



**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

CARE COORDINATION FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS: LITERATURE REVIEW

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CARE COORDINATION FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS: Literature Review

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EXECUTIVE SUMMARY

Alzheimer's disease is an irreversible, progressive form of dementia that affects more than 5 million Americans (HHS, 2012). It slowly destroys memory, thinking skills, and eventually the ability to perform activities of daily living (ADLs). People with Alzheimer's disease are often reliant on others for their daily care and are heavy users of medical care and long-term services and supports (LTSS) (Tilly et al., 2011). Over 40 percent of nursing home residents have a diagnosis of dementia or Alzheimer's disease. As a result, Alzheimer's disease has an enormous impact on both affected individuals and their caregivers.

Given the projected growth of the elderly population and the high prevalence rate of Alzheimer's disease among older Americans, the number of affected individuals is expected to increase by 40 percent between 2000 and 2025 (Alzheimer's Association, 2013). People with Alzheimer's disease depend heavily on Medicare and Medicaid to finance their LTSS and medical services. An increase in the prevalence of Alzheimer's disease will increase the demand for care and Medicare and Medicaid expenditures.

People with Alzheimer's disease frequently need care from a wide range of providers, from nurse aides and home health care workers to geriatricians and psychiatrists, but care is often provided in a fragmented and uncoordinated fashion (Alzheimer's Association, 2013). Care coordination has the potential to address the multidisciplinary needs of people with Alzheimer's disease and informal caregivers and improve health outcomes for both parties. It may also reduce Medicare and Medicaid expenditures by eliminating unnecessary care and by encouraging services that keep people healthier. Care coordination is a widely used but ill-defined term. For people with Alzheimer's disease, a care coordinator typically is assigned to a person/informal caregiver and becomes responsible for managing services for the person with Alzheimer's disease, providing support to their caregivers and coordinating the use of medical care or LTSS.

The goal of this literature review is to better understand existing care coordination models for people with Alzheimer's disease and related dementias and the effects of these programs on outcomes, including use of medical care and LTSS, expenditures, and psychosocial outcomes such as quality of life on people with Alzheimer's disease and their caregivers. The reviewed studies used different terminology to refer to the intervention, including case management, care management, disease management, and care coordination. For the purposes of this review, we use the term care coordination to refer to all of the interventions. We particularly focus on the coordination of medical care and LTSS.

SUMMARY OF PREVIOUS REVIEW ARTICLES

This review builds on previous examinations of the research literature on the effect of care coordination on people with Alzheimer's disease and their caregivers.

Pimouguet et al. (2010) recently published a systematic review of eight randomized controlled trials (RCTs) of case management for people with dementia and their caregivers, concluding that the evidence is weak in terms of cost and resource usage. They suggest that future research should focus on which subgroups of patients are most likely to benefit from case management (such as those with multiple comorbidities, frailty, social isolation, or complexity).

Koch et al. (2012) reviewed seven studies (observational and RCTs), with a slightly more optimistic conclusion. They cite two long-term studies that found that care management delayed admission to nursing homes. They urge that future research use a common definition for care coordination, look at people with Alzheimer's disease and caregiver quality of life, and follow participants for longer periods. They also advocate for a more inclusive approach to measuring cost-effectiveness, in which costs and benefits are evaluated from the societal perspective and take into account such outcomes as work and leisure time and caregiver health and well-being (Koch et al., 2012).

Somme et al. (2012) conducted another recent review of six RCTs of case management programs for patients with Alzheimer's disease and other dementias. The authors analyzed the intensity of the intervention using Pacala's scale (1995), which rates the intensity of care management according to a number of criteria. Somme et al. (2012) concluded that there appeared to be a correlation between case management intensity and outcomes. The two programs that were determined to be intensive reported at least moderate clinical effects. In addition, one medium-intensity intervention reported a moderate effect on resource utilization, and the three low-intensity programs reported slight effects.

LITERATURE REVIEW METHODS

We conducted literature searches in PubMed, Web of Science, Scopus, Cochrane, and Ageline using the keywords “Care Coordination” and “Case Management,” focusing on health care or long-term services and supports (LTSS) settings, and limited to persons with dementia or Alzheimer’s disease. Searches in PubMed combined the MeSH term “Alzheimer disease” with the above keywords.

