Alzheimer’s Disease and Related Dementias in Managed Care: Patient and Caregiver Benefits

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Introduction

The effective and affordable management of healthcare for the elderly, specifically those with Alzheimer’s disease and related dementia (ADRD) is becoming increasingly important as the baby-boom generation ages and the number of elderly requiring continuing care swells. In addition, more than 5 million Americans have Alzheimer’s disease (AD), and by 2050 it is expected that as many as 16 million Americans will have the disease (Facts and Figures, 2011). Both directly and indirectly, the disease costs the nation $183 billion annually. Costs include those costs attributed to lost productivity and the poor health of caregivers for persons with AD. Caregivers not only suffer emotionally but also physically. Because of the toll of care giving on their own health, Alzheimer’s and dementia caregivers had $7.9 billion in additional health care costs in 2010 (Facts and Figures, 2011). The increasing prevalence of ADRD will affect virtually all health plans including those with Medicare Advantage plans, as well as Medicare itself and Medicaid. Managed care faces challenges, both now and in the future, to deal with the deleterious effects of the disease.
It has been suggested that the care for this population should emphasize the improvement of the coordination of services, particularly acute and long-term care, which is expected to lead to better patient outcomes, and recognition of the interconnectedness of housing, social support and health care (Gross, 2004). A review of the current scientific literature surrounding the care of persons with ADRD in managed health care is literature is presented here; specifically literature surrounding the issues of healthcare coordination for persons with ADRD and those that care for them, quality of life for both the patient and their caregivers and the empirical results of the coordinated care systems that have been evaluated in various settings. Improving the care management of ADRD is essential not only for patient and caregiver quality of life, but it is also critical for managing dementia-related healthcare costs.

Coordination of Care

From its inception, the philosophy of managed care has placed high value on health information and support services to prevent crisis episodes and excessive healthcare utilization and to help patients and caregivers cope emotionally with illness (Lasker & Committee on Medicine and Public Health, 1997). In one study, the investigators explore the outcomes of ADRD patients and family caregivers of an experimental partnership between a managed care health system and a community agency that provides information and support services (Bass et al., 2003). They found that caregivers participating in the partnership program (intervention) whose patients had not yet received a specific diagnosis had increased satisfaction with the managed care services, which is likely due to the evidence that has been found regarding the importance of formal ADRD diagnosis for the well-being of caregivers (Carpenter et al., 2008; Laakonen et al., 2008). The investigators also found that caregivers reporting that their patients
have more severe memory impairment are more satisfied with the services offered by the health plan; and in addition caregivers in the intervention group had a significant decrease in depression compared to the control group (Bass et al., 2003). The results of this study show that partnerships between managed care organizations and community agencies acting as care consultants maybe a promising strategy for improving care for ADRD patients and their caregivers, and particularly those patients who were lacking formal diagnosis.

An interdisciplinary take on ADRD care enables the focuses to shift on to the prevention of excess disability and quality of life promotion for the patient and requires a focus on the family or care giving community as the unit of care (Geldmacher, 2000). This is a departure from medicine’s traditional treatment focus being the disease and the patient as an individual.

Managing Alzheimer’s disease care in the era of managed care and managed Medicare is a special challenge. Alzheimer’s disease, which demands coordination of care from a variety of providers, is difficult to deliver in managed care where public systems of care, medical care, and psychiatric care may all be separated into different systems with different providers (Kettl, 2003). This potential disjoint in service provision can be the root of poor care.

In order to alleviate the negative consequences following behavioral outbursts among patients with dementia, a collaborative approach between the medical and behavioral departments of one managed care organization was developed (Aliberti et al., 2011). Because dementia is considered a medical condition (per the insurance benefits’ definition), perhaps admission under the medical benefit geropsychiatric unit could be authorized. By doing so these members may experience improved health outcomes under the specialized treatment of a geriatric psychiatrist; and the team believed that by developing this collaborative approach the
health plan would realize improved care outcomes while limiting inappropriate and inadequate hospital and emergency room utilization (Aliberti et al., 2011). Six months after the program began they found a significant reduction in subsequent hospital admissions, bed days and emergency room visits for this population which resulted in financial savings; and in addition both patient outcomes and patient/caregiver satisfaction was improved (Aliberti, 2011). Currently, there is no cure or disease altering treatment of ADRD (Facts and Figures, 2011), which makes the subsequent treatment of the symptoms and progression of the disease of utmost importance.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer’s and other dementias can significantly improve quality of life through all stages of the disease for individuals with ADRD and their caregivers both formal and informal (Voisin & Vellas, 2009). According to the Alzheimer’s Association, active management includes: appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan, coordination of care among physicians, other healthcare professionals and informal caregivers and finally the use of activity and support groups, adult day care programs and other supportive services.

