours on duty. The findings all were significant at p=.01 or less, using t Tests to compare mean scores on the intervention and control groups. The five findings included: the intervention group's mean level of frequency of memory and problem behaviors decreased by 5 points while the control group increased by 18 points (p = .010); the intervention group's mean frequency of repeating question behavior decreased by 17 points while the control group remained unchanged (p = .002); the intervention group's mean frequency of following the caregiver around decreased by 5 points while the control group increased by 65 points (p = .015); the mean frequency of caregivers' hours doing things for the care recipient in the intervention group decreased by half an hour while the control group increased by nearly 3 hours (p = .001); and the mean frequency of caregivers' hours on duty for the intervention group decreased by nearly 5 hours compared to a 2 hour increase for the control group (p = .001).

Mittelman (2002, 2004) and colleagues (Mittelman, et al., 1993, 1995, 1996, 2003, 2004a, 2004b) have conducted studies of support and counseling intervention programs with Alzheimer's patients and their caregivers residing at home for 17 years at New York University Medical Center. Most of their studies have used randomly-assigned control and treatment groups. Zarit & Femia (2008) assert the strength of the Mittelman and Mittelman and colleagues research is that they validate the most effective psychosocial interventions are those which allow flexibility in approaches used with subjects and the length of treatment. In general, Zarit & Femia (2008) assert these studies and others in dementia care demonstrate that treatment effectiveness increases with increases in the amount and length of treatment. Overall, they assert the Mittelman and colleagues research "results have been consistently positive with reduced [caregiver] depression and burden and increased time to institutionalization of the care recipient" (Zarit & Femia, 2008, p. 51). Furthermore, Mittelman and her colleagues' research is considered so effective that SAMHSA has listed their intervention on their National Registry of Evidence-based Programs and Practices (NREPP, 2008b).

Mittelman, et al. (1993) conducted a randomized controlled trial with 103 spouse-caregivers of Alzheimer's disease patients each in a treatment group (i.e., individual & family counseling, support group participation, and ad-hoc consultation) and a control group (routine support only). The participants were spouse-caregivers of patients at the New York University Aging and Dementia Research Center (NYU-ADRC). The findings indicated that, using a chi square analysis, in the first year after intake the treatment group had 54% fewer nursing home placements than the control

group when caregiver sex and age, patient age, patient income, and need for assistance with activities with activities of daily living (ADL) were taken into account ($p<.05$).

The study used logistic regression to measure the potential impact of other variables on likelihood of nursing home placement. The sex of the caregiver was not found to be statistically significant. Both caregiver and patient age were found to have statistically significant effects using a chi-square test ($p<.05$). Specifically, this means that (1) for any given patient age, the younger the caregiver, the more likely the patient was to be placed in the nursing home and (2) for any given caregiver age, the older the patient, the more likely nursing home placement. Patient income also was subjected to chi square analysis and found to be statistically significant ($p<.05$), meaning lower income increased the odds of placement. Lastly, need for assistance with ADL also had a statistically significant impact through chi square analysis ($p<.01$), meaning the greater the ADL needs, the more likely placement. The need for ADL assistance was so significant that it offset the influence of patient income significantly. When ADL assistance need was added to the patient income variable, the odds of placement of a patient at the high end of the income scale were approximately four times as high as a person at the low end of the income scale. The authors indicated "an exploratory analysis" (Mittelman, et al., 1993, p. 737) indicated that incontinence accounted for most of the variance explained by ADL. Financial cost savings to the patient, spouse-caregiver, and insurers were not included in the study.

Mittelman, Roth, Haley & Zarit (2004b) conducted a randomized controlled trial of 203 spouse-caregivers of Alzheimer's disease patients each in a treatment group (i.e., two individual & four family counseling sessions in the initial four months; weekly

caregiver support groups ; and continuous ad-hoc telephone counseling for families and caregivers) and a control group. The participants were spouse-caregivers of NYU-ADRC patients. The findings both at one year follow-up ($p = .037$) and the four-year follow-up (ps < .02) indicated that the intervention group reported significantly lower levels of negative reactions to patient problem behaviors, even though the frequency of patient problem behaviors did not decrease. The decreased negative caregiver reactions, or appraisals as termed in the study, also are significant because in prior research (Mittelman, et al., 1996) the severity of caregiver reactions to patient problem behaviors was a significant predictor of nursing home placement and accounted for most of the effect of depression on caregivers seeking the placement.

A three country study (United States, Australia, and England) using a similar comprehensive support and counseling intervention in randomized controlled trials found improved caregiver satisfaction with assistance from their social network ($p = .006$) and decreased depression ($p = .001$)(Mittelman, 2004a). Other researchers have found positive outcomes for caregiver support group interventions (Gendron, Poitras, Dastoor, & Perodeau, 1996; Yale, 1999). A Cochrane systematic review found research design problems and limited evidence of effectiveness for Alzheimer's caregiver support group interventions, but did not recommend they be withdrawn (Thompson & Spilsbury, 2003).

Mittelman, Haley, Clay, & Roth (2006) analyzed the results of their intervention on 406 Alzheimer's disease spouse caregivers who had enrolled in their program over a 9.5 year period. They found, consistent with their other studies, that the intervention group receiving the enhanced counseling and support: had a 28.3% reduction (or 557 days) in placing their spouse in a nursing home compared to the control group ($p = .025$).

The caregiver's satisfaction with support they received from family and friends, increased ability tolerate problem behaviors of their spouse, and decreased symptoms of depression combined accounted for 61.2% of the delayed nursing home placement outcome using a hazard analysis. Mittelman, Roth, Clay, & Haley (2007), using the same database, found that, controlling for baseline (mean 7.24), intervention group spouses had significantly better self-rated health (SRH) both at four months (6.87 versus 7.21 for control group) and at two years (6.70 versus 7.01 for control group). The authors assert use of the caregiver interventions effectively improves patient outcomes and urge their adoption.

Mittelman (2008a) further reported that the NYU Caregiver Intervention (NYUCI) began pilot randomized controlled replications in November 2007 at the Metropolitan Jewish Health care System (NY) and Fletcher Allen Healthcare (Burlington, VT). Both pilots are funded jointly by Johnson and Johnson and the Rosalynn Carter Institute Caregivers Program. Mittelman (2008b) also reports that the federal Administration on Aging has approved funding a nine-site pilot replication in Minnesota. No results are available at this time. Joling, van Hout, Scheltens, Vernooj-Dassen, van den Berg, Bosmans, Gillisen, Mittelman, & van Marwijk (2008) also reported the initiation of a randomized controlled trial replication of the NYUCI family meetings intervention studying progress of intervention and controlled group dyads at baseline compared to one year follow-up. The study is funded by the Dutch government, conducted in the Netherlands, and will measure the impact of an intervention of four family meetings with family and close friends on overall care costs and caregiver anxiety and depression levels.

Support Networks, Reminiscence Therapy, and Group Interventions

Most, though not all, studies of cognitive impairment indicate that persons with more extensive social networks have a reduced risk of cognitive impairment (Bennett, Schneider, Tang, Arnold, & Wilson, 2006). More recently, research indicates that the existence of social networks positively impacts, or protects against, the rate of cognitive decline as Alzheimer's disease progresses ($p = .016$) (Bennett, Schneider, Tang, Arnold, & Wilson, 2006). The research is significant because it is the first to find a positive association between a psychosocial or palliative care intervention (i.e., social networks) and physiological outcomes (i.e., rate of cognitive decline as Alzheimer's disease progresses).The results also are significant because they are based on annual clinical evaluations (i.e., twenty-one clinical performance tests) and autopsies of the first 89 elderly people without known dementia participating in the 1,100 person Rush Memory and Aging Project.

Nursing home-based research also supports the positive effects of support networks. Caufield (2006) reported research on the positive effect of club groups for dementia patients in a skilled nursing facility. The club is a group of residents with a daily routine including activities such as exercise, meals, games, current events discussion, and music. The study of 28 club participants found a decrease in use of psychoactive medications ($p < .01$), weight loss ($p < .001$), and a decrease in feelings of social isolation ($p < .01$).

Several researchers emphasize the need to individualize treatment plans and utilize interdisciplinary planning (Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000; Kennet, et al., 2000; Levine, 2003; Schulz, et al., 2003), though Thompson and

Spilsbury (2003) find supporting research evidence limited. A 2006 REACH II randomized controlled study of a multi-faceted, personalized intervention found significant quality of life improvements for caregivers of people with dementia (National Institute of Aging News, 2006). The study involved 642 individuals at five sites and followed subjects for six months post-intervention. The intervention included trained staff making nine home visits, three half-hour telephone calls, and offering five structured telephone support sessions. The results found improvements in caregivers' level of depressive symptoms and problem behaviors and increase in self care.

Individual and group reminiscence therapy has been advocated for dementia patients and their caregivers (Bornat, 1994; Woods, 1999). A Cochrane systematic review found reminiscence therapy had statistically significant results for improving cognition, mood, and general behavioral function for older people with dementia (Woods, Spector, Jones, Orrell, Davies, 2006). The same review also found a statistically significant decrease in strain for caregivers participating in reminiscence groups with their relatives with dementia. Other researchers assert there are no firm conclusions regarding reminiscence therapy effectiveness (Lai, Chi, & Kaiser-Jones, 2003).

There are many accounts of individual client and group therapy interventions asserting that use of art, music, or drama improves patient quality of life (Basting, 2001; Caufield, 2006; Coenen, 1991; Richardson & Barusch, 2005). Preliminary results of the first longitudinal randomized controlled trial of a community-based arts program for persons aged 65 and older indicates the participants receiving the arts program at one year follow-up experienced fewer falls, improved their number of activities, and had

greater improvements on the depression, loneliness, and morale assessment scales than control group participants (Cohen, 2006).

A Cochrane systematic review asserts that five randomized controlled trials produced generally poor results for music therapy having positive impacts on treating behavioral, social, cognitive, and emotional problems of elderly with dementia (Vink, Birks, Bruinsma, & Scholten, 2006). A Cochrane systematic review found insufficient evidence from randomized trials at this time to make a conclusion regarding the efficacy of validation therapy for persons with Alzheimer's disease and other dementias (Neal & Briggs, 2006). However, Feil (1993), the founder of validation therapy, and others (Richardson & Barusch, 2005) report quality of life improvements for individual clients. Validation therapy, usually practiced in groups for dementia patients, is premised on accepting the reality and personal truth of the dementia person's experience, and uses empathy and positive reinforcement. The Cochrane systematic reviews have stringent requirements in using only randomized controlled trials (RCTs) as the basis of their reviews, thus limiting the ability to make positive findings in areas where other quantitative and qualitative research designs dominate.

Other Interventions: Respite, Occupational Therapy, Cognitive Training, Light Therapy, and Snoezelen Therapy

Respite care has mixed results. Some caregivers find respite helpful while others assert it increases their stress levels. This latter response is attributed to the intrusion of formal caregivers in the informal caregiver's home and the informal caregiver's anxiety about care being rendered in their absence (Montgomery, Karner, & Kosloski, 2002a, 2002b). A systematic respite care literature review indicates limited evidence of statistically significant positive results, while endorsing further research and continuing

use (Lee & Cameron, 2004). Alternatively, occupational therapy (Gitlin, et al., 2003b; Graff, et al., 2006) and speech therapy (Mahendra and Arkin, 2003; Savundranayagam, Hummert, and Montgomery, 2005) have been found effective in short-term improvement of patient mobility and communication, decreasing caregiver and patient burden.

Cognitive rehabilitation and cognitive training interventions have mixed results. A Cochrane Systematic Review found no statistically significant results in six randomized controlled trials for cognitive training and cognitive rehabilitation improving memory functioning for persons with early-stage Alzheimer's disease or vascular dementia (Clare, et al., 2006). Bayles & Kim (2003) assert that cognitive interventions are effective. The American Psychiatric Association also has found limited benefit for such interventions (Richardson & Barusch, 2005). These interventions seek improvement in cognitive and activities of daily living (ADL) functions through individual, group, and patient-caregiver interventions. Interventions include: memory exercises (Bourgeois, 1992; Camp, et. al., 1993), memory aids (Bourgeois, 1992), tasks with familiar stimuli (Quayhagen & Quayhagen, 1989), and priming (McKitrick, Camp, & Black, 1995).

A Cochrane systematic review found insufficient evidence to assess the effectiveness of light therapy for managing sleep, behavior, and mood disturbances in dementia (Forbes, Morgan, Bangma, Peacok, Pelletier & Adamson, 2006). Light therapy is used with dementia patients in nursing homes and other long term care facilities. There is mixed evidence on the effectives of Snoezelen, another long term care facility-based dementia intervention. Snoezelen uses lighting effects, tactile surfaces, meditative music, and the odor of certain oils to stimulate the senses of sight, touch, hearing, smell, and taste. A Cochrane systematic review could not make a substantive conclusion on the short

term effects of Snoezelen for people with dementia (Cung & Lai, 2006). However, Brown (1999) reports that use of Snoezelen before and after bathing 29 patients with a resistive behavior history decreased their resistive behavior. Mahoney, et al ((1999) reports that use of Snoezelen with 13 residents with a resistive behavior history before and after bathing combined with reminiscence therapy during bathing decreased their resistive behavior.

Methodological Issues Regarding Practice Intervention Research

While the literature indicates significant clinical and practical significance in non-pharmacological research, it also presents methodological limitations in studying the Alzheimer's disease and dementia populations. Zarit & Femia (2008) recently summarized both the strengths and methodological limitations of the behavioral and psychosocial intervention dementia care caregiver and care recipient research literature. The strengths are that the most effective interventions are psycho-educational or psycho-therapeutic as opposed to education only and that effectiveness increases the more the intervention is multidimensional, flexible, and has sufficient amounts and length of care. In terms of limitations, they highlight studies which: mismatch caregiver or care recipient needs or eligibility criteria to the intervention; mismatch treatment intervention to caregiver or care recipient needs or risk factors; pre-determine caregiver or care recipient goals instead of deriving goals from the subjects; and fail to segregate caregiver and care recipient social roles and characteristics, creating excessive heterogeneity among the subjects.

Other studies have identified the same or additional methodological issues. One problem is that few intervention studies have common variables and methods. For

example, literature indicates that common elements which vary in Alzheimer's disease and dementia policy and practice interventions research include: the types and combinations of Dementia; disease stages; disease levels; screening and assessment processes and instruments; socioeconomic and cultural composition and geographic location of the intervention population; residential or caregiving settings; length or longitudinality of the intervention; category of person, with some studying patients only, others caregivers only, and others studying both, sometimes in spousal or non-spousal dyads; health profile of target population, including existence of multiple diagnoses; and research design and methodology differences including sample sizes, tests and acceptable levels of statistical significance, and a variety of different quantitative and qualitative methods. Droes, et al. (2006) also cite the variations in definition of quality of life among Alzheimer's disease and dementia researchers, patients, and caregivers.

Another issue is defining an appropriate sampling frame because caregivers represent a highly variable population and the stage and comparability of Alzheimer's disease is difficult to assess and detect. For example, Schulz, et al. (2003) note that, "With rare exception, caregivers typically do not fall into single syndromal clinical categories that lend themselves to a clearly targeted intervention" (p. 519). Sadick and Wilson (2003) observe that Alzheimer's disease may not be diagnosed in its early stage either because the early signs are subtle and symptom onset gradual or because the symptoms are confused with symptoms of normal aging, depression, stroke, Parkinson's Disease, and other non-AD dementias. There also is no medical consensus on the value or significance of various stage models (Lyman, 1989; Whitehouse, Maurer, and Ballenger, 2000).

Another issue is the limited ability to generalize from a cross-sectional study or from other research conducted at one point in time, or for a limited time period, with a specific population in a specific practice setting (Epstein, 1977, 2001; Weiss, 1997; Yin, 2003). For example, in Alzheimer's disease and dementia research many of the non-pharmacological interventions are predominantly nursing-home based, requiring a 24/7 controlled physical environment and available staff, and apply only to late-stage Alzheimer's disease and dementia persons (Hyer & Intrieri, 2006; Kaplan & Hoffman, 1998; Mahoney, Volicer, and Hurley, 2000; Richardson & Barusch, 2006). These and other studies often encounter problems with participant recruitment, participant attrition, sample size, variations in the unit of analysis (i.e., patients, caregivers, patient-caregiver dyads), and other sampling bias issues (Cohen-Mansfield, 2001; Schulz, et al., 2003).

However, at least two home-based interventions have confirmed non-pharmacological intervention models based on multiple randomized controlled studies: the multi-component home environmental assessment, modification, and skills-building program (Gitlin, 2003; Gitlin, et al., 2003a, 2003b, 2006) and the multi-component support group and counseling program (Mittelman, 2004a; Mittleman, et al., 1993, 2003a).

In addition, there are many other research-based, non-pharmacological interventions which appear effective as an arsenal of interventions for practice. For example, in evaluating the five different interventions in the eight-year REACH I research, Schulz, et al. (2003) observed that though the interventions derive from different theories, "they are all consistent with basic health-stressor models in which the

goal is to change the nature of specific stressors (e.g., problem behavior of the care recipient), their appraisal, and/or the caregivers' response to the stressors" (p. 514).

Schulz, et al. (2003) observed that "because the caregiving experience in racial and ethnic minority families is particularly neglected in this field, a strong emphasis was placed on the inclusion of African American and Hispanic caregivers" (Schulz,et al., 2003, p. 514). The conclusion from these studies is:

> Overall, these studies provide a rich array of effective intervention strategies that can be used to enhance different outcomes for caregivers of persons with dementia. They also emphasize the interactive nature of different treatment approaches with caregiver characteristics and provide important leads about which types of interventions work with which types of caregivers. (Schulz, et al, 2003, p. 518)

The REACH II is in progress and uses randomized clinical trial testing of a multi-component individually-tailored intervention at multiple sites with ethnically diverse caregivers.

Both Cohen-Mansfield (2001) and Schulz, et al. (2003) find a variety of effective individual client and caregiver non-pharmacological interventions and identify similar areas for improvement in future research. Cohen-Mansfield (2001) identifies six broad issues to address: "individualization and proper selection of treatments….; the specifics of the interventions…….; the issue of costs………; the basic understanding of quality of care in dementia….; system change…." and "Finally, as such knowledge is gained, concomitant changes in reimbursement and the structure of system-of-care need to take place in order to improve the practice of dementia care" (p. 378). Schulz, et al. (2003)

also concludes that “a ‘one size fits all’ approach to caregiver interventions is likely to be ineffective” and “interventions need to allow for some degree of tailoring of intervention components to meet the specific needs of the individual” (p. 519).

Kennet, et al. (2000) analyzed forty studies covering multiple non-pharmacological family caregiver interventions, primarily with Dementia, from 1990-1997 and concluded that there is no “silver bullet solution to alleviating caregiver stress” (p.79); “… interventions which are comprehensive, intensive, and individually tailored are likely to be more effective…” (p.79); and “new and promising strategies” exist in some current intervention studies which are “simultaneously treating the care recipient (e.g., giving medications or memory retraining) and/or altering the social and physical environment of the caregiver/care recipient dyad” (p. 79). Kennet, et al. (2000) also observe that “The existing literature also points to a rich array of methods for delivering interventions to caregivers including microcomputers, the telephone, and individual and group sessions” (p.79).

Many of the interventions discussed in this section are summarized in a matrix in Appendix One.