Publications were limited to articles published in the year 2000 or later and written in English. Abstracts and titles were reviewed and articles meeting the following criteria were included:

- An RCT or observational study.
- A sample population in which at least 75 percent had Alzheimer’s disease or a related dementia.
- A defined statistical analysis.
- An intervention that targeted either the person with Alzheimer’s disease/caregiver dyad or the person with dementia and involved some kind of care coordination (medical, LTSS, or both).

We netted a total of 60 articles from the electronic bibliographical search. Based on examination of the titles and the content of their abstracts, 29 articles were excluded as not appearing to meet our criteria. Full texts of the remaining 31 were obtained and reviewed. A hand search of these 31 articles identified nine additional articles. A total of 13 interventions (described in 16 articles) that met our selection criteria were included in the final analysis. Nine of the studies included in this review were RCTs, whereas four were observational studies. Seven of the studies took place in an international setting, and the remaining six took place in the United States. Only care management programs that explicitly targeted people with Alzheimer’s disease were included. The included studies are summarized in **Table 1**.

TABLE 1. Summaries of Included Studies of Care Coordination for People with Alzheimer's Disease and Their Caregivers

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Bass et al. Clark et al.	2003 2004	Kaiser Permanente of Ohio, Managed Care	<ul style="list-style-type: none"> 157 participants with either a specific diagnosis or symptom code for memory loss. 	<ul style="list-style-type: none"> Intervention: A 1-year telephone-based care coordination focusing on education & coordination community-based services. Families were randomly assigned to either the care coordination services (intervention) or typical managed care services (control). <u>Care Consultant:</u> Representative from Alzheimer's Association (majority social workers). All services were provided free of charge. 	<ul style="list-style-type: none"> Reduction in depression (slope = -0.12, p ≤ 0.05), as measured by modification of CES-D. Those using other Alzheimer's Association services in combination with care coordination showed reduced health deterioration (slope = -0.33, p = 0.03) & role captivity (slope = -0.51, p = 0.02). 	NA	<ul style="list-style-type: none"> Fewer health services [Kaiser care coordination (p ≤ 0.01, OR = 0.18) & direct care community services (p ≤ 0.10)] There was no significant difference in emergency department visits, hospital admissions, & physician visits between groups
Callahan et al.	2006	Two primary care practices within a university-affiliated health care system.	<ul style="list-style-type: none"> 135 participants from either a community-based health system serving the medically indigent or a primary care practice within a Veterans Affairs (VA) Medical Center. Most participants had multiple comorbid chronic conditions & were socioeconomically disadvantaged. Dementia evaluated & confirmed according the Diagnostic & Statistical Manual of Mental Disorders, third edition. 	<ul style="list-style-type: none"> A 12-month collaborative care coordination program which incorporates 10 published Alzheimer's disease treatment guidelines into the improvement of participant behavioral & psychological symptoms. <u>Care Coordinator:</u> Geriatric Nurse Practitioner. No mention of payment method. 	<ul style="list-style-type: none"> Significant improvement in caregiver stress (Neuropsychiatric Inventory [NPI]) at the end of the intervention but not at 18 months (p = 0.03, difference of -2.2 on NPI). Improved caregiver mood at 18 months (Caregiver Patient Health questionnaire, improvement of 1.6 points, p = 0.02). 	<ul style="list-style-type: none"> Improved NPI which persisted 6 months after the intervention (p = 0.03, Difference of -5.6 on NPI). No significant change in depression (Cornell Scale for Depression in Dementia), cognition (telephone interviews for cognitive status) or function (Alzheimer's Disease Cooperative Study ADLs). 	<ul style="list-style-type: none"> Intervention participants reported more nursing and primary care visits (mean visits 9.3, p = 0.03). No difference in hospitalization or nursing home placement.