Costs of ADRD Care

According to the U.S. Department of Health and Human Services (2008), many older people with ADRD have Medicare and their high use of hospital and other healthcare services translates in high costs for Medicare. For people with ADRD, aggregate payments for health care, long-term care and hospice are projected to increase from $183 billion in 2011 to $1.1
trillion in 2050; and Medicare and Medicaid cover about 70% of the costs of care (Facts and Figures, 2011). Business estimates of cost vary greatly from $67 billion annually in the United States to twice that amount (Koppel, 2002). Perhaps one reason for the paucity and variability of such data is that the full scope of the economic burden of this disease is not simple to quantify. This is likely due to a large indirect component of the costs especially unpaid caregiver time (Ernst et al., 1994). Although cost of care is woven throughout the literature in this area, and a number of current cost studies were found but for the purpose of this review, exclusive cost studies with managed were not reviewed in depth.

Medicare and Medicaid are now offering more managed care options. It has been suggested the availability of these options makes it more likely to be utilized by the current generations because of their life-long familiarity with managed care (Stefanacci, 2007; Linkins & Lloyd, 2000). Therefore, it is unlikely that managed care organizations (MCOs) will escape the increased prevalence and costs associated with ADRD (Rice et al., 2001). Opportunities exist through patient management programs targeted toward early detection and diagnosis, effective use of medications, control of co morbidities, and patient and family support to partially offset these costs while providing quality patient care (Rice et al., 2001). In one study done by Joyce and colleagues (2007), it was shown that the average total costs for AD patients were more than five-fold higher compared with controls ($28,262 vs. $5,880). These cost disparities are caused by the complexity and intensity of the treatment and prognosis of ADRD. By better managing the care of those who suffer from ADRD could alleviate some of these cost disparities and overall improve the quality of care.
Results of a randomized, controlled trial that utilized a coordinated, integrated disease management model for dementia care that involved 18 primary-care clinics, 408 patients with dementia aged 65 and older, 408 informal caregivers, and three health care organizations in southern California are discussed here (Vickrey et al., 2006). The research team embedded dementia-care guidelines in the program, which studied a patient population with a 79% Medicare managed care program enrollment rate. A key intervention in this 12-month trial included the utilization of MCO-employed and community-based specially-trained care managers (primarily social workers). In collaboration with the community agencies, they worked individually with each patient-caregiver dyad and used Internet-based care-management software for care planning and coordination. Patients who received the intervention reported higher care quality and had higher proportions that received community agency assistance than those who received usual care (Vickrey et al., 2006). Patient health-related quality of life, overall quality of patient care, care giving quality, social support, and level of unmet caregiver needs were better for participants in the intervention group than for those receiving usual care (Vickrey et al., 2006). These results emphasize the impact that coordinated care has on the quality of life and patient care.

One other randomized control trial done by Duru and colleagues (2009) calculated the intervention costs and the potential cost offset of that same care management intervention that improved the quality of dementia care. The intervention included that providers received standardized interactive educational seminars on relevant care issues such as the evaluation of acute behavior changes and a care manager was assigned to each patient-caregiver dyad in the treatment group. The care managers performed a structured home assessment, identified
problems, initiated care plan actions, and sent a summary to the primary care physician and other designated providers. Although their analysis of a dementia care management intervention did not demonstrate a significant cost offset (Duru et al., 2009), the intervention program did lead to substantial improvements in quality of care. Together, these results exhibit the benefits of a coordinated care program for those suffering from ADRD, specifically provider education, family inclusion and community-based service participation.

Fillit, Hill & Futterman (2002) conducted a retrospective analysis of administrative data for 1,366 patients with AD and 12,660 age-gender matched controls in a large Medicare managed care organization. Co morbid conditions were based on the diagnostic classifications from the Charlson comorbidity index (Charlson et al., 1987). Health care costs and utilization for MCO covered services for cases were compared to controls. They also used presence of complications of AD associated with later-stage disease to classify patients as being early-stage or late stage Alzheimer’s disease. After controlling for a variety of factors, they found that annual costs were $3,805 higher for AD patients resulting in excess costs of $5 million to the managed care organization. Utilization costs for AD patients were higher compared to controls and were substantially higher for patients with both AD and co morbid diseases commonly targeted for disease management and earlier stage AD and pharmacotherapy were associated with lower costs (Fillit, Hill, & Futterman, 2002). These findings, along with the findings of the two RCTs indicate that better treatment and care management of AD could reduce the costs of co morbid conditions commonly suffered by AD patients and consequently their care givers and families as well as improve the health-related quality of life for these people and their families.