Choice of the Research Question

Several unaddressed research questions emerged from the literature review. The research question selected is: **What factors impact home care nurse and home care social worker care decisions regarding persons with Alzheimer’s disease in Medicare-certified home health agencies?** The unit of analysis is the home care nurses and social workers. The population is all home care nurses and home care social workers in the United States. These decision-makers were selected for study because they have

the most significant direct service contact with persons with Alzheimer's disease and their caregivers. As a result it is important to know whether their insights are congruent with the research on non-pharmacological interventions, or provide additional insights or issues not addressed in the studies. Nurses are particularly important because they control initial and ongoing care plan decisions. As a result, nurses' views on client needs and intervention effectiveness and their intervention knowledge level is important. While social workers do not have significant control in home care decision-making, their insights as trained psychosocial intervention practitioners are important for determining the best match of interventions to the needs of persons with Alzheimer's disease and their caregivers.

The literature review indicated that Medicare eligibility, reimbursement, and coverage requirements generally impinge upon nurse and social worker decisions across many Medicare provider types. However, the empirical literature revealed no studies specific to the impact of Medicare eligibility, reimbursement, and coverage requirements on home care nurses and social workers and, even more specifically, on their decisions regarding the Alzheimer's disease population. The literature further revealed no studies specific to other factors which might influence these professionals care decisions, such as: education; professional experience; home care experience; personal experience; family availability and demands; patient contact and demands; supervisory direction; and agency policy and procedures, among others. Although these may be factors in their decision making, little is known about that process and I felt I could not depend on speculation to identify important variables that may contribute to their course of action. The study was intended to address these gaps and to use the nurse and social worker

interviews to research client needs, appropriate evidence-based interventions, and policy and practice barriers to more appropriate matching of interventions to the needs of persons with Alzheimer's disease and their caregivers.

As noted earlier, home care nurses were selected as one population of interest because research indicated that they control decision-making, including the nature and extent of social work utilization. As noted in the literature review, they make initial intake decisions, develop and manage the patient's plan of care, do initial and ongoing patient assessments, deliver care, decide the nature and frequency of services provided, coordinate all direct service home care agency personnel and informal caregivers (i.e., family and friends), and decide on length of stay, transfers, and discharges.

Home care social workers were selected because they are the primary home care professionals trained and responsible for psychosocial interventions with persons with Alzheimer's disease and their caregivers. Home-based psychosocial interventions are significant because the literature review revealed a dissonance between Alzheimer's disease persons' needs, research on effective psychosocial interventions, and Medicare home heath policy which limits use of such interventions. The National Association of Social Workers code of ethics also emphasizes the primacy of client need in assessing and providing care (National Association of Social Workers, 1996).

Thus, interviews of home care nurses and social workers appeared the most beneficial design to explore the relationship between Medicare regulatory requirements and decisions about the Medicare home health Alzheimer's disease population.

The research question also is relevant to a broader policy concern identified and not addressed in the literature review: **What is the impact of Medicare home health**

policy on the care of persons with Alzheimer's disease? The literature review identified Medicare home health policy as based on a *medical model* which does not meet Alzheimer's disease client and caregiver needs and does not cover evidence-based psychosocial interventions for this population. The research question and study explore the impact of Medicare home health policy on this problem by specifically studying how Medicare eligibility, coverage, and reimbursement requirements, separate from or in conjunction with other factors, affect home care nurses' and social workers' decisions about persons with Alzheimer's disease . The results of this study are intended to further inform the policymaking process to increase the use of appropriate, research-based and evidence-informed practice interventions to reduce unmet needs and improve outcomes for home and community-based persons with Alzheimer's disease.

CHAPTER FOUR: METHODOLOGY

Purpose of the Study

The purpose of the study was to explore how fiscal requirements and other Alzheimer's policy factors influence home care nurse and social worker perceptions of and care decisions for Alzheimer's disease patients in Medicare-certified home health agencies. The study employed qualitative methods. The unit of analysis is the group of home care nurses and social workers, focusing through the research design on factors which affect their care decisions about Alzheimer's disease patients.

The study's primary research question was: What factors impact home care nurse and social worker decisions regarding persons with Alzheimer's disease in Medicare-certified home health agencies? In addition, the study explored the impact of Medicare home health policy specifically on the home health professionals' decision-making. This assumed their lived experience was not self-evident, so that propositions or hypotheses rooted in a preconceived theory independent of actual home health agency experience were inappropriate (Patton, 2002). The qualitative design used in the study to explore the nature of the decision-making process allowed me to determine what, if any, hypotheses might be reasonable to test in the future. Furthermore, the qualitative design also allowed the emergence of themes which later, ex-post-facto, could be interpreted in the context of existing theories, as occurred in using Merton's anomie theory (1938, 1957), in some ways, to interpret nurse and social worker coping strategies.

Writing about evidence-based medicine, Greenhalgh (2006) has observed that in studies assessing quality of care the combination of psychosocial and medical issues often make RCTs' utility limited, if not inappropriate. She asserts that RCTs require

advance knowledge of criteria in order to form and test hypotheses about an intervention's impact whereas studies of quality issues focus on exploring and detecting patient or caregiver views of quality and care. Likewise, in exploring the lived experience of home care nurses and social workers, a qualitative design is more appropriate.

The research and policy findings presented in the literature review provided the basis for the research question; valuable information to structure interview questions; and insights for interpreting the research study findings. Understanding the reality of care decisions in the home care setting requires excavation of the experience of practitioners. The home care nurse is the practitioner most affecting care decisions due to her role in making intake, assessment, care plan development, and treatment delivery decisions. Next, home care social workers represent the professional in home care most familiar with palliative care interventions and bound by a specific professional code of ethics to give primacy to client need.

Rationale for a Qualitative Methodology and Design

Qualitative research through semi-structured interviews facilitates the exploration of multiple factors influencing home care nurse and social worker decisions (Patton, 2002; Stake, 1994). For example, fiscal requirements include whether the patient meets Medicare eligibility, coverage, and reimbursement requirements. Compliance with these requirements may change daily with changes in patient condition, patient homebound status, availability of family or other support persons, and patient, family, and physician preferences.

As indicated earlier, the present study does not meet the underlying assumptions of a quantitative design based on assumed theory. Therefore, hypothesis-testing is not

appropriate (Bloom, 2005; Epstein, 2001; Epstein & Tripodi, 1977; Janesik, 1994; Patton, 2002). Similarly, a quantitative descriptive study would not be appropriate at this point because sufficient information of decision-making factors and their relationship does not exist to allow the development of survey instrumentation (Patton, 1987, 2005). Therefore, the study was undertaken both in the tradition of Grounded Theory (Glaser & Strauss, 1967) and phenomenology (Patton, 2002; Phillips, 2005). It was conducted in this tradition assuming the interviews might lead to hypotheses and contribute to the development of theory through the inductive process of the qualitative inquiry. In fact, the interviews revealed key decision-making variables. These variables may facilitate future quantitative studies testing hypotheses about which factors affect decisions and relationships between multiple independent variables and types of decision-making.

Interviews also were designed to deliver "thick description" (Shweder, 2005) of the experience of nurses and social workers. The lived experience of the nurses and social workers is in the phenomenological tradition of generating insight on the complexity of home care nurse and social worker decision-making for Alzheimer's disease patients (Patton, 2002; Phillips, 1987). The existing literature does not provide insight into the process of professional decision-making and how home care professionals' decisions influence patient care. In addition, a brief survey was used to systematically gather attribute and demographic factors which are relevant to describe the study informants.

The interviews allowed discovery within the complicated and dynamic home care agency decision-making process. The decision-making process includes multiple key points, such as: initial care plan development and review with the authorizing physician; ongoing decisions regarding changes in the type, frequency, and length of time for

service provision; decisions regarding renewal of care and the nature of renewal every sixty days, as required by Medicare; decisions about handling family and patient needs and requests; decisions about discharge, including transfer to inpatient or outpatient care, and planning with family and community resources; decisions about when to have interdisciplinary communication and how to resolve interdisciplinary discussions; and decisions about whether and how to provide care which is deemed necessary and appropriate, but not covered by the payer. These decision points were sensitizing concepts that I used to inform the interview guide and interviewing process.

Limitations of Qualitative Research

Many prominent researchers point out the limitations of qualitative research, such as not directly contributing to practical, applied outcomes to improve patient care and limitations in the generalizability of a study with an inevitably small, non-probability sample (Gambrill, 2002; Gibbs & Gambrill, 2002; Weiss, 1998). However, the same researchers point out that the conditions under which qualitative research is most appropriate occur when the purpose of the study is to discover the lived experience of the participants. In response to concerns about bias in such qualitative studies, Denzin and Lincoln (2003) contend that the researcher's values are present in all types of research, including quantitative inquiry.

The interviews were envisioned as providing a multiple case study of home care nurses and social workers located in different home care agencies. Such a *multiple case study*, or multiple-case design (Yin, 2003) uses more than a single case to gain insight on the research question. The multiple case study design also has the advantage of providing the equivalent of multiple experiments, "that is, to follow a 'replication logic'"

(Yin, 2003, p.47). Both Yin (2003) and Patton (2002) assert the use of multiple case studies enhances the credibility of the research findings. However, Yin's (2003) approach seems predicated on having the subjects located in different agencies, with the agencies being the multiple cases. I was unsuccessful in accessing agencies as the route to conduct interviews, thus limiting my ability to use the Yin (2003) logic.

However, a form of multiple case studies exits in my study, albeit not in the precise form envisioned by Yin (2003). Yin (2003) distinguishes the use of multiple cases as multiple experiments from the conception of multiple cases as multiple respondents in a sample, or what he terms "sampling" logic. Each home care nurse and social worker interviewed, according to Yin's replication logic, provided the opportunity to replicate the findings about the factors influencing home care nurse and social worker decision-making regarding Alzheimer's disease patients. More specifically each of the individual cases is carefully selected "so that it either (a) predicts similar results (a *literal replication)* or (b) predicts contrasting results but for predictable reasons (a *theoretical replication*)." (Yin, 2003, p. 47).

In the study of home care nurse and social worker social construction of care decisions, the theoretical replication related to contrasting results regarding decision-influencing factors among individual nurses and social workers. For example, some nurses and social workers based care decisions primarily on the agency's protocol for treating the identified medical problem, without any regard for the Alzheimer's disease psychosocial symptoms and needs. Others were more open, recognizing and providing care for the Alzheimer's disease needs either within or despite agency protocols linked to fiscal requirements.

Frameworks Orienting Method & Design Choice

The two frameworks which justify the choice of the qualitative method and design are phenomenology and social constructionism. They provide an ongoing framework to integrate the development and research of the research question.

Patton (2002) asserts that the foundational question in phenomenology is: "What is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?" (p.104). This foundational question is the essence of the study's question and intent. The research question focused on how fiscal requirements and other factors affect home care nurse and social worker care decisions for Alzheimer's disease patients. The study's intent was to address the meaning, structure, and essence of the lived experience of the particular decision-making for the nurses and social workers through the survey and interviews. The study examined the phenomenon of how home care nurses and social workers socially construct care decision-making for the purpose of creating a better fit between research, policy and practice (i.e., home care treatment for Alzheimer's disease patient needs). Thus, phenomenology fit as an orienting framework for the study which contributes to knowledge-building about the phenomenon of factors affecting home care nurse and social worker care decisions about Alzheimer's disease patients.

Patton (2002) asserts that the foundational questions for social construction include:

> How have the people in this setting constructed reality? What are their reported perceptions, "truths", explanations, beliefs, and world-view? What are the consequences of their constructions for their behaviors and

for those with whom they interact. (p.96)

In developing the concept of the social construction of reality or social constructionism, Berger and Luckmann (1997) discuss the concept as reflecting the sociology of knowledge. They observe that the focus must be “with whatever passes for knowledge in society, regardless of the ultimate validity or invalidity (by whatever criteria) of such knowledge” (p. 3). They continue that the focus should be on how “human ‘knowledge’ is developed, transmitted, and maintained” in order to understand how “a taken-for-granted ‘reality’ congeals for the man in the street” (p.3). Multiple authors (Anspach, 1997; Armstrong, 2000, 2003; Conrad, 2005; Gusfield, 1972, 1981; & Schneider and Ingram, 2005) have analyzed and researched the relevance of reality construction to a multitude of health, welfare, and social policies and practice decisions.

Methodology, Design, and Data Analysis Procedures

An interview guide was used for in-person interviews from a snowball convenience sample of home care nurses and social workers. The interview guide appears in Appendix Two. I initially designed the interview guide as part of a qualitative pilot project for Professor Michael Fabricant’s Fall 2005 qualitative research doctoral course at The Hunter College School of Social Work. It was modified as a result of the pilot study experience, resulting in the interview guide approved by the IRB. At the end of the interview, participants were asked for information on age, gender, highest educational degree, years of professional experience, and years of home care experience. The data enabled me to describe the characteristics of the sample.

The sample included thirty-three (33) home care nurses and thirty-nine (39) social workers identified by professionals with whom I worked during 17 years in the home

care industry. Most participants resided and worked in the New York City metropolitan area.

All study procedures followed the two approvals of the Hunter College Institutional Review Board (IRB). The proposed study was initially approved for one year on August 8, 2007 as Protocol HC-070712721 and IRB Registration Number 00004471. The approval was renewed for another year on July 23, 2008 as Protocol HC-070822251 and IRB Registration Number 00000136. Participation was voluntary and all participants signed an IRB-approved informed consent prior to their interview. Interviews were conducted at locations convenient to participants and off-site from their workplace. All information is confidentially maintained and stored in a locked, secured space at my residence.

Participants were given the option of having their interview tape-recorded, recorded by notes, or both, with most (65 or 90%) opting for notes only. Participants were given the option of terminating the interview at any time for any reason, though none exercised the option. I questioned several interviewees about why they were reluctant to be taped, though I did not add this specific question to the interview guide. In general the interviewees said that while they were comfortable with my confidentiality assurances, they were nevertheless anxious and concerned their employer might discover their participation in the study. This fear of detection and potential adverse consequences appears consistent with the overall anomie and conformist coping strategy adopted by most nurses and social workers.

The limited quantitative data analysis was done with the Statistical Package for the Social Sciences (SPSS), version 13.0. Qualitative data analysis was not conducted

using software. Qualitative analysis began shortly after the initial data were collected. The initial data analysis resulted in additional questions and probes that were applied to subsequent interviews, in an ongoing iterative process.

The analysis was conducted by me categorizing the interview data which was made up of words, phrases, and sentences. This open coding is a generally-accepted analysis framework in qualitative research (Denzin & Lincoln, 1994; Miles & Huberman, 1994; Patton, 1994; Strauss, 1987, 1993; Strauss & Corbin, 1990; Werner & Schoepfle, 1987). The purpose is to fracture the data to "identify some categories, their properties, and dimensional locations" (Strauss & Corbin, 1990, p.97). The coding and classification generated a list of 322 codes. Code and category labels were created. Categories are units of information composed of "events, happenings, objects, actions/interactions that are found to be conceptually similar in nature or related in meaning" (Strauss & Corbin, 1990, p. 102). Codes and categories were systematically sorted, compared and contrasted until they were complete, with no new codes or categories produced and all data accounted for. The analysis sorted separately for home care nurse and social worker to detect commonality and variation.

Axial coding was the next step, which was putting data "back together in new ways by *making connections between a category and its subcategories*" (italics in original, Strauss & Corbin, 1990, p.97). This was accomplished by identifying multiple phenomena from the connected categories and subcategories. Categories of conditions that affected each phenomenon were explored; factors and actions resulting from the phenomenon were specified; the broader context and intervening conditions were identified; and the consequences for the phenomenon were delineated. The phenomena

included the Medicare decision-making framework, home care nurse and social worker perceptions of persons with Alzheimer's disease, home care nurse and social worker coping strategies, actualization of professional altruism, corporate influence, and policy views. These phenomena became the basis for my findings chapters.

The final step was selective coding, where I identified a "story line" and wrote a "story" that integrated the axial coding phenomena (Strauss & Corbin, 1990). Strauss & Corbin (1990) define selective coding as an "integrative process of selecting the core category, systematically relating it to other categories, and validating those relationships and filling in categories that need further refinement and development" (p.116). The phenomena which emerged in the axial coding process seemed to have potential as elements for a theoretical framework in the form of the story of the core category. Strauss (1987) defines the core category in terms of its relation to other categories, frequency of appearance in the data, clarity and inclusiveness, and its theoretical power for a more general theory. The story which emerged was the influence of the Medicare home health policy framework, mediated by home health agencies and home care nurses and social workers, on care decisions affecting persons with Alzheimer's disease and their families.

The data analysis and interpretation was facilitated by memo writing which helped move empirical data to a conceptual level, expanded and refined the data and codes, developed core categories and inter-relationships, and integrated the experiences, interactions and processes embodied in the data (Creswell, 1998; Strauss & Corbin, 1990). I wrote both analytical and self-reflective memos throughout the data analysis, as well as notes during the data collection. Analytic memos consisted of questions, insights, understandings, and emerging concepts related to the interview data. Self-reflective

memos were my personal reflections on individual interviews (Miles & Huberman, 1994).

The analysis was sensitive to sorting and analyzing data based on key decision-making factors and stages identified through the indigenous concepts discovered in the data. In designing the interview guide, some sensitizing concepts of key decision-making factors were included, such as regulatory requirements; supervisory input; patient needs; availability and nature of family; agency policies and procedures; and professional's level of personal and professional experience. Similarly, sensitizing concepts used to structure the interview guide regarding decision-making stages were intake; initial assessment; initial plan of care development and implementation; recertification assessment and plan of care development; discharge and discharge planning; and readmission. These concepts were used to sensitize the interview guide construction and implementation.

There were limitations to the design. Convenience sampling limits the geography and ability to stratify respondents by age, gender, ethnicity, experience levels, agency type and size, among other demographic variables. These limitations may limit the ability to generalize study results. However, generalizabilty is not the purpose of the study. The study was conceived as an exploratory study.

Another advantage of the convenience sampling was increasing my ability to recruit more than thirty home care nurse and thirty social worker participants, particularly social workers. Individual agencies on average employ one full-time equivalent (FTE) social worker for every twenty-three nurse FTEs (National Association for Home Care and Hospice, 2004). This ratio might have made difficult recruitment of more than thirty social workers through multiple home health agencies, especially if some agencies were

small. Convenience sampling allowed me to recruit through a network of home care social workers without being dependent on the number of social workers employed by individual agencies. The individual nurses and social workers also related multiple agency experiences in the interviews; not simply experiences from their most current employer. I decided to stop sampling for several reasons. One reason was that I had achieved my objective of a total of more than seventy interviews, which my chairperson and others indicated was a robust sample size for a qualitative study. A second reason was that my coding, which was ongoing and contemporaneous with conducting interviews, was surfacing significant themes. The third reason was that I wanted to move my dissertation process forward so the results did not become stale.

Characteristics of the Sample

The convenience sample was composed of 72 subjects: 39 home care social workers and 33 home care nurses. SPSS version 13.0 was used to produce a frequency distribution of the key characteristics of the sample. Almost all study participants are female (approximately 90%) and three-quarters are White. Nurses are slightly older than social workers (44% vs. 40%) and more social workers than nurses are single (49% vs. 18%). While the overwhelming majority of study participants (approximately 90%) are currently working in home care, both groups have limited hospice experience, having worked in hospice for less than one year. The characteristics of the sample are detailed further on Table 1 on the following page.