TABLE 1 (continued)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Challis et al.	2002	Community mental health teams for the elderly in the United Kingdom. Mostly home visits.	• 43 pairs (Cases & Control) with a diagnosis of dementia & a perceived risk of institutionalization.	• <u>Intervention:</u> A 2-year care coordination program incorporating both health and community-based LTSS. • <u>Care Coordinator:</u> Social Worker. • Quasi-experimental design which matched participants from 1 mental health team that provided care coordination to a team that did not provide care coordination. • Social workers had a budget to purchase care.	• Greater reduction in input hours (-9.60), felt burden (-1.46), overall needs (-4.22), & risk (-0.64) associated with certain activities (ADL assistance, personal care) ($p < 0.05$). • No difference in objective burden, malaise (stress), & strain.	• More individuals in the care coordination group remained in their homes & were not displaced compared to individuals in the comparison group after 2 years (51% vs. 33%) with divergence beginning after 18 months. • Less dissatisfaction with home environment after 6 months (-0.67, $p < 0.05$), & improved social contacts (7.44, $p < 0.05$, based on caregiver response). • No significant differences in frequency of activities at home, dependency (CAPE), & depression (CARE schedule).	• Compared to the intervention group, the comparison group received more visits from the mental health team (4.2 days/year) & less home health care (8.6 days/year) ($p < 0.001$). • The experimental group spent more on social services (\$4,139) & professional visits (\$1,344) compared to controls ($p < 0.001$). • Overall, there was no difference in costs to society.

TABLE 1 (*continued*)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Chu et al.	2000	Participants recruited from outpatient clinics in a Northern Alberta geriatric program & referrals from area physicians. The intervention was provided via monthly telephone calls & home visits.	<ul style="list-style-type: none"> 75 pairs of caregivers & clients. Diagnosis of early Alzheimer's disease done by referring physicians & project coordinator using criteria from both the National Institute of Neurological & Communicative Disorders & Stroke & the Alzheimer Disease & Related Disorders Association. No concomitant disease or risk of institutionalization. 	<ul style="list-style-type: none"> <u>Intervention:</u> An 18-month home care intervention focused on preparing families with Alzheimer's disease through education & supportive counseling, & early planning for LTSS. Participants were randomly assigned to either the Home intervention or Control (an information package on community resources). <u>Care Coordinator:</u> Social Worker. No discussion of payment method. 	<ul style="list-style-type: none"> Less burden (the Burden Interview) at 6 months ($p < 0.05$). No difference in depression (Center for Epidemiological Studies Depression Scale). 	<ul style="list-style-type: none"> No difference in amount of days spent in community, level of cognitive impairment (Mini-Mental State Examination [MMSE]), & depressive symptoms (Geriatric Depression Scale). 	<ul style="list-style-type: none"> No significant difference in the number of community services used. 7.7 more hours/month of care coordination for intervention group ($p < 0.05$). Clients with mild to moderate cognitive impairment (MMSE ≤ 23) in the control group were more likely to be placed in a long-term care institution, with mild to moderate treatment clients staying on average 52 days longer (no discussion of significance).
Eloniemi-Sulkava et al.	2001	Home-based care in 1 of 5 Municipalities.	<ul style="list-style-type: none"> 100 participants with dementia registered for Social Insurance. Participants were subsequently reexamined by a neurologist for dementia according to the Diagnostic & Statistical Manual of Mental Disorders (V3). 	<ul style="list-style-type: none"> <u>Intervention:</u> A 2-year nurse care coordination program providing assisted arrangements for social & health care services. Participants were randomized to either receive the nurse care coordination program or usual services. Payments came from Social Insurance Institution for Community Care & depends on need for care. 	NA	NA	<ul style="list-style-type: none"> Lower rate of institutionalization ($p = 0.042$, Hazard Ratio = 0.12) in the first months but decreasing rate over time ($p = 0.028$). Among participants with severe dementia, intervention participants relative to control (Severe MMSE = 0-11) remained in the community for a longer period of time; no mention of significance.