PACE
The Program of All-Inclusive Care for the Elderly (PACE) is a unique model of care providing a full spectrum of health care services, from primary to acute to long-term care for the frail elderly certified to require nursing home care (Gross et al., 2004). It is a capitated benefit authorized by the Balanced Budget Act of 1997 that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. For most participants, the comprehensive service package permits them to continue living at home while receiving services rather than be institutionalized. Capitated financing allows providers to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems.

Using risk-adjustment models, one study of PACE found substantial variation across 28 PACE sites in terms of performance, but no correlation between performance outcomes with respect to health outcomes such as mortality, change in functional status and self-rated health (Mukamel et al., 2004). This lack of correlation between performance measures for different outcomes has been found in other settings as well; nursing homes (Mukamel & Brower, 1998), hospitals (Rosenthal, 1997). Taking these findings together points to the notion of a multidimensionality of quality of care; meaning that there may be other processes of care that lead to different outcomes.

Although PACE is a unique program in that it provides comprehensive services addressing all the needs of a frail and older population, the lessons learned from PACE might offer useful insight to the coordination of care in other programs serving frail populations like the ADRD population. The integration of acute and long-term care has been envisioned as one of
the key steps in improving care for those with co morbid chronic conditions and complex care needs (Mukamel et al., 2007), which could include those with ADRD diagnoses.

One study examined the strength of the associations between 5 measures of need that are potentially modifiable in degenerative dementia patients and direct costs of care from 5 payer perspectives in the US healthcare system. The investigators measured the need variables at baseline and utilization of healthcare in the year before and after baseline. From Medicare's perspective, co morbid medical conditions were the most important predictor of Medicare costs. From Medicaid's perspective, neuropsychiatric symptoms and signs of Parkinson’s disease were additional significant predictors. From the perspective of patients, their families and society, all of the need variables were significant predictors of direct costs (i.e., cognitive impairment, and dependency). The relationship between evaluated need variables and direct costs depends on the perspective of the payer and provides insight into which need variables could be targeted with interventions to control costs and improve patient outcomes (Murman et al., 2007).

Based on data from Massachusetts Medicaid nursing home database, O’Brien & Caro (2001) found that on average a resident with ADRD requires 229 more hours of care annually than a resident without dementia, which also resulted in an average additional $3,865 per patient with dementia per year. One other research study done on PACE identified program characteristics that were associated with better risk-adjusted health outcomes (Mukamel et al., 2007). The authors found that persons enrolled in programs whose medical director was a trained geriatrician had better functional outcomes; and those whose medical directors spent some time in direct patient care and more time in general in PACE (i.e., higher FTE) were associated with
better functional outcomes. These findings suggest that the medical director may play an important role in an all-inclusive managed care program like PACE, even though many of the program’s services are not medical (i.e., home and personal care). The authors also found that higher staffing levels were associated with better self-rated health (Mukamel et al., 2007); it may be that higher staffing allows for more time with patients and increased interaction time may influence patient’s well-being and thereby rating their health as better. Overall it is important to note that program features of a coordinated care program like PACE do seem to matter in terms of patient health. The PACE model of care relies on interdisciplinary teamwork for both planning and delivering care (Temkin-Greener et al., 2004). This interdisciplinary team of care is necessary for the health care quality of patients suffering from ADRD and the well-being of their families.

Temkin-Greener and colleagues (2005) examined the process of advanced care planning in managed care programs serving the frail elderly and assessed the contributions of individual characteristics versus program characteristics on choices made. Data came from nine PACE sites and regressions further examined the association between independent variables and end-of-life treatment choices (Temkin-Greener et al., 2005). Results showed that after all patient characteristics are accounted for, substantial amount of variation attributable to the program-indicators remains. Differences in program attributes explained 36% of the variation in the do-not-resuscitate choice, 66% in the choice of artificial feeding, and 50% relating to the presence of health care proxies. The variation in treatment choices attributable to the program of enrollment suggests that provider practice styles are important in determining patients’ choices at the end of life. Yet again, the role of the provider in terms of managing the care of the patient
should be a target of future interventions surrounding advance care planning. Further, because PACE already promotes facilitating discussion among various care providers and shifting planning from hospitals to the community—it provides an excellent laboratory for exploring issues related to managing the care of ADRD patients.