Table 1

Demographic Characteristics of Study Participants--Social Workers Compared With Nurses

	Social Workers n=39 Number (%)	Nurses N=33 Number (%)
Gender		
Female	34 (90%)	29 (91%)
Male	4 (10%)	3 (9%)
Age (Mean)	39.8	43.8
Race		
White	29 (74%)	25 (76%)
Black	6 (15%)	4 (12%)
Hispanic	4 (10%)	4 (12%)
Marital Status		
Married	18 (46%)	20 (61%)
Single	19 (49%)	6 (18%)
Separated	1 (3%)	2 (6%)
Divorced	1 (3%)	4 (12%)
Widowed	0 (0%)	1 (3%)
Education		
Associates Degree (Nursing)	0 (0%)	9 (27%)
College (Bachelors Degree)	11 (29%)	24 (73%)
Masters Degree*	27 (71%)	0 (0%)
Years in Home Care (Mean)	8.3	12.8
Years in Hospice (Mean)	0.9	0.6
Current Place of Employment		
Home Care	35 (90%)	29 (88%)
Hospice	4 (10%)	3 (9%)
Hospital	0 (0%)	1 (3%)

* Since none of the nurses had Master's degrees, all study participants with a Master's had their degrees in Social Work

CHAPTER FIVE: FINDINGS

Medicare Requirements as a Limiting Frame for Home Care Nurse and Social Worker Decision-Making

Overall, the Medicare home health regulatory framework, as mediated by the home care agency, influences how nurses and social workers perceive, cope with, and make decisions about persons with Alzheimer's disease and their caregivers. The interviews consistently indicated the dominant impact of Medicare home health legislation, regulations, and Medicare program and fiscal intermediary guidance on nurse and social worker decisions. The path for identifying and interpreting such guidance was nuanced as between the Medicare program, home health agency managers and supervisors, and nurses and social workers, as other chapters will discuss. Thus, it is important to understand the regulatory framework in order to understand nurse and social worker interview comments.

The Medicare home health benefit is based on the medical model. The *medical model* asserts that illness is a biologically-caused disease which makes a normally well person sick (Friedson, 1988; Parsons, 1951). The model emerged with germ theory in the twentieth century and increasingly asserts that skilled interventions by medical professionals and use of medical technology and pharmacology can cure a disease or limit its progression (Avorn, 2004; Conrad, 2001; Dubos, 1959; Starr, 1984, 2004). The *medical model* has dominated American physical and mental health policy (American Psychiatric Association, 2000; Anspach, 1997; Armstrong, 2000, 2003; Conrad, 2005; Hacker, 2002; Kutchins & Kirk, 1997; Marmor, 2000; Oberlander, 2003; Rosenberg, 1987; Rothman, 2002, 2003; Starr 1984, 2004; Stevens, 1998, 1999; Trattner, 1999).

There been a geometric growth of the medical model or what is known as medicalization (Clarke, et al., 2003; Conrad, 2005; Gallagher & Sionean, 2004) with particularly adverse impacts on persons with dementia (Kitwood, 1997; Lyman, 1989; Woods, 1999).

Historically, the Benefit is an acute care medical benefit which never was intended to assist patients with chronic disease, let alone any patient with psychosocial, emotional, or behavioral needs. It was created to decrease hospital and nursing home costs (Mottram, Pitkala, & Lees, 2002; Vladeck, 1997). The Benefit supports only homebound patients who have pre-requisite medical needs such as a need of skilled, part-time or intermittent nursing or physical therapy and a condition with a finite and definite end point (Health Care Financing Administration, 1999). If the requirements are met, the patient may receive support such as skilled nursing, physical therapy, speech therapy, occupational therapy, home health aides, or social work services (Health Care Financing Review, 2002). Consequently, many persons with Alzheimer's disease do not qualify for Medicare home health because they are not homebound, do not require skilled nursing or physical therapy, or because their condition is viewed as chronic, without a finite and definite end point (*Duggan, et al. v. Bowen,* 1988; Fried, 2004).

The Benefit was created as a post-hospital acute care benefit which assumed the patient could be discharged to self care after a single, short home health stay. However, multiple authors have noted that the assumption of discharge to self care and a single short stays were regulatory fictions (Buhler-Wilkinson, 2003; Vladeck, 1997). Other experts have observed that the self care and single stay fictions have become exacerbated by the fact that increasing numbers of the elderly population have multiple, chronic conditions and either live alone or with caregivers who themselves are chronic (Clark,

Burkhauser, Moon, Quinn, & Smeeding, 2004; Dartmouth Atlas Project, 2006; Hokenstad, et al., 2005, 2006; Levine, 2000, 2003; Levine, et al., 2006; Moon, 1996; Vladeck, 2002, 2004).

The home care nurse is the gatekeeper based on Medicare home health Conditions of Participation and regulations (Health Care Financing Administration, 1999; MedPac, 2008). S/he decides at intake whether to admit the prospective patient, as the person is called in home health agencies; conducts the initial and subsequent home health visits and assessment; develops the plan of care (POC) for required physician signature, which specifies the type, frequency and duration of visits and projected length of stay; decides whether to change the POC during the patient stay; and decides whether, and how often, to recertify and to discharge. The nurses' perception of Medicare requirements creates their framework for these various care decisions.

The dominant and limiting regulatory requirement is that Medicare home health is not a long-term benefit and is reflected in the following statements by nurses interviewed. I included both small and long segments of quotes in order to give a full flavor of the nurses' perceptions of the impact of regulatory requirements.

> It never has been anything but acute care. That's why we do not treat the psychosocial needs of Alzheimer's patients and families. That's just the way it is.
>
> Nurse FS

> The Alzheimer's patients just do not fit. We are focused on quick, cost-effective turnaround of patients. We need to be planning their exit as they enter. If we do not get them out quickly, after dealing with the acute care piece, the nurses are liable to feel sympathetic and keep them on. That's not good because the case becomes difficult to justify to Medicare, hard to document [a medical need], and costly. And then the nurses become frustrated—they get very emotional and stressed the more they try to balance patients' needs, Medicare criteria, and their own nursing and personal views of what's right. We are told, at least at the two agencies where I've worked, to avoid getting into those

> situations. It is bad for the agency and bad for us.
>
> Nurse AS
>
> You are oriented not to admit anyone who is chronic or who needs custodial care. That's the "MO" [mode of operation] and it's been that way forever. We see Alzheimer's patients as chronic and custodial---they are not going to improve or change in their stay with us; there will not be progress. That's what Medicare says; every supervisor I have had has reinforced that. So, they [the Alzheimer's disease patient] do not get admitted or treated unless they have another acute care medical issue. That is, that's the way it works if everyone follows the regs [Medicare regulations]. Nurse GM
>
> I've been trained for over thirty years in half a dozen [home health] agencies in just as many different states not to admit anyone unless they have a short-term, finite, skilled nursing or PT [physical therapy] need. And I have been trained to discharge the patient if they are admitted with a short-term need, but then their need becomes chronic or long-term or undefined—not finite. That automatically eliminates a lot of conditions that the elderly have, or so we have been trained. Conditions like MS [Multiple Sclerosis], dementia of any kind, Parkinson's [disease], or even chronic pulmonary, cardiac, or circulatory conditions are eliminated unless there is a need to treat a urinary tract infection, some problem resulting from a fall, some additional post-hospital [physical] rehab or the exacerbation of some other condition like an acute episode for a diabetic. PPS [the Medicare prospective payment system implemented October 1, 2000] just puts more negative financial consequences on the [home health] agency if you do not follow the short-term requirement, but it's always been this way.
>
> Nurse SL

The result is that the person with Alzheimer's disease either is not admitted or, if admitted, receives restricted care.

PPS further limited the historical restriction of Alzheimer's home health care by integrating fiscal requirements, practice decisions, and outcomes measurement. The de-facto policy occurs through Medicare's first national home health assessment instrument, the OASIS (Outcome and Assessment Information Set). OASIS is a fifteen-page, seventy-five question, mandatory standardized assessment and outcomes tool. OASIS is used to simultaneously assess the patient, develop patient care plans, measure outcomes, and determine length of stay and reimbursement. Scores from twenty-three OASIS

questions are used to create 153 episode payment categories, known as Home Health Resource Groups (HHRGs), with reimbursement ranging from as little as $100 to over $5,000 per episode (Medicare Payment Advisory Commission, 2004, 2005). The original PPS regulations created only 80 HHRGs; the 153 HHRG matrix became effective January 1, 2008 (Medicare Payment Advisory Commission, 2008).

The home health agency is assumed to operate on a managed care model, having to absorb any financial loss on episode cost above the HHRG payment and also being able to retain as profit any HHRG episode payments in excess of episode cost. The OASIS restricts Alzheimer's disease patient care by: (1) not making it a diagnosis which yields a high payment level; (2) encouraging shorter stays and fewer services to increase profits on HHRGs; and (3) creating the highest payment incentives for persons with short-stay, intensive physical therapy needs, which is not a characteristic of persons with Alzheimer's disease.

> Before [Pre-PPS] the diagnosis wasn't linked to a per episode payment. Now it's a key factor, one of twenty some questions that affect your HHRG score. So that's different - the reimbursement impact is more direct now. And the diagnosis is based largely on what provides the most reimbursement.
>
> Nurse AS
>
> PPS makes it worse than it ever was, at least where I've worked. The OASIS is geared to physical assessment and to assessing changes in patient; physical status. Many nurses are trained to identify these, develop a plan, and get the patient in and out as soon as possible so they can get paid. That leaves the Alzheimer's patient out. Psychological and behavioral symptoms do not contribute to high reimbursement. They just generate more care and costs. I agree nurses must be fiscally sensible and protect [agency] resources, but some get carried away. There needs to be balance. We need to focus on identifying all patient needs even if we can't treat them all.
>
> Nurse JB

These requirements also impact social workers.

As indicated earlier, social workers play only a minor role in Medicare home health. Medicare reimbursement regulations, program manual guidance, and Conditions

of Participation limit the nature and extent of social work coverage (Centers for Medicare and Medicaid Services, 2006; Health Care Financing Administration, 1999; MedPac, 2008). Social work historically represents only 1-2% of all national Medicare home health visits (MedPac, 2008; National Association for Home Care & Hospice, 2007). In addition to the limitation on social work inherent in the regulations, social workers emphasized a highly restrictive Medicare regulatory impact on framing their practice decisions and patient care.

> Sometimes I wonder why they [Medicare] even bother. My hands are tied and the nurses' hands are tied. Before PPS they could not refer to us because Medicare limits social work coverage—they do not see us helping with a short-term medical need; we are seen as doing separate support or mental health care and they [Medicare] do not see that as related to the acute medical need. Can you believe that? Anyway, we don't have time for that discussion; maybe later. Now, since PPS, we have the same limitations but it is worse because a social work visit is seen as an added cost generally with no positive impact on the outcomes measured by OASIS and PPS, all of which are acute medical outcomes. We simply are not seen as a valuable service. We never were; it's worse now. Social Worker WJ

> Yes, the Medicare regulations are what guide my decisions. I often want to change or challenge them. Sometimes I try to get a more flexible interpretation from the nurse to help meet a patient need. Whatever I do though always comes back to the regs as the starting point. Social Worker SG

> It's all in the Medicare regulations. That is what determines whether I get a referral, which I rarely do; how much care I can give; how long a visit I can make; everything. Even if I get a referral, I am limited maybe to one or two visits to check on the home and family; tell them about resources. But there is no counseling, which is what most of them [the patients and families] need. There is no active case management, no counseling, nothing that resembles [mental health] therapy of any kind. Every time I ever have asked "why not?", I am told the regs don't allow it. Social Worker BT

> It's always the regulations. It just depends which ones. It is the same with Medicare and Medicaid, but it depends on the state. I worked in Texas and Medicaid barely covered social work. I was told social work is not required to be covered by Medicaid; it's up to the individual state. So New York [state] is much better. The [basic] Medicaid program has social work coverage and

> it's pretty flexible. It really helps with dual eligibles [persons simultaneously eligible and covered under both Medicare and Medicaid]. Medicare gives no social work coverage; well nothing to speak of; a few visits here and there. Medicaid in New York let's you give more social work after those few Medicare visits. And then the [New York Medicaid Nursing Home Without Walls] Lombardi program really helps. It is long term home health coverage if you can show the person's plan of care can keep them safely at home at less cost than sending them to a nursing home. It's really great and you get much more social work and [home health] aide coverage than you'd ever get with Medicare, or even Medicaid. So, see, it really depends on the payer and their requirements. They guide your admissions and discharge decisions, whether you get a SW [social work] referral, how long you can stay in, how many visits you can give, what you can do on a visit---everything, they determine everything.
>
> Social Worker EH

> I always view Medicare as our therapist. They set the boundaries on our relationships with the nurses, aides, PTs [physical therapists], the patients, the docs and the families. In social work school we learned the importance of boundary-setting with clients so I understand what they are doing. I just believe the regulations, or at least how the agency interprets them, really sets the boundaries inappropriately; in a way that doesn't help. They're too restrictive. I guess that is the difference from what I learned about boundary setting in school. There you were taught to set boundaries to help and improve the outcomes of the therapeutic relationship with the client. Here, in Medicare home health, it restricts the relationship and outcomes; true needs go unmet. What a shame.
>
> Social Worker CV

The regulatory frame also impacts how home care nurses and social workers perceive Alzheimer's disease clients and their families, as well as their coping strategies, as the subsequent chapters reveal.

Nurse Perceptions of Persons with Alzheimer's disease As the Phantoms of Home Care And Their Caregivers as Hidden Patients

Overall, nurses asserted they often either did not recognize the psychosocial needs of persons with Alzheimer's disease or their caregivers or recognized them fleetingly, with the result being an inability to meet client needs. Nurses characterized the unmet medical and psychological needs of persons with Alzheimer's disease resulting from

regulatory requirements as though they were talking about a separate patient or a patient within the patient; two patients in one. One nurse described this as a ghost patient; another as a phantom patient. One described the two patients in one as the one with the acute medical need and the other with the psychological needs. Another nurse spoke of a haunting side of the patient which she recognized and sensed, but whose needs she could not meet. And one nurse spoke of caregivers as hidden patients; others as simply lost.

> The psychosocial is usually lost, unless the nurse is really sharp and concerned. The AD [Alzheimer's disease] or dementia symptoms usually get lost in treatment, unless they are adversely affecting the patient's physical safety or functioning. It's like a ghost diagnosis in the background.
>
> Nurse MO

> They [the nurses] feel there is nothing they can do. It's all about the medical need and they're told dementia is a psychological need, not a medical need. They are blinded to it. It's like it's not there. And their caregivers—we never deal with them. They need care. They are like hidden patients. They have needs, but we are not allowed to deal with them. So we hide from them and they are hidden.
>
> Nurse JB

> We really do not deal with the Alzheimer's disease. It's in the background. Medicare doesn't see it, so we don't see it. It's only relevant as a cause and Medicare doesn't reimburse for causes, or even for symptoms. They reimburse for medical need, and only acute medical need for a limited time. And the caregivers are just lost in the mix. We can't care for them—I mean we could but it's not Medicare-covered.
>
> Nurse AS

> It drives me crazy sometimes. I see it. I see they have Alzheimer's or dementia. It's usually in the chart somewhere. But then it isn't on the OASIS; it doesn't get on the plan of care; we don't treat it. It is like a phantom. It is there, but it isn't. You see it, but it disappears. It affects you, but you get so numb to not treating it that you don't see it. It is weird. It defies everything I learned in nursing school. It really bothers me.
>
> Nurse LT

The phantom metaphor seems most appropriate and pervasive. The patient is there, alive in a sense, not dead. However, the unmet medical and psychological needs

and symptom management of Alzheimer's disease recede to the background. It is sensed by nurses to varying degrees, but has no substantial existence in care.

The unmet needs are substantial. Persons with Alzheimer's disease experience multiple, ongoing cognitive and functional problems (Small, et al., 1997).Cognitive problems include memory impairment, aphasia (limitation in ability to speak or comprehend language), apraxia (a voluntary movement disorder), disorientation, visuo-spatial dysfunction, and impaired judgment. Functional problems include difficulty performing or an inability to perform activities of daily living(ADL), such as eating, dressing, bathing, toileting, walking, grooming, and getting in/out of bed, or instrumental activities of daily living (IADL), such as meal preparation, shopping, moving within and outside the house, money management, using the telephone or computer, and taking medication (Dunkle, 2001). Cognitive problems often create or exacerbate functional problems, and vice versa. Both contribute to psychological and behavioral problems, including personality changes, irritability, anxiety, depression, delusions, hallucinations, aggression, loss of sleep, increased personal isolation, identity loss, and increased physical and mental health (Eisdorfer, et al., 2003; Sadik and Wilcock, 2003; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004; Schulz, et al., 2003; Wisniewski, et al., 2003).

Much like a phantom, the receded being of the person with Alzheimer's disease often surges forward from the shadow of care. The phantom surfaces when the unmet needs become overwhelming.

> I had a patient who had Alzheimer's and was severely depressed. We admitted him post-hospital to help with the rehab of a broken leg. We could only keep him on service for a short time. The break and hospital time made him more depressed. We couldn't treat the depression. Medicare wouldn't pay. He

> became so depressed he tried to commit suicide. And his wife was depressed. We couldn't deal with that. It's a red flag—caregiver need means not covered.
> Nurse MP

And when the phantom surges, others become more stressed and frustrated. Caregivers typically experience increased stress, depression, substance abuse, loss of sleep, increased personal isolation, identity loss, increased physical and mental health problems, and a perceived decline in quality of life (Eisdorfer, et al., 2003; Sadik and Wilcock, 2003; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004; Schulz, et al., 2003; Wisniewski, et al., 2003).

The result of increased caregiver stress may be to chase away or expel the phantom back into the recesses of life. In the case of the attempted suicide, the nurse said:

> They [the family] couldn't handle it any more. Now the family has him in a nursing home where he's usually sedated. Nurse MP

Social workers similarly either characterized themselves as often not recognizing the person with Alzheimer's disease or their caregivers or recognizing them, but not being able to deliver appropriate care.

Social Worker Perceptions of the Designed Neglect of Persons with Alzheimer's disease

Overall, social workers perceived the Alzheimer's clients similar to the nurses, though they did not use the phantom or ghost metaphors. They characterized these clients and their caregivers as "victims of designed neglect" (Social Worker AP), "fell between the cracks" (Social Worker AN), "forgotten souls" (Social Worker CA), and "lost in the shuffle" (Social Worker EH). Much like the nurses, their perceptions, as nourished by the regulatory framework, resulted in decisions to limit care.

While an effort was made to use social worker interview segments to support the emergence of this theme, several longer quotes were included to give a fuller flavor of these perceptions.