TABLE 1 (*continued*)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Fox et al.	2000	Participants recruited from 8 cities across the United States.	• 8,905 Medicare beneficiaries (enrolled in Part A or B) with a diagnosis of irreversible dementia.	• A 3-year Medicare-funded care coordination & community care benefit for persons with dementia. • Participants were randomized to either the care coordination/ community care benefit or control. • 2 models were tested with 1 model having a smaller care coordinator to client ratio & higher monthly reimbursement benefit, similar to the Channeling demonstration. • Monthly per client reimbursement caps with 20% copay; fee for service.	• No difference in total hours of care provided by caregivers, provision of ADLs, nursing home entries, depression (short form geriatric depression scale) and burden (adapted Zarit Carer Burden Interview) across groups. • Small (clinically insignificant) reduction in caregiver burden & depression for a subset of sites that was significant & persistent over time. • Difference of 1-4 points on scale with p values ranging from less than 0.05-0.001. • Caregivers reported fewer tasks in which they required assistance (no discussion of significance).	• Participants more likely to use community-based long-term care [home care (OR = 2.77, p < 0.001) & adult day care (OR = 2.61, p < 0.05)]. Among those using these services, treatment & control, there was no difference in the amount of services.	• Lower Medicare expenditures (\$500 on average) but savings did not compensate for the cost of the intervention. No difference in savings from either model. • No difference in time to institutionalization.
Newcomer et al.	1999						
Newcomer et al.	1999						
Miller et al.	1999						
Jansen et al.	2011	Primary care practices in West-Friesland, the Netherlands Home & telephone-based intervention.	• 99 dyads with early dementia ≤ 24 on MMSE or ≥ 50% dementia risk based on 7 Minute Screen.	• <u>Intervention:</u> A 1-year care coordination program focusing on the health & LTSS of persons with dementia & their caregivers. • Persons with dementia were randomized to either the intervention or usual care. • <u>Care Coordinator:</u> District Nurse. • No mention of payment.	• Differences in depressive symptoms (Center for Epidemiologic Studies Depression Scale), burden (Self-Perceived Pressure by Informal Care) & quality of life (SF 36) were not statistically significant.	• No difference in quality of life (Dementia Quality of Life Instrument).	• Only statistically significant difference was utilization of Care Coordination, which increased.

TABLE 1 (continued)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Judge et al. Agency for Healthcare Research and Quality (AHRQ)	2011 2012	U.S. Department of Veterans Affairs (VA) across multiple cities	<ul style="list-style-type: none">• 508 veterans• Most participants (82%) had moderate to severe difficulties with instrumental ADLs.• Past (within 2 years) diagnosis.	<ul style="list-style-type: none">• A 12-month telephone-based care coordination called Partners in Dementia Care (PDC). It involved a formal collaboration between the VA & local Alzheimer's Associations.• <u>Care Coordinator:</u> 1 based at the VA & another based at the Alzheimer's Association.	<ul style="list-style-type: none">• 8/11 psychological outcomes were statistically significantly better for participants compared to controls (either all participants or a subset of participants).• Improvement in depression (15% fewer symptoms), use of support services & satisfaction with VA health services after 6 months.• Less strain, feelings of being trapped, unmet needs & physical health strain among caregivers of severely impaired persons with dementia at 6 months & between months 7 & 12.	<ul style="list-style-type: none">• 6/8 psychosocial outcomes were better for care recipients relative to controls (mostly those with more severe impairments).• Less relationship strain, fewer unmet needs & lower levels of depression.• Temporary reduction in embarrassment about memory problems.• Among participants with behavioral problems, there was 20% reduction in hospital readmissions for intervention participants relative to control.• Participants with greater cognitive impairment were less likely to be placed in nursing homes or assisted living facilities (20% vs. 33%).	<ul style="list-style-type: none">• Intervention veterans were more likely to have mental health visits, telephone-based care, & neurology visits. More primary care visits for veterans with more personal care dependencies. No difference in volume of these services.• No effect on inpatient admission or emergency department visits.

TABLE 1 (*continued*)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Lam et al.	2010	Recruited from psychogeriatric outpatient & memory clinics in a teaching hospital located in Hong Kong. Home visits initially, then telephone calls & follow-up at the hospital clinics.	<ul style="list-style-type: none"> • 102 participants. • Mild dementia: Chinese MMSE score of 15 or above & a clinical dementia rating of 1. • No other chronic disease. 	<ul style="list-style-type: none"> • Intervention: A 4-month care coordination program providing support, skills training, health coordination, & referrals for local social services. • Participants were randomly assigned to either care coordination or a control group. • Care Coordinator: Occupational Therapist. • No discussion of payment. 	<ul style="list-style-type: none"> • Changes in stress (Zarit Carer Burden Interview), psychological health (General Health Questionnaire), & Subjective Quality of Life (Personal Well-Being Index) were not significant across groups. 	<ul style="list-style-type: none"> • Changes in dementia score (CMMSE), Depression (CSDD), psychiatric symptoms & behavioral disturbances (NPI) & Quality of Life (PWI-ID) were not significant across groups. • Change in Depression at 4 months was significant for the intervention group but not the control (p = 0.002 CI = -4.8-1.0). 	<ul style="list-style-type: none"> • Caregivers in the intervention group used more domestic helpers & day care at month 4 & 12 than caregivers in the control group (p < 0.05).
Meeuwsen et al.	2012	Participants recruited from 9 Dutch memory clinics in a university hospital, general hospital, or old age psychiatric clinic. Home & telephone consults involved.	<ul style="list-style-type: none"> • 175 dyads. • Newly diagnosed dementia according to the Diagnostic & Statistical Manual of Mental Disorders (DSM-IV) & a clinical dementia rating of 0.5, 1 or 2. 	<ul style="list-style-type: none"> • Intervention: A 12-month disease management program focused on dementia Rx drug guidance, & referrals to health & LTSS. • Dyads were randomly assigned to either the memory clinic or a general practitioner. • No discussion of payment. 	<ul style="list-style-type: none"> • No significant difference in self-perceived burden at 6 & 12 months (Sense of competence questionnaire). 	<ul style="list-style-type: none"> • No significant difference in quality of life rated by caregiver at 6 & 12 months (Quality of life in Alzheimer's disease instrument). 	NA