**Role of Primary Care**

Until 2006, most state Medicaid programs had open formularies, and access to dementia medications was not an issue (Stefancci, 2007). More recently however, 80% of older adults who previously did not have prescription coverage are now enrolled in Medicare Part D (Neuman et al., 2007). Ensuring that ADRD patients select the right plan for optimal access to medication is an important aspect of care management. However, a 2006 survey by Novartis revealed a lack of understanding of Medicare Part D among clinicians (Piturro, 2006; Pettey, 2006). This study also showed that clinicians (medical doctors, directors of nursing, pharmacists and nurse practitioners) had the most difficulty gaining access to dementia medication compared to any other drug classes.

Despite the evidence about the appropriate management of ADRD, evaluations of the quality of care provided by primary care physicians has suggested that care is poor. For example, only 35% of recommended care processes (quality indicators) for dementia are performed (Wenger, 2003). When examining the deficiencies in quality of care physicians appear to be more confident managing the medical components of treatment than with the counseling/education aspects of dementia care (Wenger, 2009) which due to the fact that ADRD is without a cure and treatment plans are limited are very important aspects of the medical
treatment plan. In support of the “chronic care model” which posits that linking medical and community base services is of utmost importance in successful health care provision; Reuben et al. (2009) reviews the potential benefits of physicians referring to local Alzheimer’s Association chapters as a way of improving ADRD care. The author suggests that many physicians are unaware of the services available through the association’s chapters, but recognize the need to provide support to families, ensure patient safety, and manage behavioral problems. At present, systems to promote referrals and communication with local chapters are lacking. Practice redesign may facilitate linkages between practices and Alzheimer’s Association chapters. However, if these linkages are to be adopted and sustained they must demonstrate a relative advantage to doctors beyond the care they currently provide, and must be compatible with how care is currently delivered (Reuben et al., 2009). From a healthcare system approach, physicians are in a unique place to help family caregivers reduce risks of adverse outcomes by carefully explaining the dementia disease process advising how to manage symptoms as they occur and linking caregivers with appropriate support services (Maslow, 1990). And as the majority of care provided at home is provided by the families, it is important component of any successful managed care ADRD treatment program to not only engage family caregivers but to continue post-acute care in gaining the needed supports from community-based and other support services.

End of Life

Regardless of ADRD diagnosis, end-of-life care can be the most intensive, emotional and complex of treatment for all people with chronic illness. Long-term care facilities are increasingly faced with caring for patients at the end of life. Some data have demonstrated that
only 1% of dementia patients were assessed to be at end of life admission, yet more than 70% of patients died within 6 months (Mitchell, Kiely & Hamel, 2004). Thus, clinicians must efficiently identify the symptoms and stage of ADRD that signals the end of life in order to adjust care and treatment accordingly. Termination of AD medication is complex. In theory, when a patient is dependent for all activities of daily living, mute, incapable of walking and is essentially in the terminal stage of dementia, it is considered an appropriate time to stop ADRD drug regimens and start palliative care (Stefanacci, 2007). However, heightened surveillance of patient responses after cessation of dementia medication is essential. If behavioral symptoms emerge that significantly compromise the patient’s quality of life, resumption of medication could be considered. Yet it is also worth noting that what a family member finds beneficial and what the clinician finds beneficial are not always similar; therefore it is important to have open discussions with family members to ease the transition. Despite the epidemic of ADRD diagnoses in recent years; in many clinical settings ADRD remain undiagnosed. Early detection in addition to the use of non-pharmological interventions and dementia-related drug regimens can delay cognitive and functional decline, resulting in improved patient outcomes and reduced caregiver burden (Stefanacci, 2007). Together, these practices may also postpone institutionalization and reduce costs.

Patient Quality of Life

Prior research has shown that dementia is often undiagnosed in primary care; and research has emphasized the importance of a clinical diagnosis of ADRD to quality of life for both patient and family (Facts and Figures, 2011). Studies in primary care have settings have shown that only 12% to 41% of people with dementia have a dementia diagnosis or other
indication of dementia in their primary record (Boise et al., 2004; Ganguli et al., 2006). Measuring quality of life in people with ADRD is difficult and in many cases not done often (Maslow & Heck, 2005).