> So, my favorite [patient] is Miss Nelly. She is 85. She's originally from Atlanta, Georgia. She was moved here by her daughter, but does not live with her. She's close by though. Her daughter is very caring. I visited officially once each of the three times she was on our service this year [2007]. I also have visited her probably twenty times on my own in the evenings and on the weekends just to check in and talk to her; make sure she's okay. Sometimes her daughter is there. I'm not supposed to do this. It is against agency policy, but I do not care. Well, you want to know what I do there? I talk to her about the old days, play old music, and occasionally watch an old movie. She reminds me of my mother, except for the southern accent. My mother is dead so this visiting is good for me. Nelly has dementia, no doubt about it, but she is not angry or aggressive or depressed like a lot of the others. She's just forgetful, actually pleasantly forgetful. I just worry about her mobility. It is poor and she could easily fall. The apartment is old and not well adapted for an old frail person. I also worry about her socialization. I see so many [patients] who do not or can't get out much and don't have many visitors. Their health declines, their memory gets worse, they really get disoriented and depressed. I do not want that to happen to Nelly. So it is personal with Nelly. I wish I could do more and I wish I could do it on company time with Medicare paying. But that's not about to happen from what I hear. People like Nelly just fell between the cracks with Medicare. The needs are there, but Medicare won't cover them.
> Social Worker AN

> It is as though they [Medicare] designed the system to neglect certain types of patients, like Alzheimer's [disease] patients or others with chronic needs or with psychosocial needs. It think that is pretty clear. I'm sure the politicians would be shocked to hear that, especially since a lot of them are pretty old or have elderly parents. But it is what has happened. Certain patients are either excluded from [home health] care or their care is limited, regardless of need. I remember this policy professor I had [in social work school] who always talked about policy being the result of choices made about what was a problem and how you decided to address it in distributing resources—whether you decided to make a policy or not and [if so] the way you defined eligibility, coverage, and reimbursement. I never really got his point clearly until I worked in home health. Need and care gets redefined by the policy; the regulations I guess. It's not professional. Social Worker DM

> Yes, I'd agree with what you said that social worker [Social Worker DM] said. Alzheimer's [disease] patients and their caregivers definitely are victims of

> designed neglect. Medicare home health coverage is not for them. I think it should be, but it is not. My parents both need; I probably will. But it is a conscious decision not to provide social work or even nursing at home to these patients. The regulations, the policy I guess, just leaves it to people in these circumstances to deal with it themselves until they get so poor and bad off that they can get [Medicaid] nursing home or hospice coverage. It doesn't make sense to me. Here they are at home and they have the need. But the coverage isn't there; the government won't pay. So it becomes a personal burden and makes people even more unhealthy. And it is a conscious decision to neglect these needs. How frustrating!
>
> Social Worker AP

> There is no doubt patient needs are neglected, especially patients with chronic care needs like Alzheimer's [disease] patients. I call them forgotten souls. They just wander around among us home care workers and we forget them. At some level I guess we know they are there, but all we see is the medical need. Their dementia is like some separate, wandering soul; like a vapor you can't put your hands on so you just let it float away. And so many have dementia. They are old. It is normal. But we do not treat it.
>
> Social Worker CA

> I had a patient with a lot of needs, but all we [the home health agency] dealt with was her recovery from an acute spike in her diabetes post-hospital. If you saw her [medical] records, you'd see her primary diagnosis was Alzheimer's disease. But it wasn't treated; not inpatient or outpatient and certainly not by us in home care. I made one visit to discuss ways to ensure medication compliance and to give them some community and internet resources for dealing with the diabetes. The dementia needs were clear and substantial, but not dealt with. They just got lost in the shuffle.
>
> Social Worker EH

Just as nurses and social workers had similar, though not identical, perceptions of regulatory impacts on care decisions, they also expressed similar, though not identical, views on how they managed or coped with the situations, as discussed in the next two sections.

Nurse Variation Managing the Phantom: Conformists, Innovators, and Rebels

Introduction

Overall, nurses used mainly conforming (33%) and innovative (49%) coping strategies to deal with the regulatory requirements and their perceptions of persons with Alzheimer's disease and their caregivers. Another 18% coped as rebels. They also asserted that the more their behavior conformed to agency expectations, the less care and greater the unmet needs of persons with Alzheimer's disease and their caregivers.

As noted earlier, nurses experienced stress and frustration dealing with persons with Alzheimer's disease. They identified that their care decisions were always affected by Medicare requirements, often in a manner that restricted care contrary to assessed need. Many described the resulting unmet psychosocial and medical needs as a separate phantom-like patient. Thus, the Medicare requirements create a tension with nurses' role perceptions, nurse practice standards, and patients' needs. Nurses vary in how they handle the tension. The result is that nurses vary in the degree to which they recognize the phantom and their care decisions, including whether to admit the patient; how they assess the patient; and the amount and type of care they provide and length of service they tolerate for persons with Alzheimer's disease.

Applicability of Anomie and Merton's Analytic Framework

In coding the interviews for common themes and reviewing them with Professor Harriet Goodman, she suggested that anomie theory and Merton's five mode typology of individual adaptation to cultural goals and institutional means might provide a useful analytic framework (Merton, 1957). Anomie theory posits that individuals may become alienated, disconnected or adrift from dominant societal norms, particularly at times of

rapid change (Durkheim, 1997; Merton, 1938, 1957). This condition may be the result of individuals not having sufficient access to accepted societal means to achieve accepted societal goals, resulting in their deviating in some way either from adherence to accepted goals or the means to achieve the goals. Merton (1957) referred to the goals or norms as ends, focusing on the pursuit of wealth and success as legitimate ends in American capitalist society and the legitimate means as legitimate work, education, and savings. Merton and others (Cloward, 1959; Cloward & Ohlin, 1960; Featherstone & Deflem, 2003) asserted that the differential availability of opportunities for work, education, housing, and other resources and assets necessary to using legitimate means to achieve legitimate ends might affect whether and how individuals deviated from adherence to legitimate means and ends.

While Merton's typology was aimed at broader cultural norms, social structure, and political and social action, it appeared conceptually applicable to individual coping strategies and organizational goals. As I reviewed the interviews, it became apparent that not all nurses and social workers accepted both the goals and means to achieve their home health agency's policies and procedures interpreting Medicare and other requirements. There were nurses and social workers with varying degrees of frustration with the acute care goal of Medicare home health and the inability to have the means to meet many of the needs of persons with Alzheimer's disease. The varying levels of frustration resulted in varying coping strategies which seemed analogous to Merton's analytic framework.

Merton's first type was the conformist who accepted goals and their institutionalized means of achievement. Second was the innovator who accepted the

goals, but devised different means of achievement. Third was the ritualist who scaled down or modified goals to increase likelihood of achievement while accepting the institutional means of achievement. Fourth was the retreatist who retreated virtually into their own world, creating different goals and means of achievement. Fifth was the rebel who viewed the goals as either totally or partially illegitimate and used a combination of existing institutional means and new means to achieve their goals. In their study of social work decision-making as "street-level bureaucrats", Evans and Harris (2004) take a similar perspective to Merton, albeit not using his analytic framework. Extending the work of Lipsky (1980), they note that the increased proliferation of rules and regulations may produce varying responses depending on the individual worker ---- in some cases less and in other cases more discretion by the professional. They further suggest that expanded professional discretion may not always have positive results. While they were not specific about the contexts for negative results, they implied that the high variability in individual professionals' values might result in varying perceptions and consequences for clients.

The interviews indicated variance among nurses either on their willingness to accept either the goal of the acute care medical model or the means for caring for persons with Alzheimer's disease. Using the Merton (1957) typology, the three adaptation or coping strategies most evident were *conformists, innovators,* and *rebels*. The same strategies were evident among social workers, albeit to a different degree. Of the thirty-three (33) nurses interviewed, most were *innovators* (16), many were *conformists* (11), and some were *rebels* (6). I did not find either the *ritualist* or *retreatist* coping strategy appropriate to explaining nurse or social worker coping strategies. The *retreatist* was

characterized by Merton as retreating virtually into their own world, creating different goals and means of achievement much like substance abusers and other deviant groups, such as in Cloward and Ohlin's (1960) delinquent gang typology. None of the interviewees articulated this approach. The *ritualist* coping strategy seemed similar to the *conformist*, except that the *ritualist* was distinguished, in Merton's typology, by the scaling down or modifying goals. None of the nurses or social workers articulated this view. The *conformists* and *innovators* accepted the corporate goals, as they perceived them, but adopted different means. The *rebels* did not scale down or modify goals; rather they rejected the corporate goals as totally or partially illegitimate, and dealt with them by using either institutional or new means.

The dominance of the conformist and innovator role among both nurses and social workers appears consistent with the literature review on the increasing acceptance of the bureaucratic role over the professional role among social workers and nurses. Lubove (1965) observed the development of the social work profession beginning in the Progressive Era. However, Fabricant and Fischer (2002), among others, documented the increasing tendency of social workers and others in the human services to operate increasingly as bureaucrats, focusing on achieving corporate goals more than meeting client needs by adhering to professional standards. Rosenberg (1997) made the same observation of social workers and all health care professionals, particularly with the increased focus on managed care. Epstein (1970) observed that social workers' bureaucratic orientation had a conservatizing effect on their sensitivity to client orientation and client-perceived needs. Bernstein (1991) found the same in her 1987 interviews of eighteen managers in seventeen New York City human service agencies

doing contracted services. She found they coped with the pressures of meeting payer, and therefore agency, requirements by learning how to play the game. This involved learning tolerance points with the seemingly rigid requirements so that they prudently exercise flexibility and balance implementation reporting and service delivery requirements against the reality of staff, organizational, and client needs. Such an approach parallels the dominance of conformists and innovators in my study.

Another conservatizing effect might be most nurses' and social workers' concern for job security. Those who remained in home care, which included everyone in my sample, wanted or needed the job. They seemed sensitive to organizational requirements on productivity, volume of services, patient length of stay, and cost. If they wanted to maintain their job they either had to conform or to innovate within reasonable boundaries; only the few *rebels* seemed willing to take significant risk. This fear or conservatizing factor also surfaced in many nurse and social worker explanations of why they would not allow me to tape the interviews. When I asked them why they would allow only manual recording, most indicated they were concerned about their agency hearing about their comments, despite the promise of confidentiality and privacy in the informed consent document.

It is difficult to ascertain why no *ritualists* emerged in the study. These would have been nurses or social workers who scaled down or modified goals to increase likelihood of achievement while accepting the institutional means of achievement. The major explanation for finding no *ritualists appears* to be that all nurses and social workers interviewed, other than the *rebels,* accepted their perception of organizational goals, primarily through the plan of care, either as mandatory (*conformists*) or minimum

mandatory (*innovators*). None articulated that the goals should be scaled down or reduced. They varied only in whether they also accepted the prescribed means (i.e., the *conformists*), or modified the means to increase the likelihood the client would achieve the prescribed goals or more (i.e., the *innovators*). The *rebels* modified the goals to meet client needs as well as the means to achieve them. The absence of *retreatists* might best be explained by the fact that social workers or nurses who had retreated into their own world simply might no longer be working in home care. They may have burned out or otherwise left home care or their respective professions because of their inability to tolerate the limitations of goals and means relative to client need and professional goals (Figley, 1995). This seems a distinct possibility given the interviewees' comments on the frustration in achieving professional goals, as discussed later in the Findings section.

Conformist nurses are highly restrictive types, adhering literally to the requirements, providing limited, acute medical care only to Alzheimer's disease patients. They focus on a set of limited, authorized tasks within the instructions of their perception of the Medicare regulations. They do not recognize Alzheimer's disease as a primary or secondary diagnosis. They provide limited nursing care, focusing only on the acute care medical need, such as improving the condition of a wound, lowering the patient's diabetes level, turning a patient in bed to avoid bed sores, or, with a physical therapist, helping improve a patient's mobility after a fall or bone break or sprain. They plan a short stay and early discharge. Social work is rarely used. They truly see the psychological and behavioral symptoms and long term medical problems of the patient as a phantom.

> I was taught to be task-oriented in nursing school so that's what I do. The Alzheimer's patients do not belong in home care. They are chronic; not acute. They need a lot of social work and support and we do not provide it. So I just look for an acute care need. If it is there, I treat it. If not, I do not. Nurse TD

> You just look for routine ways to process. Alzheimer's patients are really complicated and have extensive needs so you don't bother. You can't deal with their needs—the depression, wandering, counseling, social support. So you just look for the medical need and that's that. If it's not there, you do not admit.
>
> Nurse LT

> Most nurses get it hammered into them that Alzheimer's, MS, Parkinson and other chronic patients are not covered by Medicare unless there is an immediate short term medical need. So most nurses do not even look for or assess for dementia, even if it's on the physical and history.
>
> Nurse OH

> You mean the AD patient needs or others? Oh, both. Well, like I said, we do not deal with the patient's mental health issues whether you call them emotional, psychological, spiritual, whatever. And we definitely do not treat the family or caregiver. Maybe we talk to them a bit but that is it. It's not covered we are told. Sure, there's a huge need for it. But I guess the government sees that as a personal responsibility from what my supervisor tells me and, like I said, I follow the script.
>
> Nurse DT

At the other extreme are nurses who practice virtually as *rebels*, doing as much as possible for persons with Alzheimer's disease and their caregivers, despite the Medicare requirements. These are the most radical nurses, doing what they believe is appropriate and right as nurses and human beings. They speak and practice as patient advocates, much as adherents of radical social work (Mullaly, 1997). They are willing to test the boundaries of Medicare. They tend to: identify Alzheimer's disease as a primary or secondary diagnosis in the plan of care; order more home health aide and social work care to assist with patient and family burden; have longer patient lengths of stay; and be actively involved in discharge planning and, in some cases, personally involved in post-discharge care.

> You can't treat much in Alzheimer's patients, unless you are a really aggressive nurse. You have to do what you feel is right to meet patient needs. That's my first priority- patient needs. I figure you always can find a way to make it fit under Medicare. Not all nurses do. Let me give you an example. One of the few times we can help AD [Alzheimer's disease] patients is when they also have significant PT [physical therapy] needs. This often happens because their mobility problems cause falls so they eventually need rehab. If you have or can justify 10 or more [physical, speech, or occupational] therapy visits in an [PPS] episode, you get much more money [for the episode]. I've been told on average it's $2,000 or $3,000 more. So that should be an incentive. But I've dealt with nurses and physical therapists who felt the need was there but were worried about a denial if they gave the care. So I push for that care even if there is only a marginal need because that opens the gateway to lots more [home health] aide and nursing care. No, I do not worry about being accused of fraud or abuse. If so, so be it. The patient needs the care and I will do anything to get it for them.
>
> Nurse SJ

Ironically, since PPS Medicare has become more flexible about recognizing the phantom diagnosis of dementia, though many home care nurses do not appear to know or care about this policy change. Prior to 2001, Medicare routinely denied home health claims with Alzheimer's disease as the primary diagnosis (Smarr & Carson, 2006). The underlying logic was that Alzheimer's disease and other forms of dementia were chronic diseases, resulting in progressive deterioration with no effective treatment or cure. It was a phantom diagnosis for the federal government. However, a collaborative effort by the American Bar Association and national Alzheimer's Association resulted in a policy change. In 2001, Medicare advised its contract home health intermediaries that "Contractors may not install edits that result in the automatic denial of services based solely on ICD-9 codes for dementia" (Smarr & Carson, 2006).

Another home health Alzheimer's disease clarification was released in 2002 by the federal Center for Medicare and Medicaid Services (CMS) recognizing "… that certain

therapies [physical, speech, and occupational therapies] can be helpful in slowing a beneficiary's decline" (Smarr & Carson, 2006). As recently as 2005, Palmetto GBA, one of Medicare's largest home health contract intermediaries overseeing sixteen southern and Midwestern states, issued a local medical review policy indicating that the management of problem behaviors by Alzheimer's disease patients is an appropriate Medicare home health service (Alzheimer's Association, 2005; Smarr & Carson, 2006).

Rebel nurses seem to sense the policy, even if they may not literally have seen the federal program memorandums. They do not recognize the phantom. The patient is one patient to them; a whole person with medical, behavioral, and psychological needs.

> I think you have a lot more latitude in treating Alzheimer's patients under PPS. But most nurses either do not realize it or realize it and are afraid their supervisor or Medicare reviewer will question them. I tend to be liberal so I put in a lot more social work and aide services. I think it makes sense. It helps the patient and family so it helps their physical health. I've had my decisions questioned, but I don't care. I do what I think is right, and I know how to document it. Other nurses? I don't know. Nurse SH

> I use home health aides and social workers as much as I can for the Alzheimer's patient. It is what they need. Yes, it does not fit with acute care, but I decided many years ago that is not my concern. My concern is the patient and their family. So I am constantly under surveillance by management because of my utilization patterns. If they don't like it, they can fire me. At least I can sleep at night knowing I did the right thing. Nurse MJ

Most nurses are *innovators*. They practice in the middle, trying to adhere to the requirements while trying to create some limited additional care for patients. These nurses are willing to take more risks than the conformists, but not as many as rebel nurses. They tend to: give some recognition to Alzheimer's disease in their plan of care, if not as a diagnosis; provide more care for longer periods than the conformists, though not as extensive as the rebels; and actively work with the family on post-discharge resources, though they rarely get personally involved post-discharge. At most they are

playing a balancing game, much as some bureaucrats in the human services industry (Fabricant & Fisher, 2002).

> It's always been frustrating. You try to do your best. I was taught in nursing school to assess and treat the whole person. That's not how Medicare is structured. You do the best you can. You accept the system and try to be as nice as possible to the patient and their family. I always push the system a little; not too much. An example? I often order more care for an Alzheimer's patient or try to keep them on [service] longer than I do the typical acute care patient. Technically I shouldn't because it may look like chronic care. It is a fine line. I do not feel I am so excessive that it is blatantly against the regs and it is a small way I can help give the patient more than they might otherwise get
>
> Nurse AR

> It is really difficult to deal with Alzheimer's patients. I see what they need. I see what their family needs. But I can't give them much. So I am always balancing. It's as though I'm walking a tightrope. Medicare and my agency are on one end and the patient and their family on the other. I try to be creative --- give them a few more visits here and there; stay longer on some of my visits; maybe do some social work type interventions --- you know, counseling, talking about resources – because it is difficult to justify social work visits.
>
> Nurse TS

> Medicare won't help. They see it as the family and patient's responsibility. Alzheimer's is chronic and psychological. That's how see it and they don't cover that. So most nurses learn it that way and don't do much treatment. It varies by nurse, but most provide limited care. I always try to give a little extra. The patients and families seem so needy. I feel I should have some flexibility.
>
> Nurse KJ

One nurse elaborated her experience extensively. I decided to include it because of her insights and their similarity to Bernstein (1991) observing the game theme in human service agencies, though qualitative research writing usually relates shorter quote segments.

> Well, it is Medicare home care so it is mainly frail elderly persons. I see some kids covered under Medicaid, but our agency is in a fairly affluent area so we don't have much of a Medicaid population. The patients mostly have chronic needs but we treat them for acute episodes, which is what Medicare pays for. It is a game and you need to learn it if you want to be sane. Otherwise you might as well quit or go work in a doctor's office. My mother taught me that. It was good advice.

