
Whither Palliative Home Care Interventions for Alzheimer's Disease?
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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 (Federal Interagency Forum on Aging Related Statistics, 2004; Sadick & Wilcock, 2003). Alzheimer's 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).

Approximately 4 million Americans age 65 years and older had Alzheimer's disease in 2000, with prevalence increasing beyond age 65 (Sadick & Wilcock, 2003; Wimo, Winbald, Agüero-Torres, & von Strauss, 2003). This equates to 12.5% of the American aged 65 and older population in 2000, with projections at 14 million or 16.5% by 2050 (Federal Interagency Forum on Aging Related Statistics, 2004; Sadick & Wilcock, 2003). 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, and 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).

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 is also a major issue (Kennet, Burgio, & Schulz, 2000; Levine, 2000, 2003; O'Brien, 2004; Robert Wood Johnson Foundation, 2001). An estimated 70% of Alzheimer's patients live at home, where approximately 75% of care is provided by family members and significant others (McConnell & Riggs, 1999). Most caregivers report increased financial burden supporting the household and paying out-of-pocket health care costs. Caregivers' informal care reflects the dominance of personal and family responsibility in Alzheimer's care. Employers, government, and private insurers provide limited coverage to assist patients and caregivers dealing with the burdens of home-based care (McConnell, 2004; McConnell & Riggs, 1999; Society for Human Resource Management, 2003).

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 burnout may result in the patient's placement in an institution, though placement may not significantly reduce caregiver burden (Mittelman, Roth, Haley, & Zarit, 2004).

Alzheimer's disease is frustrating and burdensome because there is no known effective medical or pharmacological cure or treatment. Despite significant medical research on Alzheimer's disease (Albert, 2001; Santaguida, et al. 2004), there has been limited progress in effective medical and pharmacological diagnosis and treatment of Alzheimer's disease. Studies indicate no medical cure (Gauthier, 2002; Whitehouse, 2001) and little effective medical and pharmacological treatment (Evans, Wilcock, & Birks, 2004; Santaguida, et al., 2004). However, research indicates there are effective **non-pharmacological** interventions for improving both patient and caregiver symptom management, quality of life, and potentially financial burdens (Cohen-Mansfield, 2001; Mittelman, 2004; Schulz, et al., 2003).

Non-pharmacological and social interventions have varying effectiveness of improving patient and caregiver quality of life and symptom management (Cohen-Mansfield, 2001; Schulz, et al., 2003; Sloane, et al., 2002). Support groups, counseling services, and environmental assessment and modification services generate the most evidence of positive outcomes for both patients and caregivers, though there is evidence of benefits from recreational therapies, respite care, and other therapies (Cohen-Mansfield, 2001, 2004; Gitlin, Liebman, & Winter, 2003; Gitlin, Winter, Dennis, Corcoran, Schinfeld, & Hauck, 2006; Mittelman, 2002, 2004; Schulz, et al., 2003). Evidence supports that social and non-pharmacological interventions may reduce both caregiver and patient costs of medically-based home, community, or institutional care (Brumley, Enguidanos, & Cherin, 2003; Gage, et al., 2000; Newcomer, Miller, Clay, & Fox, 1999). A recent longitudinal study extends research further, asserting that social networks actually provide a

protective effect on cognition as pathology increases in Alzheimer's disease (Bennett, Schneider, Tang, Arnold, & Wilson, 2006).

Despite the empirical support for the benefits of home and community-based social services, the Medicare home health program does not cover such interventions (Fried, 2004; McConnell & Riggs, 1999). The Medicare home health benefit is the major home benefit in America's *medical model* health care policy. American health care policy relies on personal responsibility and employment-based health coverage, except for government coverage of the poor and elderly through Medicaid and Medicare (Hacker, 1997, 2002; Starr, 1984, 2004; Vladeck, 1997). The *medical model assumes* patient conditions are acute and can be treated and cured using medical technology, treatments, and drugs (Conrad, 1997; Dubos, 1959). 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). Some literature refers to the *medical model* as the *biomedical model*.

Medicare provides a limited home health benefit based on the medical model. The result for Alzheimer's disease patients and caregivers is that the Benefit addresses only specific acute medical problems of the patients (i.e., diabetes, wound care, cardiovascular problems). Management of patient psychological symptoms, which may cause and exacerbate medical problems, is not covered by the Benefit. Caregiver symptom management, which may limit caregiver ability to provide in-home care and support, also is not covered.

The Benefit is based on pre-requisite medical needs for homebound patients and was created to decrease hospital and nursing home costs (Mottram, Pitkala, & Lees, 2002; Vladeck, 1997). Eligibility requires patients be homebound; in need of skilled, part-time or intermittent nursing or physical therapy; have a condition with a finite and definite end point; and 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% national home health visits (Medicare Payment Advisory Commission, 2003, 2004). Social work historically represents 2% or less of home health visits (Medicare Payment Advisory Commission, 2003, 2004).

Non-covered services include case management; in-home companion, homemaker, live-in, and other personal care services; respite care; support groups and counseling; personal assistive devices; home and environmental assessments, modifications, and training; and other non-pharmacological interventions and therapies (Cherry, 1999; Greene & Feinberg, 1999; Lee & Cameron, 2004; McConnell & Riggs, 1999).

Ironically, palliative home care is covered for end-stage Alzheimer's disease and dementia patients and caregivers through the Hospice Medicare Benefit (HMB). In effect if you are dying from Alzheimer's disease you and your caregiver may receive palliative home care, but if you have early-mid stage Alzheimer's disease such care is not available. HMB, unlike the home health benefit, assumes treatment is not curative, and focuses on patient, caregiver, and family psychosocial and spiritual needs, symptom management, and quality of life (National Hospice and Palliative Care Organization, 2004a). Coverage includes respite care, pastoral care, and volunteer services as well as the six Medicare Home Health Benefit services. Social work is more extensive in hospice care, representing an estimated 10% of all hospice visits compared to approximately 2% of all Medicare home health visits (National Hospice and Palliative Care Organization, 2003b; National Association for Home Care, 2003).

Research Implications

There are three separate but related significant research gaps. *First* is that much of the research is based in institutional settings, such as nursing homes and residential care and assisted living facilities, where patients have moderate or severe dementia (Cohen-Mansfield, 2001; Zimmerman, et al., 2003), and adult day and medical day care facilities. 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). There are no studies of the quality of life and cost-effectiveness impact of palliative home care interventions with Alzheimer's disease patients and caregivers receiving Medicare home health care.

Second is that government-sponsored policy research has not tested the potential positive quality of life and cost reduction benefits for patients and caregivers and cost benefits for Medicare which are embedded in the research on palliative home care for the Alzheimer's disease population. Such research existed for palliative home care and end-of-life care in the 1970s. The research 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 demonstrative results were positive, leading to passage of the Hospice Medicare benefit and positive results have continued (Gage, et al., 2000; Mor & Kidder, 1985; National Hospice and Palliative Care Organization, 2004b, 2004c).

Third is that research has not 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. Research indicates no studies of 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. Research also reveals no studies of practice stakeholders opinions on whether and how Medicare home health policy, practice should be changed for the care of Alzheimer's patients and their caregivers.

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