One study of assisted living residents with dementia found an association between better resident perceptions about their own quality of life and greater staff involvement in care planning (Zimmerman et al., 2005). An association between better nursing assistants’ perceptions of residents’ quality of life, the nursing assistants’ positive attitudes about person-centered care and their positive evaluation of the adequacy of their training about dementia care and they found an association between staff members’ confidence in their ability to provide good dementia care, positive attitudes about person-centered care and higher self-reported job satisfaction (Zimmerman et al., 2005). Although these findings are a result of a cross-sectional design, one component was longitudinal. The change in staff perceptions of resident’s quality of life during a 6-month period, found less decline in quality of life for facilities that had more staff training centered around dementia care and more frequent activities and staff encouragement of resident participation in activities (Zimmerman et al., 2005). An association has been found between greater involvement of families of the patient with ADRD and greater resident participation in activities (Dobbs et al., 2005). These findings suggest that the inclusion of the family is one integral aspect of managing ADRD care.

Dementing diseases like ADRD present particular challenges because there can be strong social and behavioral components to disease management. In one pre-post design study, behavior change was assessed by medical record review and both provider and patient satisfaction with care was assessed via a survey; the intervention was the dissemination of a series of ADRD
treatment guidelines surrounding the assessment, treatment, patient/caregiver education and support and reporting requirements (Cherry et al., 2004). Results showed that compared with baseline measurements, higher rates of provider and caregiver satisfaction with the system of dementia care were found at the post-intervention follow-up (Cherry et al., 2004). Managed care organizations offer some unique possibilities for quality improvement in dementia care and this study highlights the provision of communication lines for dissemination of treatment guidelines.

Managed care and consumer-directed care have both been identified as potential mechanisms toward providing services more efficiently (Grabowski, 2005). One study of Medicare recipients in three San Diego-based healthcare organizations was done to describe the quality of dementia care and to investigate associations between variations in quality and patient, caregiver, and health system characteristics (Chodosh et al., 2007). Using caregiver surveys and medical record abstraction to assess 18 dementia care processes drawn from existing guidelines, the authors found that there was vast variability among the different care processes and that caregiver knowledge was associated with higher quality of care in three out of four dimensions (Chodosh et al., 2007).

Research findings have been mixed on the impact of anosognosia (unawareness of deficit) among ADRD patients. Several studies have found increased anosognosia as a function of disease severity (Michelet et al., 2007; Starkstein et al., 1997). However, other studies have found no relationships between anosognosia and the severity of cognitive deficit (Gil et al., 2001; Michon et al., 1994). Meanwhile, Al-Aloucy et al. (2011) investigated the impact of anosognosia in ADRD patients on professional health care burden. Their findings showed a significant positive correlation between the measure of health care burden and patients’ unawareness of deficit; however they found no significant correlation between the severity of the burden and the
severity of cognitive decline or functional impairment (Al-Aloucy et al., 2011). Anosognosia in ADRD patients has a negative impact upon caregiver burden above and beyond the cognitive deficit and functional impairments. Yet another factor contributing to the burden of ADRD caregivers is identified, emphasizing the importance of therapeutic strategies aimed at improving the capacity to cope with ADRD caregiving.

Many persons with ADRD have other serious co morbid conditions (McCormick et al., 2001). These other medical conditions and the medications and treatments used for them can worsen cognitive status or exacerbate other symptoms of dementia. Likewise, dementia can complicate the treatment of other medical conditions (Maslow, 2004). People with dementia and other serious conditions are likely to use acute medical care often and in all stages of their ADRD illness. They come into the emergency room or are admitted to a hospital or intensive care unit for treatment of the coexisting condition (Maslow, 2004) which becomes quite costly to both families and providers.

Caregiver Quality of Life

Caregiving is not a new phenomenon. Before the enactment of Social Security and Medicare, family members were the primary and often only source of support for disabled elderly people. What has changed in the last half-century is the number of individuals involved in caregiving, the duration of the caregiving role, and the types of caregiving tasks performed. Because of increases in life expectancy and the aging of the population, the shift from acute to chronic diseases and their associated disabilities, changes in healthcare reimbursement, and advances in medical technology, caregiving has become commonplace. Currently, 80% of care
provided to persons with ADRD at home is delivered by family caregivers (Facts and Figures, 2011). For some individuals, the care giving role lasts many years, even decades, and caregivers are increasingly being asked to perform complex tasks similar to those carried out by paid health or social service providers. Caregivers play a critical role in the diagnosis and treatment of patients with dementia. Because caregivers have around-the-clock access to patient behavior and the knowledgebase to identify significant changes in patient functioning, they serve as a critical source of information for the clinical assessment of the patient. Also, treatments and behavioral interventions for the patient are typically implemented by the caregiver, who has day-to-day contact with the patient.