> Oh, the game—it is to balance patient needs with the restrictions on Medicare. Medicare only pays for acute interventions. They want it short. They want it something you can show pretty immediate progress on. They really don't care if the patient comes back often. At least they don't say that. The regulations allow a patient to keep coming back as long as they have a qualifying intermittent nursing or physical therapy need. So, we see a lot of repeaters. My friends at other agencies call them frequent fliers. I have a lot of diabetic patients. We have no diabetes management program, unless there is a special program with one of the commercial insurers or HMOs. Medicare doesn't cover it. Medicaid doesn't either, unless the state has some special waiver program. I don't think New York does. I'm not aware of it. So a patient comes in because they spike [in their diabetic condition] and need care. The doctor either sends them directly to us or to the hospital and then to us. We treat and stabilize them; send them home alone. We do no post-discharge follow-up on their compliance with meds or diet or exercise. So, they come back. That is real typical. Falls are recurring too. They often are related to what you're interested in, the dementia crowd. Since our patients are old and frail most have lots of memory and mobility problems. That is the norm. We all recognize it and I guess we call it Alzheimer's or dementia for shorthand even though I am not sure that's clinically correct—it's just our slang—the symptoms go with dementia so we call it dementia and we call most dementia patients Alzheimer's patients these days. My mother tells me Alzheimer's was not all the rage when she was a nurse so everything was just dementia or senile dementia.
>
> Yes, the game part. So, that's a lot of my patients—the two Ds—dementia and diabetes. The game is to try to give as much care as possible—meet as much of the patient needs as you can while they are here--- without violating Medicare guidelines. Yes, you are right; it does depend where you work. My guidelines come from my supervisor generally and our initial orientation and in-services. Other nurses I know get their guidance the same way, but they don't all get the same guidance. It varies with the agency.
>
> Nurse KT

Regardless of practice type, the most restrictive practice occurs at intake. Intake is the gatekeeper to entering the agency, focusing on pre-requisite eligibility requirements. The highly restrictive acceptance of persons with Alzheimer's disease at intake may account for the fact that while 12.5% of the American aged 65 and older population had

Alzheimer’s disease in 2000, less than 1% of Medicare home health patients have either a primary or secondary diagnosis of Alzheimer’s disease or any other form of dementia.

Social Worker Variation Managing the Phantom: Conformists, Innovators, and Rebels

Overall, social workers were more conforming than nurses (54% versus 33% for nurses) and less innovative (33% versus 49% for nurses) in using coping strategies to deal with the regulatory requirements and their perceptions of persons with Alzheimer’s disease and their caregivers. Another 13% coped as rebels. Like the nurses, the social workers said that the more their behavior conformed to agency expectations, the less care they provided, resulting in greater unmet needs of persons with Alzheimer’s disease and their caregivers.

As noted earlier, unlike nursing, social work has a limited role in Medicare and Medicaid home health. Medicare regulations do not permit social workers to initially assess clients or develop the plan of care. Nurses, or in some instances physical therapists, must initially assess and develop the client’s plan of care for physician certification. Covered social work services are limited to assessing the client, only upon a nurse or physical therapist referral; assisting the client to obtain community resources, though social workers may not assist the client or family in completing Medicaid or other applications; and making two to three counseling visits to the client’s family member or caregiver, only if designed to remove a clear and direct impediment to client treatment or rate of recovery (Centers for Medicare & Medicaid Services [CMS], 2006). As a result, social work historically represents only 1-2% of all national Medicare home health visits (Medicare Payment Advisory Commission, 2003, 2004a, 2004b). There is even less use

of social work services in Medicaid home health because social work is not a required service under federal Medicaid basic benefit legislation, with estimates at less than 1% of all Medicaid home health visits (National Association for Home Care & Hospice, 2006).

Further evidence of the limited coverage and value granted social work is the small number of social workers employed in Medicare-certified home health agencies. In 2003, social workers were second only to occupational therapists with fewest full-time equivalent (FTE) employees in all Medicare-certified home health agencies. There were 4,598 social worker FTEs compared to 132,691 nurse FTEs, 53, 332 home health aide FTEs, and 16,693 physical therapist FTEs (National Association for Home Care & Hospice, 2006).

In contrast to the nurses, most of the thirty-nine (39) home care social workers interviewed were *conformists* (21), some were *innovators* (13), and a few were *rebels* (5). Much like the *nurse conformist*, the *social worker conformist* is the ultimate organization person, taking the agency's corporate guidelines as gospel, regardless of patient need.

> I just do what I'm told. It's no different than ever. Social work is not viewed as important. It's all about the wound, or the hip, the diabetes, the urinary problem. It's about medical issues. The people part is irrelevant. So, if I get a referral, I just do what little I can and block out the patient's needs. Social Worker AS

> I started doing home care twenty years ago. I thought it would be fulfilling. Then I realized there's no social work in home care. It's a joke. At first I complained about us not dealing with patient needs. It made no difference. I had to make a choice: leave or stay and accept the routine. I stayed. They tell me how many visits to do and that's what I do. Life is too short to be Don Quixote. Social Worker IP

> Home care is not a long-term benefit. It's not for chronic patients. It doesn't matter that most of our patients are chronic. That's the way it is. The nurses and [physical] therapists treat the medical problems and I do a social work visit, if they ask me to. That's the playbook and there's no point in deviating. Social Worker ER

> I wish there was more I could do, but I can't. I feel it would be illegal. There are so many unmet needs, even with patients who have a lot of support at home. They [the patients and caregivers] really could benefit from more support. I just don't understand why Medicare won't pay for [individual and family] counseling, support groups, more social work, and other therapies, like art and music therapy. I think this would help many patients and allow some caregivers to care for longer periods with less stress. It would save money for everyone, but it's not allowed. I think of it as my fantasy world, but I can't let intrude on reality. I just make the visits the nurse includes in the care plan. That's it.
>
> Social Worker GA

As noted in the previous section, there has been an increasing tendency for social workers to operate as bureaucrats, placing a higher priority on adherence to corporate goals than client needs. This trend is consistent with the dominance of conformists *and innovators* among home care social workers. Fabricant and Fischer (2002) documented the increasing tendency of social workers and others in the human services to operate as bureaucrats, focusing on achieving corporate goals more than meeting client needs by adhering to professional standards. Finch (1976) found a similar trend in his literature review. Gitterman and Miller (1989) noted the pervasive influence of agency policy and organizational imperatives on social worker problem definitions, assessment and intervention, service delivery, and client outcomes. Rosenberg (1997) made the same observation of social workers and all health care professionals, particularly with the increased focus on managed care. Epstein (1970) observed that social workers' bureaucratic orientation had a conservatizing affect on their sensitivity to client orientation and client-perceived needs. Wasserman (1971) similarly documents the tendency of social workers to preserve the status quo in his study of a large public social services agency.

Watson and West (2008) have noted the recognition of the over-bureaucratization trend in a major national review of social work in Scotland. The report calls for an increased inclusive approach, bringing in more social worker and client input in establishing rules and guidelines. Bernstein (1991) found the same in her 1987 interviews of eighteen managers in seventeen New York City human service agencies doing contracted services. She found they coped with the pressures of meeting payer, and therefore agency, requirements by learning how to play the game. This involved learning tolerance points with the seemingly rigid requirements so that they prudently exercise flexibility and balance implementation reporting and service delivery requirements against the reality of staff, organizational, and client needs. Such an approach parallels the dominance of conformists and innovators in my study.

Despite the focus on acute care and PPS, there are some social workers who are *innovators,* attempting to find flexibility in the corporate guidelines.

> There's always room for more than meets the eye. You have to be a bit assertive with the nurses, but not too pushy. I talk to them informally and usually always they'll refer me an assessment visit. Some even let me come on their initial assessment. I find I can identify and communicate the patient needs better with the nurses. I usually get more social work visits from them, which is the whole point. If I do not get in early and politely to the nurses, then the patients get less. Social Worker SG

> It's simple. If you really read and know the regulations you know there is a lot of gray area. Some people just won't take the time. I do. It helps me advocate for the patient. They all have social work needs. The nurses know I know the regs so they trust me. Other social workers don't, so their patients get less. It's not because their patients do not have needs. It is because they take the easy way out. They do not take the time to become knowledgeable and advocate for their patients. I try talking about it in our [social work] supervisory meetings and in [interdisciplinary] team meetings, but we can't. Those meetings are all business- quick case reviews and back to the field to do visits. It's more productive to approach the nurses one-on-one. Social Worker RG

> I know our [home health] patients would be better off if they had home modifications. Most have some level of dementia and mobility problems. So I convinced the quality assurance person to let me give an in-service on the value of a home environmental assessment by a nurse, PT [physical therapist], or social worker. I used material from another agency. It went over really well. The QA [quality assurance] person liked it so much she did a three-month pilot of a mandatory home environmental assessment protocol. She used social workers because she felt we could learn it and we cost less [than nurses and PTs]. She found it reduced the number and severity of falls which reduced our per Episode cost and length of stay. I wish they'd use us [social workers] more.
>
> Social Worker EH

> The few I see are very needy and wonderful. The little time I am with them is very fulfilling. I wish I could spend more time directly with them. I spend most of my time lobbying nurses to try to get more referrals. It's a constant battle—I'd say almost 50% of my time is referral shopping here.
>
> Social Worker JW

Social work has a long history of advocating for social justice (Mullaly, 1997; Reisch & Andrews, 2002) and the NASW Code of Ethics presents social justice and advocacy as ethical obligations for social workers (NASW, 2003). There were a few home care social workers who, heeding this call, are best described as *rebels*.

> I became a social worker to help people. I never expect the system to be fair. If it was fair, there'd be no need for social workers. I go to work every day ready to fight for my client. I constantly meet and call nurses and therapists. I push them for social work referrals. Once I get them I do what is needed. I don't care if they ordered only two visits. If I feel four or five or more are necessary, then I do it and explain after. The nurses usually don't have a problem. They know there's more need for social work. They just don't want to get in trouble authorizing a lot upfront. I make it easy for them. They blame it on me, I take the flack, and the patient benefits. That's my goal, help the patient.
>
> Social Worker CA

> I think [Saul] Alinsky when I do home care. The end justifies the means. I am here to help people so I find a way to do it. That's what it's all about. I get at least two-to-three times as many social work visits for my patients than others, even now with PPS. And my patients are no different than most.

> I just think I'm not as intimidated. It's not that other social workers don't care. They do, but they are worried about the rules, keeping their job, their evals, you now. I don't. I can always do social work somewhere. I shadow the nurses and [physical] therapists. I get them to let me do a lot of co-visits. They don't need to put that in the care plan so I get to give more visits and they don't get in trouble for violating rules or visit volume requirements. And I do free visits. I just go out on my own after regular hours and do visits. I document and record notes but it doesn't increase my cost to the agency. I figure: no cost, no harm and I help the patients. You can't be intimidated. That's not being a social worker. Social Worker BI

> Sometimes I wonder about politicians. Maybe they need to have a loved one with a chronic condition, or themselves, who wants to stay home. They think they'd get all this supportive care with counseling, resource management, family planning and support groups. That's hospice; not home care. Most times I stick to the plan. Every so often I just get fed up. It happened last week. Here is this poor dual eligible [a patient covered by Medicare and Medicaid] with dementia who constantly gets discharged and readmitted. He's always falling. They [the nurse managing the case] would not make a social work referral. I was furious so I just took it on myself to make a visit. The home was not adapted in any way to the patient's mobility limitations. I identified what had to be done, talked to the family, and had my husband, who's in construction, do it [the modifications] for free.
> Social Worker KF

In addition to coping strategy variation, social workers discussed how the Medicare frame affected their job satisfaction, as discussed in the next section.

Actualizing Professional Altruism: Further Impact of the Medicare Regulatory Frame on Home Care Nurses and Social Workers

Introduction

A theme also emerged as to how the Medicare requirements frame affected the ability of nurses and social workers to fulfill their desire to help and care for patients and caregivers. The interview guide did not include questions about this topic. However, the theme emerged from social workers' and nurses' comments related to their adaptation or coping strategies and care decisions. There were extensive comments about how the workplace, framed by Medicare requirements, affected nurses' and social workers' ability

to fulfill or actualize their desire to help and care. Lubove's (1965) concept of professional altruism seemed to best capture this desire to help and care for people, albeit originally developed only to apply to social workers.

Lubove (1965) wrote of the change in social work from volunteer-based altruism to professional altruism as social work became professionalized from 1880-1930. The professionalism involved the creation of professional practice standards, schools of social work, national organizations, and paid public and private career opportunities as social workers. These developments formalized the vehicles for actualizing or delivering altruism—the unselfish desire or interest in improving the welfare of others. The shift from voluntarism to professional altruism also was a shift from character rehabilitation and supervision of the poor to provision of resources, support, direct care and policy change to not only the poor but a broader population of persons with unmet financial, physical health, and mental health needs. In more recent years, the concept has been used to fuel a debate on the impact on client and patient needs of the emergence of social work into an increasingly bureaucratized world of health and human services policy, practice, and delivery (Fabricant & Fisher, 2002; Polsky,1991; Reisch & Andrews, 2002; Reisch & Gambrill, 1997; Specht & Courtney, 1994; Wenocur & Reisch, 1989).

Overall Findings

Overall social worker felt they were unable to use their interpersonal practice, service planning, assessment and diagnosis, treatment and advocacy skills because of regulatory requirements. In contrast, home care nurses, felt the opposite. They felt that they were able to actualize their altruism professionally in this work; their professional training is more relevant to actual practice; their patients and caregivers have fewer

unmet psychosocial needs; and their care is less constrained by payers. The nurses conveyed they generally could perform technical nursing medical interventions despite the limitations of regulatory requirements. The remainder of this section discusses the findings supporting the major themes.

Frustrating the Desire to Care

Home care social workers believed the Medicare home health practice setting frustrated their desire to help or care for others.

> I became a home care social worker in 2002.It has always been frustrating. PPS [the Medicare Home Health Prospective Payment System instituted October 1, 2000] makes it impossible for me in good conscience to call myself a social worker. You want to help people improve their quality of life, but you can't. I have friends who do hospice. It is totally different. You have time to talk to patients and family, get them resources, help them value their lives and each other. It always sounds so wonderful. I may change [to hospice].
> Social Worker HM

> I became a social worker because a social worker saved my life. I was into drugs and had a lot of issues. I was placed in a program and the social worker helped me straighten out. I wanted to be able to do the same for others. That's why I became a social worker. Home care does not allow me to do that. I can't give the patient and their family what they need. There are so many boundaries on the caring. That job every day –trying to care with all these boundaries.
> Social Worker TM

> I left the hospital to become a home care social worker. I heard you could do more for people. I was wrong. There is so little work that I have to work part-time at one [home care] agency and do per diem for several others. I want to help people with their problems, but I can't do that. The Medicare regs [regulations] are not built for people's needs, except some nursing and [physical, speech, and occupational] therapy. I'm not sure why they even have it. It would be better to leave people in the hospital longer for the little we are allowed to do at home. Social Worker JW

In contrast, home care nurses felt the Medicare home health practice setting generally enabled their desire to help or care for others, albeit not all the time.

> There are restrictions, but compared to hospital work it is much easier to help people. First of all you do not have the doctor dictating as much of what you do. We draw up the plans of care and they sign them; rarely do they question us. In the hospital, we take orders from them [the physicians]. And, we are in the patient's home so there is a lot of latitude to help them with some small tasks that really aren't nursing strictly speaking, but they need help on. That makes me feel good. Yes, there are PPS restrictions, but overall this is a step up. Nurse SJ

> Well, I have been doing this for thirty years and it seems tough at times. There have been lots of battles over homebound definitions, coverage, payments, you know. But to answer your question, overall I do come home every day feeling that I helped and cared for my patients and their families. I don't also get to do everything I want—to stay as long as I like, or do as many visits, or get in more services. There are productivity and cost issues, you know. But, overall I definitely feel I am adding to the quality of their life.
>
> Nurse KD

> I was in hospice and I definitely felt I was caring more there. I had much more latitude; not so many cost or productivity pressures, though that is beginning to change in hospice too. Home care is fine. It is not great for the patient and I feel frustrated at times. You asked "in general", and I'd definitely say I generally feel I am caring for my patients. I do not feel I give so little that I neglect them. So, it makes me feel good; not totally fulfilled, but good that my nursing is helping.
>
> Nurse NF

Frustrating the Use of Training

Home care social workers expressed frustration in not being able to use their social work training in Medicare home health, except for some limited resource mobilization training.

> I specialized in mental health and trauma in social work school. I do not get to use these skills in home care. It's especially frustrating because those skills are essential for helping people deal with the anticipated or actual loss of death. Social Worker ED

> My [social work graduate] concentration was group work. Home care does not allow me to utilize my group work training. I was surprised, because all the basic group work skills are relevant to dealing with the patient, the family, the other [professional and informal] caregivers, and friends.
> Social Worker DR

> I was trained in mental health casework. I thought that is what I'd be doing in home care. Instead I spend most of my time planning not to care for the patient but to find resources for them later, after we discharge them. I'm not sure all those thousands of dollars for a graduate degree in social work was worth it.
> Social Worker JT

> My [social work] training has nothing to do with my home care job, except for being an advocate. I learned that in social work school, but learned to do it to advocate for people's rights and needs with government agencies and to access resources. The closest I get in home care is advocating for myself with the nurse to convince her to allow me to see the patient.
> Social Worker RM

In contrast, home care nurses felt they used their nurse training regularly in Medicare home health.

> Of course I do. Nursing is technical. I use my pharmacology and wound care training all the time. Everything I do, well almost everything, I learned in nursing school or in-services. I do not always get to do as much as I'd like, but I certainly feel my [nursing] education prepared me for home care.
> Nurse SL

> Absolutely. It is all about training from assessment to sterile technique to changing dressing to knowing how to move a patient without risking a fall. I do it every day.
> Nurse GM

> Why do you ask? We are nurses. If we weren't trained, we could not do what we do. Oh, well, yes, I understand. Social workers are a different story. They don't get to do anything, well virtually nothing, because of Medicare. So I see where they are frustrated. Not me; not most of my colleagues. We get to do what we were trained to do, with some limits I must admit.
> Nurse LH

Frustrating the Desire and Ability to Meet Patient Needs

Home care social workers once again expressed significant frustration with the Medicare home health setting thwarting their desire to help patients, thus resulting in significant patient and caregiver unmet needs.