TABLE 1 (*continued*)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Nourhashemi et al.	2010	Memory clinics in university or general hospitals in France.	<ul style="list-style-type: none"> • 1,131 participants. • Dementia based on criteria of the National Institute of Neurological & Communicative Disorders & Stroke/ Alzheimer Disease & Related Disorders Association for probable or possible Alzheimer's disease. • MMSE of 12-26. 	<ul style="list-style-type: none"> • A biannual guideline-based care consultation service provided by physicians at a memory clinic. • <u>Duration:</u> 1 year. • <u>Care coordinator:</u> Physicians at the Memory Clinic. 	NA	<ul style="list-style-type: none"> • No difference in functional decline (Alzheimer's Disease Cooperative Study ADLs score). 	<ul style="list-style-type: none"> • No difference in risk of being admitted to institutional care or mortality. • Among those admitted, intervention participants were most likely to be admitted for reasons related to caregivers (61.5% vs. 38.5%) & for control participants, worsening medical conditions (70.59% vs. 29.41%) p = 0.0046.
Specht et al.	2009	<p>Participants were recruited from 8 counties in rural Iowa.</p> <p>Home visit & telephone contacts if needed.</p>	<ul style="list-style-type: none"> • 249 families of participants with suspected memory impairment. 	<ul style="list-style-type: none"> • A 4-year enhanced service delivery model (care coordination) focusing on coordination of LTSS. • Counties receiving either the enhanced nursing care coordination model or existing CMPFE program were randomly selected. • <u>Care Coordinator:</u> Nurse Trained in Dementia Care. • No discussion of payment. 	<ul style="list-style-type: none"> • Lower odds of extensive/substantial stress (p = 0.019, CI = 1.27-24.37), extremely or substantially. • Compromised well-being (p = 0.038, CI = 1.10-59.32) & inadequate/slightly inadequate endurance (No p value given, Nursing Outcomes Classification at the University of Iowa). • No difference in health status (SF-36). 	<ul style="list-style-type: none"> • No change in behavioral rating index, Cognitive Status (MMSE) & Stage of Dementia (GDS). • Increase in functional ability for the intervention group relative to the controls (p < 0.0001). 	NA

TABLE 1 (continued)

Author	Year	Setting	Participants	Study Design	Results: Caregiver	Results: Care Recipient	Utilization/Inst.
Vickrey et al.	2006	18 primary care clinics & 3 community agencies in California Services provided at intervention clinics with telephone-based follow-up & home reassessments provided.	<ul style="list-style-type: none">• 408 Medicare participants with dementia verified by physicians & diagnosis codes.• Few comorbidities.	<ul style="list-style-type: none">• <u>Intervention:</u> An ~18-month guideline-based disease management program.• Randomization was done at the clinic level. Clinics within each health care organization were assigned to either intervention or usual care.• <u>Care Coordinators:</u> Health Care Organization (Social Worker) & Representative from Community organization.• Capitated payments.	<ul style="list-style-type: none">• 30.1% mean difference in number of guidelines for which care was adherent per participant at follow-up ($p < 0.001$).	<ul style="list-style-type: none">• Caregiver ratings of health care quality for participants with dementia were higher for participants in the intervention compared to those in the usual group (mean difference of 0.5, $p \leq 0.011$).• Difference of 0.06 in decline of health-related quality of life at 18 months (HU13, $p = 0.034$).	<ul style="list-style-type: none">• Caregiver knowledge, use of adult day care, quality of life & receipt of services or information from agencies providing meals to homebound elderly did not differ significantly between groups.