There is strong consensus that caring for an elderly individual with disability is burdensome and stressful to many family members and contributes to psychiatric morbidity in the form of higher prevalence and incidence of depressive and anxiety disorders (Schulz & Martire, 2003). Researchers have also suggested that the combination of loss, prolonged distress, physical demands of care giving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems. Support for this hypothesis is found in studies showing that caregivers are less likely to engage in preventive health behaviors (Schulz et al., 1997) that they show evidence of decrements in immunity measures when compared with control subjects (Glaser & Kiecolt-Glaser, 1997) and exhibit greater cardiovascular reactivity (King et al., 1997) and slowing of wound healing (Kiecolt-Glaser et al., 1995). In one recent cross sectional study of primary caregivers, it was found that compared with non caregiver’s primary caregivers reported worse health, more doctor visits, anxiety and depression, and weight loss (Ho et al., 2009). Overall, the
convergence of evidence from these studies indicates that a meaningful risk for adverse psychiatric and physical health outcomes exists for a subgroup of caregivers who sustain high levels of caregiving demands, experience chronic stress associated with caregiving, are physiologically compromised. Because of the toll of caregiving on their own health, Alzheimer’s and dementia caregivers had $7.9 billion in additional health care costs in 2010. More than 60 percent of family caregivers report high levels of stress because of the prolonged duration of caregiving and 33 percent report symptoms of depression (Facts and Figures, 2011).

One study investigates the effects of Alzheimer’s Association care consultation delivered within a partnership between Kaiser Permanente of Ohio and the Cleveland area Alzheimer’s Association on both the utilization of managed health care services and psychosocial abilities to deal with memory problems among a population of patients (Clark et al., 2004). The authors examined the effects of a participant-based form of managed care. This study used a 12-month randomized controlled investigation of the effects of care consultation with the person with AD on his or her psychosocial well-being and appropriate use of health care resources. The care consultation process involved the person with AD in the assessment of all of the participants’ strengths, including caregivers, and needs. After the assessment, the care consultant, together with the participant, devised a plan of care for treatment of their AD, referring the person to Alzheimer’s Association services and traditional health care services. The control group did not receive care consultation but had access to all traditional resources of the Alzheimer’s Association and the health care community; however, they had to seek these services themselves. Findings suggested that the treatment group participants felt less isolated because of their disease and experienced significantly less difficulty in coping with memory problems than did the
control group. Regarding outcomes for the treatment group, participants with more severe impairment (yet still living in the community) had fewer physician visits, were less likely to have an emergency department visit or hospital admission, and experienced less depression and strain (Clark, 2004). In tandem, these findings show that interdisciplinary managed care of ADRD not only helps caregivers but actually facilitates care giving actions.

The National Institute on Aging/National Institute of Nursing Research Resources for Enhancing Alzheimer’s Caregiver Health (REACH) developed one of the first national clinical translations of a proven behavioral intervention for dementia caregivers. The intervention is structured through a protocol and individualized through a risk assessment, targeted education, support and skills training to address care giving risk areas of safety, social support, problem behaviors, depression, and health through 12 individual in home and telephone sessions and 5 telephone support group sessions (Belle, 2006). Results of a randomized controlled trial showed clinically significant benefits for caregivers including decreased burden, depression and impact of depression in daily life, care giving frustrations and a number of troubling dementia related behaviors (improved activities of daily living etc.) (Nichols et al, 2011).

Social support and Community Services

A growing interest in expanding home and community-based services (HCBS) funding recently has been rationalized by the ideas that individuals generally prefer care in the home or community and that for many people with less intensive care needs (early stage ADRD) it may be possible to provide lower per capita cost care in the home or community as opposed to a nursing home (Grabowski, 2005). However, research indicates there are effective non-
pharmacological interventions for improving 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 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, environmental assessment and modification, and skills building interventions generate the most evidence of positive outcomes for both patients and caregivers, although there is evidence of benefits from recreational therapies, respite care, and other therapies (Cohen-Mansfield, 2001, 2004; Gitlin, Liebman, & Winter, 2003; Mittelman, 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 et al., 1999).