> Home care is inflexible in meeting patient needs. I had an 82 year old client who had lung cancer, but was mentally together. I wanted to use reminiscence therapy with her and some of her friends who came to visit to help them all smile through the pain. I saw it work in my [school of social work] field placement. I was new so I asked my supervisor. She said I couldn't—that it wasn't covered- we can't do therapy. With another patient the key to their life had been music. I wanted to get a music therapist to work with me so we could collect some old songs with which the patient was familiar. It felt it would make her feel better. The answer was "no" again.
>
> Social Worker TB

> I had one patient whose family was real depressed over her chronic arthritis. The patient was mentally very together, but depressed. I wanted to spend time meeting with the various family members to work through the depression and help them deal more positively with the patient, but we can't do that in home care. It's seen as non-medical mental health counseling. It so frustrating.
>
> Social Worker AC

> I have seen the same patient on our caseload five times this year (2007). It's pretty typical—they have a need that we don't deal with so we discharge them and they're back. It is like a revolving door. I had one patient with dementia, but we don't deal with that—it's psychosocial or mental health so we don't address it. They let me make one home visit. I saw the house was not environmentally adapted to the patient's mobility limitations so I recommended a full home assessment and modification. It never happened so the patient kept falling and returning to us.
>
> Social Worker BC

> The problem is we [the social workers] rarely get to see patients. So we know they have all these needs—they are old and frail, that is why they come here [to home care]. So we don't see them, which means their needs aren't met. I hear stories all the time of patients without Medicaid, food stamps, or some type of available aid, but we only see them sporadically. And then we can only go so far because social work coverage is limited. And there is no team meeting where we can give input. It's very frustrating.
>
> Social Worker TK

> I don't visit many patients at all because of the limits on social work, but I know we have a lot of patients with dementia, or Alzheimer's. I know from talking to nurses that OASIS gives you no points for dementia so it rarely appears as a primary or secondary diagnosis, even if it is the cause of the reason they are admitted---like falls, that is a big one. They [the nurses] all know it's there but they ignore it or repress it because they can't do anything about it; they can't even give it over to me because of coverage limitations. We talk about it. Some nurses are very sympathetic, but even those usually shrug their shoulders and say "too bad, that's the system, poor people, what can you do?" It is so frustrating.
>
> Social Worker EH

> They [the patients] are really in bad shape. They all are old and frail. I read about successful and positive aging all the time. I don't know where those people are—maybe on the commercials for Viagra or whatever Dr. Jarvik advertises. They sure aren't in home care. They all have bad memories, compromised mobility, and little support at home—I mean no one to help them except either a spouse who is as old as or older than them and maybe in worse shape. Or they may have a neighbor who also is geriatric or a child who rarely comes. It is not a pleasant scene. And most are depressed and don't get out much. You see that is the whole thing, well at least part of it, with Medicare—you have to be homebound, so you can't get out much. But that gives you little support and makes you depressed, but we can't treat that. It doesn't matter that being depressed or having poor memory or limited mobility or socialization can lead to physical problems, like falls, or substance abuse, smoking, diabetes. Oh, I get sick thinking about the insanity of not providing mental health services. It makes me really frustrated. I cannot do social work so why am I here?
>
> Social Worker CA

In contrast, the home care nurses felt they met many more patient physical health and psychosocial needs than social workers, though the nurses recognized that some patient and caregiver needs remained unmet. In particular, the nurses noted their own role in meeting psychosocial needs, though the social workers consider such needs a social work domain, and a frustrated one at that.

> I know our social worker feels the patients have a lot of unmet needs, but I don't think they realize all we do. Maybe they do, but don't like it because we do some things they think they should do but Medicare won't cover. I do a lot of what some people would call social work – talking to the

> patient, the family, the spouse about the medical issues but also about how to adjust their lives, where to get support outside of the home. I deal with their depression, anxiety, and stress every day. I had some limited training in psychology, certainly not as much as the social workers, but the [Medicare home health care] benefit limits psychological care by social workers so if the patients get it, it's generally from us. I think they get a lot more than some people think, but they still have needs. Nurse OH

> There definitely are unmet needs with patients suffering severe depression. I see it all the time. I'd say it is largely an unmet, or better than that, an under-met need, if that's a word. I deal with it a lot so I know the patients get some help. But could they use more, sure. Nurse AB

> This is not a psychosocial benefit, even short-term, so there will be unmet psychosocial need. Then again, how do you draw the line? We all have mental problems, but this is not a mental health benefit. I definitely think my patients get a lot of mental health support from me, and I think my [nurse] friends think the same. We do a lot of psychosocial care. It may not be what a social worker or psych [psychiatric] nurse would do, but we do it. Some level of need is met; not all, but some. Nurse TS

Payers Thwarting Care

Home care social workers were adamant that the Medicare home health eligibility, coverage and reimbursement requirements thwarted their ability to meet patient and caregiver physical health, mental health, and resource needs.

> This is a horrible system. I am always told cost is an issue. If I identify a need and want it in the [patient] plan of care, it is the cost, not their need, that determines if they get it. Social Worker LN

> I am often told we can't afford something, even if we justify our request is related to patient need. Social Worker MT

> I have been doing hospice for 15 years. Payment never has been an issue. We just do our thing—on the [interdisciplinary] team and with

> the patient and family. In the last few years we [the social workers] have been in even more demand. They have this approach called "open access" which allows more patients to be admitted than before, especially ones requiring IV lines and treatments. Turns out the patients and families in these families have more to cope with so they need more social work. Social Worker RS

> When PPS was being talked about in the late '90s I remember some people saying it would be a great boon for [home care] social work. It hasn't. I actually think it has hurt us. You can make a profit on PPS and all the outcomes are nursing-based so social work is just another cost that decreases the bottom-line.
> Social Worker DM

> PPS is very constricting. We never could provide much care anyway, but now you can forget it. The [social work] coverage guidelines are the same restrictive guidelines we've had for years. Now the payment system allows the agency to make a profit so anything to reduce cost is welcome. And PPS does not give the agency incentives for social work visits like it does for [physical, speech and occupational] therapy. Social Worker BFS

While the home care nurses reactions to payer constraints were mixed, they generally felt much more positive than social workers about payers helping meet patient mental health, physical health, and resource needs.

> I have been around for years and I did not like changing to PPS. It definitely was something new to learn, but, you know, now that I have learned it, I think it is a lot more flexible than most people think. It is not that hard to get more care or more episodes approved if you can document it well. That's the same with the old [cost-based] system. Sometimes I think the biggest problem is not Medicare but our agency. Now that they can make money, I sometimes get the impression they want us to give less care than some patients or nurses feel are needed. Actually sometimes I have been told that. I guess it is the payer indirectly, but not really. Nurse LT

> Medicare definitely restricts our care, but they did even before PPS. And they restrict all kinds of care-hospital, hospice, outpatient, HME

> (home medical equipment). That is what these programs do; they aren't open-ended, a free-for-all. Generally I think they are more helpful on coverage. I definitely has improved once we got used to PPS. We definitely meet a lot more PT [physical therapy] and OT [occupational therapy] needs than we used to because of the PPS therapy incentive. That's good. We probably under-serve on [home health] aides, but the nurses and PTs, in my experience, pick up a lot of that slack, just like we always do on social work. Medicare [home health] just doesn't cover social work. Nurse SC

> There is a limit. There always is. I think it could be better; they could loosen it up a bit. It's not horrible. There always are unmet needs, but PPS allows us to meet a lot of needs. It's not fair to say they don't. Sure, on the long-term psychological, mental health issues, they are limited. They were before PPS. so patients with dementia, depression, borderline [personality disorder] are not going to get mental health care; only care for their acute medical need. That helps though, both physically and mentally and it's often more than they would get if they stayed in the hospital or if they did not get a home health referral. So I see Medicare as limited but helpful. Nurse SR

Further evidence of organizational influence on both home care nurse and social work decision-making emerged in the interviews, as discussed in the next section.

Operational Knowledge, Corporate Influence, and Rules of the Game

The study was not designed to focus on analyzing the organization's role as a variable in nurse and social worker decision-making about home care Alzheimer's disease persons. However, throughout the interviews the role of the home health agency emerged in identifying, interpreting, and communicating Medicare eligibility, coverage and reimbursement requirements to nurses and social workers. Nurses and social workers consistently identified managers, supervisors and other home health agency executives as the identifiers, interpreters, communicators. Thus, as I moved through axial coding to

selective coding, an overarching theme or story line (Strauss & Corbin, 1990) emerged around the home health agency. The home health agency, through its executive and management agents, was effectively an intervening or mediating variable interpreting government policy into organizational policy and practice. This policy, in turn, created the requirements framework which affected nurse and social worker practice decisions and coping strategies.

This story line seemed akin to several theoretical concepts in the sociological literature. Perrow (1991, 1999, 2002) asserted that organizations act as independent variables affecting the nature and structure of employee actions as much as the employees' actions affect the organization's structure, productivity, profit and other outcomes. Bernstein (1991), as noted earlier, observed human service agency workers learning the rules of the game to effectively cope with their perceptions of the organizational demands and context.

However, even more poignant, was Baszanger (1997), who developed the concept of "operational knowledge" (p.1). I encountered her writings on varying organizational approaches to patient chronic pain in a book of articles on grounded theory in practice (Strauss & Corbin, 1997). Baszanger (1997) asserted that health care organizations may have different underlying themes or care models which affect direct service worker practice and patient services. Her theory emerged while she was studying two hospital centers in France, each of which had a different set of assumptions about care. These models affected the type of knowledge and care boundaries available to employees, and thus the type of care they delivered. She described each hospital center as having a different pole or goal which guided the nature of operational knowledge

conveyed to workers. At one pole was “curing through techniques”, which aimed to cure pain through pharmacology, neurosurgery, and other physical methods (Baszanger, 1997, pp.2-3). At the other pole was “healing through adaptation”, which aimed to control pain through a combination of cognitive and behavioral techniques as well as pharmacology and physical therapy (Baszanger, 1997, pp. 2-3).

The operational knowledge concept seemed a powerful and appropriate metaphor to characterize what the nurses and social workers said about the home health agency’s role in their care decisions.

> I’ve worked at half-a-dozen [home care] agencies over the last twenty years and they are all different. I can do at one agency what I could never even contemplate at some others.
>
> Nurse LT

> It’s a constant adaptation to the work environment. Medicare pays, but practice is not uniform. Every [home care] agency seems to interpret the requirements somewhat differently. The rules of the game differ from place to place.
>
> Social Worker ER

> Yes, the game part. So, that’s a lot of my patients—the two Ds—dementia and diabetes. The game is to try to give as much care as possible—meet as much of the patient needs as you can while they are here--- without violating Medicare guidelines. Yes, you are right, it does depend where you work. My guidelines come from my supervisor generally and our initial orientation and in-services. Other nurses I know get their guidance the same way, but they don’t all get the same guidance. It varies with the agency.
>
> Nurse MT

> Oh, I think it varies based on who owns the agency, how much they want to make money, who you have as a supervisor, how panicked people are about Medicare audits, how smart people are, how much they care, you know, there’s a lot that goes into it.
>
> Social Worker AH

> How do I manage it all? Well the Alzheimer’s patients are a good example. Medicare won’t help. They see it as the family and patient’s responsibility. Alzheimer’s is chronic and psychological. That’s how see it and they don’t cover that. So most nurses learn it that way and don’t do much treatment. It

varies by nurse, but most provide limited care. I always try to give a little extra. The patients and families seem so needy. I feel I should have some flexibility.

Nurse GM

I give a little more just by doing it. I take the risk. I'm very confident. I have that nursing heritage and lots of experience. And my Dad was a truck driver so I'm pretty tough. I don't get pushed around easy. I assess the needs and if I think there is medical necessity I just do it. If my supervisor has a problem with how many visits or what type I order or how long my visits are or how long I keep the patient on, then I tell them I'll change it if they can show me it's not medically necessary. I'm not going to alter good practice based on some concern for profit or productivity. And I get flack on it, but I don't change. I push back and generally get what I want. That means my patients get more and leave with less unmet need. That's especially true with social work. I put social work in on almost every case. It's crazy. People have all these needs and they are indirectly medical needs because they affect their mental state, whether they are depressed, stressed, anxious, agitated—that affects a lot of physical conditions. So, why it isn't covered is beyond me. Oh, my mother keeps telling me it is a political decision—they only want to cover limited physical problems and everything else gets covered by self reliance. Well, not everyone can afford to be self reliant. So that's what we should help with.

Nurse TS

It is the guidelines my supervisor has given me, which I assume come from Medicare or whoever the payer may be. It's that way at all stages—whether or not to admit, the initial care plan, delivering care, deciding when to discharge, you know, it is all the time. You want an example. Ok, I had this 82 or 83 year old women. She was here mainly for PT after a hospital stay for a broken ankle. We did some nursing to check on meds, assess, the usual, but it was mainly PT. But she wasn't here much more than 30 days. She clearly had memory and big time mobility problems. And she was depressed and so was her husband who was 91 and her primary caregiver—and she was his. We didn't deal with that. That's a pretty typical example. At another agency we might have had more latitude, but not here, like I said, there's pretty much a script and I follow it.

Nurse DH

Like I said it is mainly the guidelines from the agency. My supervisor is real Clear on my visit volume and type of visits per stay. So, that is what I call my clinical guidance. The patients medical needs get handled within those guidelines. If they need more care, then they need to buy it privately, provide it themselves, go outpatient or inpatient, or, I guess go home, get hurt, and come back here.

Nurse JL

Well, yes, it bothers me. You said others said it bothers them and some try to

> do more. It does bother me but I am not the type to push the boundaries. I am a single mother with two young kids. I get paid well. I do not want to be job-hunting so I get bothered but I still stick to the script. The agency decides. I just follow.
>
> Nurse SH

> They set boundaries so I know what I can and can't do. Are they helpful in meeting patient needs—NO!! Social work just isn't covered much. An example? Okay. We had a team conference one day, which is rare—that's a whole other story-anyway in the conference they were discussing a patient with severe, recurring diabetic problems. She's one of our frequent flyers. She lives alone, but has some friends who stop by. She is depressed and has had multiple hospitalizations. I said why not let me go in and see if I can help. The nursing manager said there was no way Medicare would cover my visit. I said, "Well if they won't, don't we have some charity care funds?" She said there was a process with finance so I could go see them. It seems like a game at times, and it differs by agency. They all have rules, but the rules differ even though Medicare pays at all the agencies. There is no consistency except there are rules. At another agency I could have done more for that patient. It depends.
>
> Social Worker CA

> It's the family and patient needs that drive me, but I constantly must limit what I do based on what the nurses say and they get their orders from the managers, and the managers get their orders from the big shots—the CEO and CFO. I don't even have a social work supervisor. We have so few social workers—most are per diem; I am the only full-timer—that I report to the [physical] therapy supervisor. It's just someone to report to. She doesn't know social work. She's a nice person, but doesn't help. She just tells me to follow the nurses' direction; that they are in charge of the cases—and they are. So the nurses tell me if they want me to go in [to visit a patient].
>
> Social Worker TD

While the nurses and social workers consistently emphasized the organizational role as a mediator of Medicare requirements, the organization was not the unit of analysis for the study. As a result, the study did not probe as to whether there were any patterns or themes as to types of operational knowledge and their potential variance by

organizational characteristics. Such research is recommended for the future, as noted in the last chapter of the dissertation.

Summary of Findings

Overall the study found that the Medicare home health regulatory framework, as mediated by the home care agency, influences how nurses and social workers perceive, make decisions about, and cope with persons with Alzheimer's disease and their caregivers' needs. The consequences are: (1) Persons with Alzheimer's disease and their caregivers' needs often are not recognized, or are recognized but not met, especially psychosocial and bio-psychosocial needs; (2) Nurses and social workers develop a range of coping strategies (i.e., conformists, innovators, and rebels), mainly conforming to regulatory requirements (46% of all interviewees) which results in unmet client and caregiver needs; (3) Social workers (54%) conform more than nurses (33%), with more nurses (50%) being more innovative in meeting client and caregiver needs than social workers (33%); (4) The more nurses and social workers conformed, the greater the unmet needs of persons with Alzheimer's disease and their caregivers; (5) Nurses' coping strategies allow them to perform professional tasks so they feel more professionally fulfilled than social workers, though they recognize the limitations in their work; and (6) Social workers' coping strategies result in their feeling professionally unfulfilled and limited, unable to use their interpersonal practice, case management, assessment and diagnosis, service planning, and advocacy skills. In addition, none of the interviewees mentioned specific interventions, let alone any of the research-based interventions in the literature review, though there were a few references to reminiscence therapy and counseling.

These findings lead to recommended future research, policy, practice and advocacy actions to more cost-effectively meet the needs of persons with Alzheimer's disease and their caregivers receiving Medicare home health services.

CHAPTER SIX: POLICY, PRACTICE, RESEARCH, & ADVOCACY IMPLICATIONS

Introduction

Based on the present study and the literature review, it appears the unmet needs of home and community-based persons with Alzheimer's disease and their informal caregivers and professional caregivers might best be met by using evidence-based psychosocial and bio-psychosocial interventions. The research on bio-psychosocial and psychosocial interventions for caregivers and care recipients appear to address many unmet needs of the Medicare home health persons with Alzheimer's disease and their caregivers, as identified by the home care nurses and social workers. If covered under Medicare home health, such interventions also would seem effective in decreasing the professional sense of frustration of home care nurses and social workers in their interview comments on coping strategies and unfulfilled professional altruism. Thus, the present study, combined with the literature review, have significant implications for future policy, practice, research and advocacy. These opportunities present a robust research agenda which interrelates to policy, practice and advocacy opportunities.

Implications for Future Research

The study explored an area identified as a research gap in the literature review: factors that influence home care nurse and social worker decision-making regarding persons with Alzheimer's disease. I believe the study results better inform knowledge of this issue. However, there remain significant research gaps. First is that much of the research on effective psychosocial interventions for persons with Alzheimer's disease and other conditions is institutionally-based (i.e., nursing homes and residential care and

assisted living facilities) where patients have moderate or severe dementia (Cohen-Mansfield, 2001; Zimmerman, et al., 2003), or in adult day and medical day care facilities. There are only a few studies which test home-based interventions, albeit none are with persons receiving the intervention through a Medicare-certified home health agency (Gitlin, 2003; Gitlin, et al. 2003a, 2003b, 2003c, 2006). This is despite the fact 75% of all persons suffering from Alzheimer's disease reside at home with early to moderate stage dementia (Zimmerman, et al., 2005) and that my nurse and social worker interviews emphasized the need and feasibility of such care at home. This also is despite the fact that there is an increasing concern for in-home falls by the elderly being identified as early indicators of the need for more complex care. Yet there is no Medicare funding of research, let alone service delivery, of effective home environmental assessment and environmental skills-building interventions (Leland, 2008b). Similarly, despite positive evidence-based findings (Burgio, 2008; Mittelman, 2008a, 2008b), there are no research studies of support groups, counseling, and other quality of life and cost-effective interventions through Medicare home health for persons with Alzheimer's disease and their caregivers.

Second is that the extensive literature review indicates that neither government nor privately-sponsored research has used existing research results to test the potential for psychosocial home care interventions to improve quality of life and reduce costs for persons with Alzheimer's disease receiving Medicare home health services and their caregivers (Cabin, 2005). The lack of cost-effectiveness research and cost-benefit analysis is significant. Effective caregiver interventions are important because they indirectly contribute to the quality of life of persons with Alzheimer's disease and reduce

caregiver burden and costs, allowing them to remain an informal caregiver for longer time periods. The need for such research is reinforced by the nurse and social worker interviews emphasizing the need for more palliative and psychosocial care.

In contrast, research on palliative home care and end-of-life care prompted Congress and the National Cancer Institute to fund demonstration projects to test whether hospice palliative care models could simultaneously reduce Medicare end-of-life care costs and improve patient and caregiver quality of life outcomes. The demonstration results were positive, leading to passage of the Hospice Medicare Benefit in 1984 and ongoing positive cost reduction and improved quality of life results (Gage, et al., 2000; Mor & Kidder, 1985; National Hospice and Palliative Care Organization, 2004b, 2004c). There also is significant research proving the cost-effectiveness of providing preventative interventions for the elderly related to reduced likelihood and adverse consequences of cervical cancer, hypertension, and obesity (Fahs, Mandelblatt, Schechter, & Muller, 1992; Goldman, Cutler, Shang, & Joyce, 2006; Mandelblatt & Fahs, 1988). Such research designs might be replicated in demonstration projects to test the cost-effectiveness of evidence-based interventions which might decrease the length of institutionalization, occurrence of falls, or other adverse outcomes for persons with Alzheimer's disease.