NA = Not Available.

MODELS OF CARE COORDINATION

Approaches to care coordination were similar in most of the reviewed studies (**Table 2**). Briefly, a care coordinator was assigned to the care receiver/caregiver dyad to conduct a structured assessment, develop a care plan, provide ongoing support, and monitor their progress. For example, in the intervention described by Callahan et al. (2006), dyads met with the care manager on a bimonthly to monthly basis for symptom assessments and evaluations, caregivers were invited to participate in group support sessions led by a social psychologist, and care receivers were encouraged to engage in group chair-based exercise classes.

TABLE 2. Common Elements of Care Coordination Models in the 14 Reviewed Studies	
Element	Description
Care coordinator	Generally a social worker, geriatric nurse practitioner, or nurse trained in dementia care.
Multidisciplinary care team	In addition to the care coordinator, this team may include primary care providers, occupational & other therapists, social workers, geriatricians, or psychologists/psychiatrists. Provides care to the dyad or support to the care coordinator.
Structured needs assessment	An interview, sometimes using specialized software; done in person at a clinic or at home or by telephone. Assesses the care receiver's health, functional & cognitive abilities, the home environment, supports in place, & the caregiver's needs & concerns. Evaluates whether specific services are needed, such as special equipment & adaptations, meals & other domestic help, respite services, adult day care, home care, & nursing home care.
Care plan	Generally a written plan specifying treatments over the course of a set time period.
Referrals or direct arrangement of care	The care coordinator arranges care directly or refers patients/caregivers to providers.
Ongoing monitoring and support	Monitoring to ensure the care plan is implemented. Often includes counseling, support groups, or other therapy for the caregiver.

Care coordinators were also responsible for either referring care receivers to medical or LTSS providers or directly arranging these services. Care coordinators were typically social workers, geriatric nurse practitioners, or registered nurses trained in dementia care. Care coordination was undertaken by a variety of health and social service organizations, including managed care companies, primary care practices, mental health programs, nursing homes, specialty clinics, and home care programs. The most common measured outcomes were service utilization, time to institutionalization, caregiver stress and burden, depression, quality of life, cognition, behavioral symptoms (such as aggression), and functional ability.

Ten programs coordinated both medical services and LTSS. One program focused on medical service coordination, and two programs focused only on LTSS.

Coordinating Long-Term Services and Supports

Two studies focused on coordinating LTSS. Influenced by the National Long-Term Care Channeling Demonstration of the early 1980s, the Medicare Alzheimer Disease Demonstration and Evaluation (MADDE) was an RCT that was designed to increase access to formal LTSS through care coordination and access to additional LTSS for people with Alzheimer's disease (Fox et al., 2000; Miller et al., 1999; Newcomer et al., 1999a, b). The study did not have an explicit goal of reducing nursing home entry (Miller et al., 1999). The care coordinators were responsible for linking participants with community-based services, providing psychological support, and managing costs within the budgeted amount for LTSS. Those in the treatment group were eligible for an 80 percent discount on community care benefits, up to about \$600 per month. MADDE had the largest sample size of any study in this review, with 8,905 enrollees who remained in the demonstration for more than 30 days across eight United States cities between 1989 and 1994. Implementation--the type of care coordinator and arrangement of services--varied across sites. Only one location directly attempted to change the use of medical services. Most caregivers in this intervention had baseline scores of burden and depression that were not considered clinically problematic, making it difficult to show significant improvements.

Lam et al. (2010) evaluated care coordination for persons with mild dementia who were recruited from memory clinics at a teaching hospital in Hong Kong. The participants were randomized to either the intervention or control group. The 4-month home, clinic, and telephone-based intervention consisted of providing support, skills training, coordination of needed services, and referrals to local social services, led by an occupational therapist. The primary outcomes were caregiver burden and quality of life; secondary outcomes included changes in clinical measures (such as the MMSE) and use of care services, such as day care and home health. The limited availability of community LTSS and dementia training for domestic helpers were cited as issues affecting the intervention.