In a recent study of caregiver needs and service utilization, Peeters et al. (2010) found that almost all informal caregivers (92.6%) received some professional support. However, two thirds (67.4%) indicated they had one or more unmet needs for additional professional support. Informal caregivers often needed additional professional advice about what to do when their relative is frightened, angry or confused. Spouses reported different needs than sons or daughters (in-law): spouses relatively often need emotional support and adult children more often need information and coordination of dementia care. Future support programs, e.g. in the field of care management, should address the specific needs of informal caregivers.
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 HCBS, the Medicare home health program does not pay for 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; Vladeck, 1997). The medical model assumes that patient conditions are acute and can be treated and cured using medical technology, treatments, and drugs (Conrad, 1997). The medical model dominates research on the definition, diagnosis, cause, prevention, treatment, and cure of Alzheimer's, focusing primarily on pharmacological interventions (Whitehouse, 2001). 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, etc.). Management of patients’ psychological symptoms, which may cause or exacerbate medical problems, is not covered by the benefit. Caregiver symptom management is not covered.

Failure to treat caregiver symptoms may limit caregiver ability to provide in-home care and accelerate costly institutional placement. Uncovered 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) The research evidence indicate a dissonance between client needs, existing research on interventions, and Medicare home health policy for persons with Alzheimer's disease and their caregivers. The evidence indicates that the result is significant unmet client and caregiver needs and a high cost to clients, caregivers, and the program (Cabin, 2008). Supportive services are available in many communities, but the patient and their family may not be aware of these services or understand how the services relate to their individual needs. Adult day services can help to keep persons with dementia safe in the community.

There is a wide difference among states in terms of Medicaid waiver expenditures than with total long-term care expenditures for older Americans (Kane et al., 1998; Miller, Ramsland, & Harrington, 1999). These differences contribute to documented differences in service access and availability. Specifically, HCBS waivers are required by federal policy to be budget neutral with respect to nursing home expenditures. Studies in Colorado, Oregon, Washington and Wisconsin have concluded that HCBS service expansions were cost effective when coupled with decreased institutional capacity (Grabowski, 2006).

Many studies have documented the considerable strain that informal, nonprofessional caregivers experience when managing behavioral problems of persons with ADRD (Connor, 2006). In order to develop services that best support care management activities for informal caregivers, one study attempted to identify activities that were most strongly related with two important dimensions of caregiver strain: caregiver mastery as a positive dimension and relationship strain as a negative dimension (Connor et al., 2008). An exploratory analysis of secondary care management processes and caregiver outcomes data from the intervention arm of a clinic-level randomized controlled trial of a dementia care management quality improvement
program was conducted among 238 patient-caregiver pairs. Care management activity types extracted from an electronic database were used as predictors of caregiver mastery and relationship strain, which were measured through mailed surveys. They found that home assessments for specific needs of caregivers and persons with ADRD are associated with improvements in caregivers’ sense of mastery; highlighting the importance of integrating the health of the caregiver into the management of care for ADRD patients.

Implications of Diagnosis

One study examined the utility of guidelines for the diagnosis and treatment of dementia by different sub-specialty clinics (Kalkonde et al., 2009). They found that in a sample of 410 charts of dementia patients that were seen by neurologists, mental health professionals, geropsychiatrists, and geriatricians 40% of patients received a complete laboratory work-up to rule out co morbidities, 70% of patients received neuroimaging, 63% had a depression screen and 38% of patients underwent neuropsychological testing. The frequency with which they were obtained differed significantly across clinics. These significant differences between subspecialties in the evaluation and treatment of ADRD patients could be due to variability in the knowledge about the guidelines for evaluation of dementia, disagreement with guidelines or development of practice patterns based on personal experience (Cabana et al., 1999). Whether such differences produce different patient outcomes is yet to be determined in the literature; however, these findings suggest a need for consensus among subspecialties on the optimal investigation and treatment of ADRD as well as educating physicians about guidelines.
Lapses in the quality of medical treatment can occur during the transition between services supplied by separate facilities and providers. This can lead to the duplication of expensive tests or the omission of important services, and possibly ineffective follow-up care. It has been suggested that optimal care for patients with ADRD requires coordinated, integrated care that focuses on the physical and mental well-being of both the ADRD patient and his or her caregiver (Gorshow, 2007).