Third is that research has not sufficiently examined practitioner perspectives on home-based care for Alzheimer's disease or any type of dementia, particularly home care nurses who control most care decisions in Medicare home health settings (Cabin, 2006).The present study began the process, but more research is needed to enable policy and practice to incorporate more of the experience and practice wisdom of nurses and social workers. Other than the limited insights from this study, there are no studies of the

multiple factors which influence key practice stakeholders' (i.e., physicians; nurses; social workers; home health aides; & physical, speech, and occupational therapists) decisions regarding care of Alzheimer's disease patients in the home health setting. There also is a limited amount of research on practice stakeholders' opinions on whether and how Medicare home health policy and practice should be changed for the care of Alzheimer's patients and their caregivers. A national survey of home care nurses and social workers, with in-depth interviews of a sample of respondents, could explore these practitioners' perspectives on appropriate interventions, how Medicare home health policy influences their care decisions for Alzheimer's disease patients, and how they believe policy should be modified to match appropriate care for client needs.

Fourth, there is a need for further exploration at the organizational level regarding this study's finding that the home health organization, through its agents, acts as a mediator of how Medicare regulations are communicated to and perceived by practitioners, the resultant impact on their care decisions, and the nature and amount of care received by patients and caregivers. An organizational level analysis would focus on home health agencies with different profiles on key variables (i.e., budget size, caseload, auspice, location, payer mix, profit level) to determine whether the type of agency made a significant difference in the nature of the organizational mediation and consequences for practitioner decision-making and patient and caregiver care receipt. Such a study would require recruitment of home health agencies and might be conducted using a mixed methods design. Such a study might include a combination of research methods such as: a review of agency documents; interviews or focus groups of practitioners; interviews or focus groups of agency executives and managers; surveys of practitioners, executives,

and managers; and quantitative analysis involving the agency profile variables and quantitative survey data, or even qualitative data translated into numeric equivalents through qualitative software.

Fifth, there is a need for a clinical data-mining (Epstein, 2001) study of the actual impact of the Medicare regulations on not recognizing and attending to the needs of persons with Alzheimer's disease and their caregivers. Such a study might use a sample of actual client records to evaluate actual clinical needs against services received, OASIS assessments, OASIS reimbursement scoring and payments, OASIS-based outcomes, and met and unmet client and caregiver needs.

Policy Implications

The current study indicates that a significant number of home care nurses and social workers agree there is a need for increased social work and related psychosocial care, both to address unmet client need and improve client outcomes as well as to potentially reduce Medicare and client financial burden. A variety of policy options might be prudently, yet expeditiously, pursued, using a variety of experimental and quasi-experimental research designs to guide policy change recommendations. For example, there could be government, private foundation, or joint private-public- sponsored studies testing the results of an enhanced social work-based psychosocial care component within or outside the Medicare or Medicaid Home Health Benefit. Such pilot studies might use randomized controlled trials or other designs to test the quality of life and cost outcomes of specific new expanded social-work services. These services might include support groups and individual and family counseling, using existing evidence-based protocols for an experimental group compared to a control group (Burgio, 2008; Gitlin, 2008;

Mittelman, 2008a, 2008b). Similar studies might use a social work and occupational therapy-based environmental assessment, home modification, and environmental skills-building programs. Another option might be one or more new benefit designs for persons at high risk of falls, or other risks, for certain chronic diagnoses (i.e. Alzheimer's disease, Multiple Sclerosis, Parkinson's disease). These models would be based on collaborative medical and psychosocial assessments and interdisciplinary team care plans and management care plans.

The purpose of the pilot studies would be to test one or more collaborative models which would include, at a minimum: (1) a joint nursing and social work initial and ongoing assessment of patient and caregiver needs and (2) expanded social work service eligibility, coverage, and reimbursement. The models would not be designed to create competition between services, by reallocating current coverage and reimbursement from nursing or other services to social work to maintain cost neutrality. Instead the models, like the Hospice Medicare Benefit demonstrations, would test the simultaneous ability to decrease readmissions, length of stay, and costs while improving patient and caregiver quality of life (i.e., reduce nature and frequency of falls, depression, anxiety, stress, aggression, etc.). The potential for cost reduction might be measured by reduced cost per episode and factors such as length of stay and the longitudinal cost of the enhanced psychosocial care model patient compared to others. The costs also might include system costs outside the home health agency such as delays in nursing home admission and reduced hospitalizations

A second broad area for potential policy change might be altering the current Medicare assessment, outcomes and payment system to be more sensitive to the reality

exposed in the current study of client psychosocial needs and the adverse impact of such unmet needs on client and caregiver physical and mental health and the cascading impact of those unmet needs on Medicare program costs. For example, the current Medicare reimbursement and outcomes measurement system, based on the OASIS (Outcome and Assessment Information Set), does not use any psychosocial measures, even though OASIS has sections addressing living arrangements, supportive assistance, and neuro/emotional/behavioral status. OASIS is a fifteen-page, seventy-five question, mandatory standardized assessment and outcomes tool. OASIS is used to simultaneously assess the patient, develop patient care plans, measure outcomes, and determine length of stay and reimbursement. Scores from twenty-three OASIS questions are used to create one hundred fifty-three payment-per-sixty-day-episode categories, known as Home Health Resource Groups (HHRGs), with reimbursement ranging from as little as $100 to over $5,000 per episode (Medicare Payment Advisory Commission, 2004, 2005). The reimbursement scores are based on three scoring categories (i.e., clinical severity level, functional severity level, and service utilization level), with no scoring addressing degree of neuro/emotiona/behavioral severity (i.e., levels of depression, anxiety, confusion, cognitive functioning, problem behaviors, memory deficits, aggression, and use of psychiatric nursing service).

Medicare's quality outcome measures also do not address patient psychosocial issues and their related impact on physical and mental health. Currently Medicare maintains the Home Health Compare system online so consumers and payers can evaluate home health agency performance. This system measures and compares agency performance on twelve measures: three measures on improvement in getting around; four

measures on meeting the patient's activities of daily living; two about how home care ends; and three on patient medical emergencies (U.S. Department of Health and Human Services, 2008a). There is a broader set of reports available on ten risk-adjusted (RA) home health agency outcome groups. However, only one of these RA groups is psychosocial and it contains only one element: RA group "Improvement in Behavioral Health status" with the subject area listed as "Have Confusion Problem" (U.S. Department of Health and Human Services, 2008b).

Policymakers should re-examine this system. OASIS has limited questions relating to social work and psychosocial outcomes and only limited questions relating to nursing care impact on mental health, none of which are used for reimbursement or outcome measurement. If the reimbursement formula were to change to give social work and psychosocial outcomes HHRG monetary value or the public and other outcomes reports enhanced to give psychosocial variables more weight , perhaps the ability to increase coverage and actualize altruism would come to home care as it has to hospice. Given the hospice experience, actualization of professional altruism has proven a financial and physical and mental health benefit both to patients, their caregivers, and the government. Bringing about such policy changes would require extensive assessment of political feasibility and political advocacy and mobilization of major organizations representing social workers, nurses, and persons with Alzheimer's disease and their caregivers.

Practice and Advocacy Implications

An immediate practice implication is to disseminate more information about effective psychosocial and bio-psychosocial interventions for persons with Alzheimer's

disease and other conditions through all levels of formal social work degree-based and continuing education. The value of such approaches has been reinforced by the nurse and social worker interviews in the current study as well as the preceding literature review. The matrix in Appendix One is a valuable education tool, especially when combined with more detailed training on some of the more effective, evidence-based interventions. The updating of the matrix should be part of an ongoing research agenda, possibly pursued with the Council on Social Work Education (CSWE) and its geriatric social work initiative.

There also is an immediate advocacy opportunity for both the National Association of Social Workers (NASW) and the National Association for Home Care and Hospice Care (NAHC), as well as other professional and advocacy organizations concerned about the elderly. The voices of the social workers and nurses in the current study, as well as the extensive literature review, should enable both NASW and NAHC to modify their historic deferment to the Medicare home health acute care medical model. In NASW's 2003-2006 policy statements, there is one, fourteen-line paragraph and it does not advocate increasing home care social work coverage (National Association of Social Workers, 2007). NAHC similarly does not advocate for expanded social work coverage or alteration of the current PPS system to accommodate more coverage, eligibility and reimbursement for social work and psychosocial needs and care (National Association for Home Care and Hospice, 2008).

Appendix One:

Summary of Research Studies on Psychosocial Interventions for Persons with Dementia or Alzheimer's disease

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
I. Sensory Enhancement / Relaxation **A. Massage / Touch** Kilstoff and Chenoweth (1998)	N = 16; NHR; clients of a multicultural daycare center in Australia	Gentle hand treatment with three essential oils for 10-15 minutes	Analysis of family caregivers recording showed a decrease of over 20% in wandering and agitation / anxiety. Quantitative: secondary data analysis
Kim and Buschmann (1999)	N = 30; NHR; mean age = 76.58	Hand massage of each hand for 2.5 min., with verbalization	Sig. decrease on E-BEHAVE-AD during treatment time Quantitative: pre- and post-test one group design
Rowe and Alfred (1999)	N = 14; mean age = 76.77 (age 68-90), residing in the community	Slow-stroke massage for 5 days	Trend (NS) toward reduction of agitation (BSRS) Quantitative: pre-, post-, and concurrent one group design
Scherder et al. (1998)	N = 16; mean age, 85.7 (age 78-92), residing in a private residence	Massage (rubbing, brushing, kneading, mostly on the back)	No sig. reduction in aggressiveness (BOP) Quantitative: pre- and concurrent one group design
Snyder et al. (1995)	N = 26; AUR; age 60-97	Nurses administered hand massages to residents before care activity	Sig. decrease during the morning only Quantitative: pre- and post-test one group design
Snyder et al. (1995)	N = 18; AUR; mean age = 77.7 (age 66-90)	Hand massage, therapeutic touch, administered for 10 days each in the afternoon; (presence used as control condition)	No effect on targeted agitated behavior; sig. effect on anxious (fidgety) behaviors for 3 of the 4-to 5-day Intervention periods (not for Presence / Control). Quantitative: pre-, post-test , and concurrent one group design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
B. Music (during meals, bathing; general) Denney (1997)	N = 9; NHR; (MMSE: 0-5) mean age = 74.8	"Quiet music" during lunchtime	Sig. decrease in agitation (CMAI-GA) Quantitative: pre- and post-test one group design
Goddaer and Abraham (1994)	N = 29; NHR; mean age = 81.3 (age 67-93)	Relaxing music during lunchtime	Sig. decrease in overall agitation (CMAI-GA); no sig. difference in aggressive behaviors Quantitative: pre- and post-test one group design
Ragneskog et al. (1996)	N = 5; NHR; mean age = 80 (age 69-94)	Music (soothing, '20s and '30s pop) played during dinnertime	No effect Quantitative: pre- and post-test one group design
Clark et al. (1998)	N = 18; NHR; mean age = 82 (age 55-95)	Music during bathing; total of 20 bathing episodes (10 treatment; 10 control)	Sig. decrease in total number of behaviors and hitting behavior Quantitative: RCT
Thomas et al. (1997)	N = 14; NHR; ages 69-86	Individualized music played before and during bathing	Sig. reduced aggressive behavior (CMAI-a) during music time Quantitative: pre- and post-test one group design
Brotons and Pickett-Cooper (1996)	N = 30 in 4 NH; mean age = 82 (age 70-96)	Music therapy twice per week for 30 min. (singing, playing instruments, music game)	Sig. reduced agitation (DBRS) during music therapy sessions and after music therapy Quantitative: pre- and post-test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention
For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Cohen-Mansfield and Werner (1997)	N = 32; NHR; mean age = 87.8, 97% with dementia	1. Video tape of a family member talking to elderly person 2. one-to-one social interaction with research assistant (RA) 3. individualized music tapes, 30 minutes	Greatest decrease of VDB during one to one interaction, followed by exposure to family video, and then music. Quantitative: pre- and post-test one group design
Gerdner (2000)	N=39; mean age = 82 years, in a long-term care facility	Individualized music and classical "relaxation" music	Sig. decrease in agitation during individualized music (vs. classical music); Sig. decrease during classical music after 20 min. of intervention Quantitative: pre- and post-test one group design
Tabloski et al. (1995)	N = 20; NHR; mean age = 78.4 (68-74)	Listening to soft music with headphones for 15 min.	Sig. decrease in agitation (ABS) from 24.15 to a mean of 18.45 during intervention Quantitative: pre- and post-test one group design
Casby and Holm (1994)	1. 87-year-old woman, verbally agitated 2. 77-year-old man, verbally agitated 3. 69-year old man, verbally agitated	A. No intervention B. Relaxing classical music C. Favorite music	Decrease in vocalizations during intervention phase. Quantitative: Single subject design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Gerdner and Swanson (1993)	1. 89-year-old woman; MMSE: 0 2. 87-year-old woman; MMSE: 7; exhibiting pacing/wandering 3. 87-year-old woman; MMSE:5 4. 94-year-old woman; MMSE:0	Individually selected music presented on an audio cassette player	1. Trend in decrease of agitation (CMAI-a) and continued after the intervention 2. Decreased agitation on 4 out of 5 days 3. Decreased agitation 4. Decreased agitation Quantitative: Single subject design
C. White Noise Burgio et al. (1996)	N=13; NHR; mean age = 83.08 (age 67-99); MMSE: 1.66; verbally agitated	"White noise' audiotapes (environmental sounds)	Sig. decrease (23%) in the 9 responders; (treatment tapes were used in only 51% of the observations) Qualitative: observation
Young et al. (1988)	N = 8; mean age = 70 (age 60-82); wandering behavior in a geriatric hospital	Modified white noise (slow surf rate) at bedside	No effect overall; two patients individually analyzed showed improvement Qualitative: observation Quantitative: secondary analysis of case records
D. Sensory Stimulation Holtkamp et al. (1997)	N = 17; NHR	Activities in the "snoezelen" room	Decrease of behavioral problems in residents with "snoezelen" activities Qualitative: observation
Witucki and Twibell (1997)	N = 15; mean age = 81.13 (age 60-95); MMSE: 0-2, in a long-term care facility	Sensory stimulation (music, touch, smell)	Sig. decrease in DS-DAT, particularly in fidgety body language. Quantitative: pre- and post- test one group design
Snyder and Olson (1996)	N = 5; NHR; mean age = 92	Hand massage or music, each for 10 days	Trend toward decrease in aggressive behavior. Quantitative: pre- and post- test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Brooker et al. (1997)	N = 4; NHR; ages 74, 77, 79, 91	Aromatherapy and/or massage for 10 sessions	Clinical staff impression of benefit to all, but observational data and comparison to control condition show benefit for 2, and sig. decrease in only 1 participant; no advantage of combining massage and aromatherapy; 2 participants manifested increased agitation during treatment Qualitative: observation
II. <u>Social Contact: Real or Simulated</u> **A. Pets** Churchill et al.(1999)	N = 28; AUR; mean age = 83.3	Certified therapy dog for two 30-min. sessions	Sig. decrease in agitation (ABMI) with the dog present Quantitative: pre- and post-test one group design
Fritz et al. (1995)	N = 64; mean age = 74.6 (age 53-92), in a private residence	Companion animals	Sig. lower prevalence of verbal aggression and anxiety in pet exposed patients Quantitative: pre- and post-test one group design
Zisselman et al. (1996)	N=33, pets intervention; only 22% w/ dementia, in a hospital	5 days for 1 hour; pets (dog)	Trend (NS) decrease in irritable behavior (MOSES); no sig. difference between pet and exercise Quantitative: pre- and post-test one group design
B. One-to-One Interaction Cohen-Mansfield and Werner (1998)	N=41; verbally agitated	One-on-one social interaction with research assistants (RAs)	Decrease in verbal agitation (five did not complete 10 sessions) Quantitative: pre- and post-test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention
For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Runci et al. (1999)	81-year-old verbally agitated woman in a long-term care facility	1. Music therapy with interaction in English 2. Music therapy with interaction in Italian	Italian interaction sig. reduced noise-making, vs. English interaction Quantitative: Single subject design
C. Simulated Interaction/Family Videos Camberg et al. (1999)	N=54; mean age = 82.7; MMSE: 5.1, in a long-term care facility	Simulated presence: interactive audiotape containing one side of a conversation	Sig. decrease in problem behaviors (SCMAI and observations) Quantitative: pre- and post-test one group design
Hall and Hare (1997)	N = 36; NHR; mean age = 76.3 (age 65-98)	Video Respite™, 21-min.-long interactive videotape of music and reminiscence	No effect Quantitative: pre- and post-test one group design
Werner et al. (2000)	N = 30; NHR; verbally agitated	Family generated videotapes, 30 min. for 10 consecutive days	46% (sig.) decrease in disruptive behaviors during videotape exposure Quantitative: pre- and post-test one group design
Woods and Ashley (1995)	N = 27; NHR; age 76-94	Simulated presence; telephone audio recording of caregiver	Sig. decrease of problem behavior 91% of the time Quantitative: pre- and post-test one group design
III. **<u>Behavior Therapy</u>** **A. Differential Reinforcement** Doyle et al. (1997)	N = 12 verbally agitated subjects in a long term care facility	Reinforcement of quiet behavior and environmental stimulation based on individual preferences	Decrease in noise-making (CMAD) in 3 cases; 4 cases w / no effect (7 of 12 completed study) Quantitative: pre- and post-test one group design
Heard and Watson (1999)	N = 4; NHR; age 79-83; exhibiting wandering	Differential reinforcement = tangible reinforcers (food) Extinction = attention given in the absence of the behavior	Decrease in wandering (from 50% to 80% reduction) Qualitative: observation