A panel of leading experts was compiled to develop consensus recommendations for the treatment and management of dementia based on currently available evidence and the panel’s informed expert opinion (Fillit et al., 2006). The panel was comprised of 12 leading experts including clinical investigators, geriatric medicine practitioners, neurologists, psychologists, psychiatrists, managed care medical and pharmacy directors, a health systems medical director and a health policy expert. Disease management programs have been developed for many chronic diseases and provide the greatest opportunity for managed care organizations to better manage dementia (Fillit et al., 1999). Frytak and colleagues (2008) assessed the disease burden of ADRD in a commercial managed care setting by comparing direct health care costs and adverse life outcomes between patients with and without ADRD. They found that ADRD patients had generally higher health care costs and higher risk of acute adverse outcomes than the control cohort (Frytak, 2008). Similar to results of comparative studies with Medicare data, the disease burden is greater for patients with AD compared with a matched control cohort, with a different mix and a greater number of co morbid health care conditions partially accounting for this difference. As membership in commercial and Medicare managed care plans increases, plans
will need to develop effective mechanisms to manage the health care of high risk, high cost
patients with ADRD.

In one study of primary care physicians, structural barriers to mental health specialists
and consequences of these barriers to care for patients with dementia and neuropsychological
symptoms and their primary care physicians were described in 40 qualitative interviews with
primary care physicians in Northern California (Franz et al., 2010). Ninety-three percent of the
physicians described problematic access to and communication with mental health specialists (in
particular psychiatrists and neuropsychologists) as impediments to effective care for ADRD
patients. The physicians viewed problems created by difficult referral systems, such as separate
managed behavioral health organizations as particularly burdensome for elderly patients with co
morbid dementia and mental health problems (Franz, 2010). These problems were cited by
physicians across different types of practice settings and they reported treating the
neurobehavioral symptoms as best they could despite lack of specialist support (Franz, 2010).
These results infer the need of a more coordinated system of care providers.

In another study it was shown that health management organizations (HMOs) provide the
advance directive information required by the Patient Self-Determination Act in written form
within new member packets; but after enrollment the dissemination of information on advance
directives becomes “spotty” (Karp, 2000). This study shows that providers don’t want to bring
the topic to surface and it is not the first priority for doctors; but because patients with early stage
AD and mild dementia retain the capacity to make an advance directive, it is important to
identify a way for the provider, physician and patient to discuss advance directives. In order to
determine the effect of an ADRD diagnosis on Medicare Expenditures at the end of life,
Medicare payment data for the 5 years before death were used to compare 5 year and 6 month intervals of expenditures for persons with and without an ADRD diagnosis (Lamb, Sloan & Nathan, 2007). Their results suggest that long-term (1+year) ADRD diagnoses do contribute to greater total Medicare costs at the end of life. Together these findings portray the importance of a formal diagnosis in regards to treatment and cost of the illness.

Conclusion

ADRD patients represent a clinical and economic burden to individuals and society, including managed care organizations. Appropriate use of anti-dementia therapy and care management is important to achieving quality of life and care for dementia patients and their caregivers (Fillit et al., 2006). Incorporating ongoing medical and non medical care management including family and caregiver information and support could encourage more consistent identification and assessment of people suffering from ADRD and may also change the perception of hopelessness that so often accompanies ADRD diagnosis (Maslow & Selstad, 2001). Although such partnerships are encouraging, the maintenance of these efforts requires the discovery of inter-organizational approaches that are most effective in coordinating care but also the independent activities required to support care coordination for patients and their families (Coon et al., 2004). Over time, this could result in a system of care that reduces negative consequences of ADRD, specifically the negative consequences that are brought on by inefficiencies or deficiencies in care, for people with the disease as well as their family caregivers.
Based on the current scientific literature, it appears that moving towards an integrated model of care for serving such a vulnerable and costly population (older adults with ADRD) with demonstrated efficacy and cost-effectiveness is going to provide the highest quality of care for patients and their families. Many people with ADRD and their families are unaware of information, programs, and services; and in some cases needed programs and services are not available in all communities and even when they are available the complexity and fragmentation of the service environment and the lack of public funding hinder access for some (Maslow & Selstad, 2001). The literature and research evidence presented here illustrates a disjoint in the patient and caregiver needs and the current availability and quality of care. The evidence further indicates that the result is significant unmet client and caregiver needs and a high cost to clients, caregivers, and the medical and insurance providers.

References


Alzheimer's Disease and Related Dementias in Managed Care


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