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Mishara (1978)	N = 80; mean age = 68.8 (±SD 5.1) in a chronic geriatric mental hospital	Token economy: rewards (tokens) for desirable behavior, could then be exchanged for secondary reinforcers. General milieu: all secondary reinforcers were available for anyone who wanted them; activities were offered for participation but not rewarded.	Sig. decreased behavior in general milieu; trend (NS) decrease in token economy Quantitative: non-equivalent comparison group design
Rogers et al. (1999)	N = 84; NHR; mean age = 82; mean MMSE: 6.07	Skill elicitation: identify and elicit retained SDL skills; habit training: reinforce and solidify skills	Sig. decrease in disruptive behavior Quantitative: pre- and post-test one group design
Birchmore and Clague (1983)	70-year old female NHR; verbally agitated	Stroking back as reward for quiet behavior	Decrease in vocalizations Quantitative: Single subject design
Boehm et al. (1995)	1. 87-year old woman 2. 55-year old man	Behavioral plan that prompted calm, cooperative behavior by reinforcing (i.e., foods, toys, and praise) for each small step toward the desired behavior	1. Decrease of disruptive behavior during bathing 2. Nearly eliminated disruptive behavior during shaving and bathing Qualitative: observation Quantitative: Single subject design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Lewin and Lundervold (1987)	1. 73-year old woman, verbally aggressive, in a foster home 2. 76-year old AU NHR; physically aggressive woman, in a foster home	1. Communication / problem-solving strategy and provider keeping record of subject's yelling episodes 2. Implementation of a new routine incompatible with aggression (e.g., supporting herself by holding towel bar)	1. Yelling behavior stopped, even at 1 month follow-up 2. Sig. decrease in aggressive behavior, but variable Quantitative Single subject design Qualitative: observation
B. <u>Stimulus Control</u> Chafetz (1990)	N = 30; AUR; mean age = 81; exit seeking	Placement of two dimensional grid in front of glass exit doors	No effect Quantitative: pre- and post-test one group design
Hussian (1988)	N = 5; mean age = 71.2; inappropriate toileting, bed misidentification, exit-seeking in a long-term care facility	<u>Verbal and / or physical prompts</u> were given to attend to enhancing stimuli (yellow restroom doors); <u>Stimulus-enhancement alone</u>	Sig. decrease of problem behavior for each resident Quantitative: pre- and post-test one group design
Hussain and Brown (1987)	N = 8; mean age = 78.5; hazardous ambulation in a public mental hospital	Various two-dimensional grid patterns placed on floor in front of exit door	Sig. decrease of hazardous ambulation; horizontal superior to vertical configuration Quantitative: pre- and post-test one group design
Mayer and Darby (1991)	N = 9; mean age = 77.8; MMSE: ≤12; exhibiting wandering behavior in a psychiatric ward	Mirrors in front of exit doors to prevent exiting	Sig. decrease in successful exiting Quantitative: pre- and post-test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Bird et al. (1995)	1. 73-year old woman 2. 62-year old man with frequent visits to bathroom residing in a private home 3. 83-year-old woman in a hostel w/ anxiety about medication 4. 88-year old woman, verbally aggressive 5. 83-year old man; MMSE: 9; urination in corners, residing in a private home	1. Stimulus control (taught to associate stop sign with stopping and walking away) 2. Stimulus control (beeper signal associated with toileting demand) 3. Spaced retrieval with fading cues 4. Spaced retrieval and fading cues 5. Spaced retrieval; taught to associate cue with location of toilet	1. Decreased in appropriate entries (mean of 43.6) 2. Decrease in anxiety while wearing beeper, but retained fear of soiling himself 3. Decrease in verbal demands for medication 4. No effect 5. Decrease in inappropriate toileting, although prompting needed at night Quantitative: Single subject design Qualitative: Observation
Hussian (Study 1) (1982)	N = 3; mean age = 73.4; pacing / wandering in a long-term care facility	First, stimuli (orange arrows, blue circles) were linked to positive and negative consequences (food, loud noise); then, stimuli were placed in areas where participants were encouraged or discouraged to walk, respectively	Decrease of entries into potentially hazardous areas Qualitative: observation
Hussain (Study 2) (1982)	N = 3; mean age = 74.67; in a long-term care facility	Trained to respond to two stimuli differently; attention to desirable stimulus resulted in reinforcement	Differential reinforcement with stimulus control resulted in reduction of behavior Qualitative: observation

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Hussain (Study 3) (1982)	64-year old male, NHR; genital exposure and masturbation in lounge areas	1=rules; 2=differential reinforcement; 3= 2+ antecedent enhancement	Decrease in appropriate behavior in public area and continued at follow-up Quantitative: Single subject design
C. Cognitive Hanley et al. (1981)	N = 57; in a psychogeriatric hospital and home for elderly	Reality-orientation (RO): cognitive retraining where orientation information is rehearsed	No effect with RO class (GRS) Quantitative: pre- and post-test one group design
IV. Staff Training Cohen-Mansfield et al. (1997)	All NHR in the participating units	In-service training for nursing staff	No effect Quantitative: pre-and post-test one group design
Matteson et al. (1997)	N = 63, in a VA nursing home, for treatment group; N=30, in a community nursing home, for control; mean age=77; mean MMSE:12.5; Completers: 43 Treatment; 14 Control	Staff training based on adapting ADL activities to resident's level on Piaget's states; also, environmental modification included cues of colors, symbols, pictures, music, etc.; psychotrophic drug withdrawal was also undertaken	No sig. decrease from pre-test to 3 mo., but sig. decreases to 12 and 18 months post-tests (NHBPS) for treatment group; control group decreased at 3 and 12 months, but increased to pre-test level at 18 months Quantitative: non-equivalent comparison group design
McCallion et al. (1999)	N = 105; NHR	Nursing Aides Communication Skills Program (NACSP)	Sig. reduction in agitated behavior (MOSES and CMAI) for at least 3 months Quantitative: pre-and post-test one group design
Mentes and Ferrario (1989)	N = 8; NHR, physically aggressive	Calming Aggressive Reactions in the Elderly (C.A.R.E.) education program for nurse aides	Decrease in agitation from 11 to 9 incidents of staff abuse after the intervention Quantitative: pre-and post-test one group design
Wells et al. (2000)	N = 40; NHR	Educational program on delivering activities; focused monitoring care	Decreased level of agitation (MBM and PAS) Quantitative: pre-and post-test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention
For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
V. <u>Structured Activities</u> **A. Indoor Activities** Aronstein et al. (1996)	N = 15; NHR; mean age = 81 (age 68-94)	Recreational interventions (manipulatives, nurturing, sorting, sewing, and music)	Decrease in agitation (CMAI) 57% of the time Quantitative: pre- and post-test one group design
Groene (1993)	N = 30; mean age = 77.5 (age 60-91); pacing/wandering in an Alzheimer unit	Mostly music (playing instruments, singing, dancing) or mostly reading for 7 days	Decreased wandering in music sessions vs. reading sessions Qualitative: observation
Sival et al. (1997)	1. 76-year-old, verbally aggressive woman 2. 82-year-old, physically agitated woman 3. 81-year-old man All in private residences	Activities program outside their units (musical activities, social activities, games, creative works, singing)	Inconclusive (SDAS-9) Quantitative: Single subject design
B. Outdoor Walks Cohen-Mansfield and Werner (1998)	N = 12; NHR	Escorting residents to an outdoor garden (one-to-one supervision)	Sig. decrease in physically aggressive and nonaggressive behaviors (CMAI) Qualitative: observation
Holmberg (1997)	N = 11; NHR; wandering and physically aggressive agitation	Group walk through common areas or outside, singing and holding hands	Sig. decrease in agitation on group days vs. non-group days Qualitative: observation
C. Physical Activities Buettner et al. (1996)	N = 36; NHR; mean age: 82.4; MMSE: 6.5	Sensorimotor program to improve strength and flexibility vs. a traditional program	Decreased agitation during the sensorimotor vs. the traditional program Qualitative: observation

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Zisselman et al.	N=25 in exercise group; only 22% had dementia	Exercise 5 days for 1 hour	NS trend of decrease in agitation (MOSES) Qualitative: observation Quantitative: pre- and post-test one group design
VI. <u>Environmental Interventions (see also section IX.)</u> **A. Wandering Areas** McMinn and Hinton[38]	N = 13 participants in a psychiatric facility	Released from mandatory confinement indoors	Decrease in verbal and physical aggression, especially among men Qualitative- observation
Namazi and Johnson	N = 22; AUR; mean age = 80 (age 69-98)	Unlocking exit door to outside walking paths	Decrease in agitated behaviors (CMAI and DBDS) when door was unlocked Quantitative: pre-and post-test one group design Qualitative: observation
Whall et al.	N = 31 in five NH	Natural environment (e.g., bird sounds, pictures, food) during bathing	Sig. decrease from baseline to first treatment and second treatment and in treatment group vs. control (CMAI-W) Quantitative: pre-and post-test one group design Qualitative: observation
B. Reduced Stimulation Cleary et al.[86]	N = 11; NHR; mean age = 87.2 (age 81-94)	Reduced Stimulation Unit	Decrease in agitation from 1.7 to 0.8 (4-point scale) Quantitative: pre-and post-test one group design Qualitative: observation
Meyer et al.	N = 11, residing in an Alzheimer's boarding home	Quiet Week, including no TV / radio; staff used quiet voices and reduced fast movements	Sig. decrease in non-calm behaviors Qualitative: observation
VII. <u>Nursing Care Interventions</u> **A. Light Therapy /Sleep** Koss and Gilmore (1998)	N = 18; NHR	Increased light intensity during dinnertime	Sig. decrease in agitated behaviors Qualitative: observation
Lovell et al. (1995)	N = 6; NHR; mean age = 89.2	Bright light (2,500 Lx) in the morning for 10 days	Sig. decrease in agitation (ABRS) Quantitative: pre-and post-test one group design Qualitative: observation
Lyketsos et al. (1999)	N = 15, in a chronic care facility	Bright-light therapy	No effect (BEHAVE-AD) vs. a control group Quantitative: pre-and post-test one group design Qualitative: observation
Mishima et al. (1994)	N = 24; mean age = 75 in an acute-care hospital	Morning-light therapy	Sig. decrease in problem behaviors from an average of 23.9 to 11.6; also, an increase in nocturnal sleep Quantitative: pre-and post-test one group design Qualitative: observation

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Okawa et al. (1991)	N = 24; mean age = 76.6; *n* = 8 (controls), in a geriatric ward w / sleep-wake disorders	Phototherapy with illumination of 3,000 lux in the morning	Effective for sleep-wake rhythm disorder in 50%; behavioral disorders decreased Qualitative: observation
Satlin et al. (1992)	N = 10; mean age = 70.1, in a VA hospital, with sundowning (MMSE: 0.6)	2-hour exposure to light (1,500-2,000 lux) while seated in a geri-chair	No effect on agitation, but a decline in severity of sundowning and sleep-wake problem patterns Quantitative: pre-and post-test one group design Qualitative: observation
Thorpe et al.(2000)	N = 16; ages 60-89 in a long-term care facility	Light administered using the Day Light Box 1,000	Trend to decreased agitation (CMAI and EBIC) vs. baseline in post-treatment week Quantitative: pre-and post-test one group design Qualitative: observation
Alessi et al. (1999)	N = 29; NHR; mean age = 88.3	Increased daytime activities and a nighttime program to reduce sleep-disruptive noise	22% decrease in agitation vs. baseline (sig. difference from control group); increase in nighttime sleep from 51.7% to 62.5% vs. controls Quantitative: pre-and post-test one group design Qualitative: observation
B. Hearing Aids Palmer et al. (1999)	N = 8; 5 men, 3 women, ages 71-89; MMSE: 5-18; community-dwelling	Hearing aids provided	Decrease in problem behavior as reported by caregiver Quantitative: pre-and post-test one group design Qualitative: observation
C. Removal of Restraints Middleton et al. (1997)	N = 4; age 69-82, in a long-term care facility	Pain management, restraint management, and beta-blockers	Decrease in the amount and intensity of aggressive behaviors (OAS) Quantitative: pre-and post-test one group design Qualitative: observation

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
Werner et al. (1997)	N = 30; NHR, no Restraints: mean age: 86.9; Restrained: *n* = 142; mean ages 86.1	Educational program for nursing staff, then removal of restraints	Sig. decrease in all types of agitation (SCMAI; only those exhibiting agitation while restrained included for analysis) Quantitative: pre-and post-test one group design Qualitative: observation
VIII. <u>Combination Therapies</u> **A. Individual Treatments** Hinchliffe et al. (1997)	N = 40; mean age = 81 (age 65-93); MMSE≥8 in the community	Individualized treatments: Combination of pharmacologic and nonpharmacological interventions (activities, if under-stimulated)	Sig. decrease in problem behaviors in first treatment group, but not in the delayed-treatment condition Quantitative: pre-and post-test one group design Qualitative: observation
Holm et al. (1999)	N = 250; mean age = 81 (SD = 8) in an acute-care hospital	Individualized inpatient program plan; pharmacologic and nonpharmacologic	Sig. decrease in agitation (RAGE); problem behaviors eliminated in 38% of patients Quantitative: pre-and post-test one group design Qualitative: observation
Matthews et al. (1996) Woods, Spector, Jones, Orrell, & Davies (2006)	N = 33; mean age = 84.2 (age 67-98) in a dementia unit Cochrane systematic review Of reminiscence therapy for older adults with dementia	Client-oriented care, residents' wishes respected; scheduled events adjusted for individual residents Reminiscence therapy	Sig. decrease in verbal agitation (CMAI) 6-8 weeks after the change. Quantitative: pre-and post-test one group design Qualitative: observation Statistically significant results in improving cognition, mood, and general behavioral function. Quantitative: Cochrane systematic review-secondary data analysis.
B. Intervention Programs Rovner et al. (1996)	N = 81; NHR; mean age = 81.6	Activity program (music, exercise crafts, relaxation, reminiscences, word games), re-evaluation of psychotropic medication, and educational rounds	Sig. decrease in agitation vs. control group (at 6 months, behavior disorder exhibited by 28.6% vs. 51.3%) Quantitative: pre-and post-test one group design Qualitative: observation
Wimo et al. (1993)	N = 31; median age = 82 (age 62-96), residing in a psychogeriatric ward	Program developed including team care, enhanced environment, etc.	No effect on irritability; worsening in restlessness vs. controls Quantitative: pre-and post-test one group design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

Reference by Intervention Category	Subjects	Intervention	Findings & Methodology
IX. Environmental Interventions			
Gitlin**,** et al**.** (2006)	319 persons aged 70 or > with difficulty with one or more ADLs	12 months of structured physical and occupational therapy program.	Self-reported treatment group Less difficulties with ADLs ($p = .03$) and IADLs ($p = .04$) than control group.Other positive results , all at $p = .05$ or less. Quantitative: RCT
Gitlin (2003) ; Gitlin**,** et al**.** (2003)	Varying combinations of Elderly clients with dementia and their caregivers	Environmental skills building Program protocol of phone and in-home training of client and caregiver and environmental modifications	Improved client ADLs; Reduced client risk of falls; Reduced caregiver and client Stress. Quantitative: one group Pre-test, post-test design
X. Counseling, Support Groups, & Social Support			
Mittelman, et al. (2003)	103 spouse-caregivers of AD patients	Treatment group received Individual & family Counseling, support group Participation, & ad-hoc phone consultation.	One year after intake, treatment group had 54% fewer nursing home placements of AD patients than control group ($p < .05$) Quantitative: RCT
Mittelman, Roth, Haley, & Zarit (2004)	203 spouse-caregivers of AD patients	Treatment group received Individual and family Counseling sessions in first four months; weekly caregiver support groups; and Continuous ad-hoc counseling for caregivers and families	At one year follow-up ($p=.04$) and at four year follow-up ($p < .02$),treatment group reported significantly lower levels of negative reactions to patient problem behaviors. Quantitative: RCT
Mittelman (2004), replication of Mittelman, et al. (2004) in U.S., Australia, and England		Same as above	Improved caregiver satisfaction with assistance from their social network ($p = .006$) and decreased depression ($p = .001$) Quantitative: RCT
Bennett, Schneider, Tang, Arnold, & Wilson (2006)	89 persons without known dementia	Annual clinical evaluations using twenty-one clinical performance tests and autopsies of participants	Social networks positively impacts, or protects against, the rate of cognitive decline as AD progresses ($p = .016$).
Caufield (2006)	28 members of a club group for dementia patients in a nursing home	Daily club group routine of exercise, games, meals, music,& current events discussion	Decrease in use of psychoactive medications ($p < .01$), decrease in weight loss ($p < .001$), and decrease in feelings of social isolation ($p < .01$). Quantitative: multiple individual pre-, post-, and concurrent one group test design Quantitative: one group Pre-test, post-test design

Matrix: Summary of Research Studies on Psychosocial Intervention For Persons with Dementia or Alzheimer's Disease

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Abbreviations Legend:
ABMI=Agitation behavior Mapping Instrument;
ABRS=Agitation Behavior Rating Scale;
ABS=Agitated behavior Scale;
AUR=Alzheimer disease unit residents;
BOP=Beoordelingsschaal Voor Oudere Patienten;
BSRS=Brief Behavior symptom Rating Scale;
CG = Caregiver
CMAI=Cohen-Mansfield Agitation Inventory; as modified by Goddaer and Abrahm;
CMAI = Short Form of the Cohen-Mansfield Agitation Inventory;
CMAI-a=Adaption of Cohen-Mansfield Agitation Inventory;
CMAI-GA Cohen-Mansfield Agitation Inventory as modified by Goddaer and Abraham;
CMAI-W=Cohen –Mansfield Agitation Inventory as modified by Chrisman et al.
DBDS=Dementia Behavior Disturbance Scale;
Dbrs = Disruptive Behavior Rating Scales;
Ds-DAT=Discomfort Scale for Dementia of the Alzheimer's Type;
E-Behave-AD adaptation by Auer et al.[108] of the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD);
EBIC=Environment Behavior Interaction Code;
GRS = Geriatric Rating Scale;
MIBM=Modified Interaction Behavior Measure;
MOSES = Multidimensional Observation Scale for Elderly Subjects;
N = number of participants in study;
NH=nursing home;
NHBPS = Nursing Home Behavior Problem Scale;
NHR=nursing home residents;
NS= not statistically significant;
OAS = Overt Aggression Scale;
PAS = Pittsburgh Agitation Scale;
PGDRS = Psychogeriatric Dependency Rating Scale;
RAGE = Rating Scale for Aggressive Behavior in the Elderly;
RCT = Randomized Controlled Trial
S=subject;
SCG = Spousal Caregiver;
SD= standard deviation;
SIG. = statistically significant;
SDAS-9 = Social Dysfunction and Aggression Scale;
VDB=verbally disruptive behavior

NOTE:

All references cited in matrix appear either in the References section of the dissertation proposal or in : Cohen-Mansfield, J. (2001).

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Appendix Two:
Home Care Nurse & Social Worker Interview Guide

Appendix Two

Home Care Nurse & Social Worker Interview Guide

I. Introduction

Research Question: What factors impact home care nurse and social worker decisions about Alzheimer's disease clients in Medicare-certified home health agencies?

Hi. How are you? I just wanted to thank you for volunteering for this interview, make sure you understand the purpose, and remind you all information will remain confidential and used without identifying you. Do you have any questions? Okay to proceed?

So, tell me, how did you get into home care?

Probe: why?

Would you tell me something the patients you care for now?

Probe: ask for a few examples, if not offered by interviewee.

Probe: ask if care for any Dementia or Alzheimer's patients.

Would you share some examples of what you like he most and the least about home care based on your experience?

II. Patient Care Decisions

Could you tell me what you take into account when you make decisions about patient care? Could you give a few specific patient examples from your personal experience?

Probe: ask if stage of care makes a difference.

Probe: ask about patient & family factors.

Would you say, in your experience, that Medicare regulations help you or not in making decisions? Could you give me a few specific examples?

Probe: Ask reaction to other (anonymous) interviewees' comments on regulations being helpful or not.

In your experience, are there any considerations you take into account more than others most of the time?

Probe: Which? Why? When?

Probe (if not addressed): Family/Patient needs; supervisor direction; agency policies and procedures.

Probe: Ask to react to contrasting responses from other interviewees.

III. Dementia Patient Care

Do you see many patients with dementia?

Probe: dementia versus Alzheimer's disease – any distinction?
Probe: If/how identified in OASIS assessment; impact on care planning? service delivery?

Based on your experience, what would you say about their needs? Would you give me a few patient examples ?

Probe: cognitive, emotional, psychological, medical, financial, spiritual
Probe: caregiver needs

How do these needs compare to those of other patients?

Would you discuss what most affects your ability to meet their needs?

Probe: Enhancement versus Constraint factors
Probe: at stages
Probe: Contrast to other interviewee responses and ask to react.

Would you give me a few patient examples from your experience?

Would you elaborate more on how you deal with constraints on meeting patient needs?

Probe: Ask for example/vignettes
Probe: Impact on patient? Caregivers? (quality of life; premature Discharge? Unmeet needs? Readmits?)

Any other thoughts you'd like to share? Questions for me? (Remind all confidential)

This has been very informative. I really want to thank you for your time.

Do you have any friends who are home care nurses or social workers who you feel might be willing to be interviewed? (Get contact information if volunteer names)

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