Coordinating Medical Services

One RCT focused on coordinating medical services for persons with dementia. Callahan et al. (2006) described a 12-month collaborative care coordination program in Indiana for persons with dementia which based care recommendations on published Alzheimer's disease treatment guidelines in the United States. Guidelines referenced included those from the American Academy of Neurology (1994); a U.S. Department of Health and Human Services (HHS) panel published in 1996; a VA publication from 1997; and a consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society published in 1997. The collaborative care model, which has been suggested as a way to improve the management of chronic illnesses, is generally distinguished by a team-based approach involving collaboration among providers, patients, and caregivers. In this intervention, the team was led by a primary care physician and a geriatric nurse practitioner, who

served as the main care coordinator. Participants with possible or probable Alzheimer's disease were recruited. Approximately half of participants were from economically disadvantaged backgrounds and had multiple comorbidities. The study outcomes included cognition, activities of daily living (ADLs), and nursing home placement.

Coordinating Medical Services and Long-Term Services and Supports

All of the remaining ten programs coordinated both medical services and LTSS. LTSS arranged by the care coordinators typically included day care, home care, social centers, and respite care. The involvement of health care professionals ranged from direct care coordination responsibilities to consultations as needed.

United States Studies

The following four studies took place in the United States. The Rural Iowa Alzheimer's Demonstration described by Specht et al. (2009) provided nurse care coordination to individuals with a suspected memory impairment. Some of the study design issues that may have posed a challenge include a lack of confirmed dementia diagnoses, inconsistent follow-up times, and differences in outcomes measures at baseline.

Three United States-based programs coordinated care for persons with dementia and their caregivers within integrated health care systems (such as Kaiser Permanente). The advantage of these programs was the availability of an integrated system which facilitated access to LTSS. The managed care environment--such as capitated payments, gatekeeping, and electronic medical records--already provided some coordination of the health care needs of the members, although they were not previously focused on people with Alzheimer's disease. The unique contribution of the interventions was to integrate LTSS into that preexisting health system.

The Cleveland Alzheimer's Managed Care demonstration described by Bass et al. and Clark et al. was a collaboration between a local Alzheimer's Association chapter and Kaiser Permanente of Ohio to provide telephone-based care coordination for one year (Bass et al., 2003; Clark et al., 2004). Families were randomly assigned to either care coordination or usual care. Most of the care coordinators, who were staff of the Alzheimer's Association chapter, were social workers, and all services were provided at no cost to participants. In addition to persons with a specific diagnosis of dementia, individuals with a symptom code for memory loss were also included. The study excluded individuals with the most severe memory impairments. Although improvements were observed for both persons with dementia and their caregivers, the intervention mainly focused on caregivers.

PDC was 12-month telephone-based care coordination collaboration, this time between the VA and local Alzheimer's Association chapters (AHRQ, 2012; Judge et al.,

2011). Built on two prior studies (the Cleveland Alzheimer's Managed Care Demonstration (Bass et al., 2003) and the Chronic Care Network for Alzheimer's Disease (Maslow et al., 2001), PDC was a 5-year research investigation that tested the effectiveness of a telephone-based care coordination intervention designed to address the unmet care needs of veterans with dementia and their family caregivers across all dementia stages. The intervention included linkages between the VA and the Alzheimer's Association, delivery system redesign and decision support, self-management training, and the development of a clinical information system. The main delivery system redesign components were the addition of two new care coordinator positions at each organization: the VA's care coordinator, who focused on veterans' medical and nonmedical needs and assisted families with effectively using VA resources; and the Alzheimer's Association care consultant, who focused on needs of informal caregivers such as care-related strain and accessing non-VA resources. The program was conducted in Houston and Boston. Judge et al. analyzed selected data from the 93 families included in the analysis and reported that those who received the intervention were similar to the general VA population. There were no outcome comparisons made in the peer-reviewed journal article, but additional outcome data on this intervention were found on AHRQ's Innovations Exchange website (AHRQ, 2012).

Vickrey et al. (2006) evaluated dementia guideline-based care coordination in primary care clinics for persons with dementia and their caregivers, who were randomly assigned at the clinic level to either the intervention or control arm. The intervention was an 18-month disease management program within a capitated system. The program involved explicit protocols whereby the representative from the LTSS agency would be notified if his or her services were needed and given access to the individual's care plan through Internet-based care coordination software.

International Studies

The following six studies took place outside of the United States, including Canada, the United Kingdom, Finland, the Netherlands, and France. The Early Home Care Program described by Chu et al. (2000) was a pilot project run by a large integrated health care system in Canada. The program, an 18-month home care intervention, targeted individuals with a diagnosis of early dementia. Participants were randomized to either the intervention group or a control group. The intervention group received case management, occupational therapy, physical therapy, social work, nursing, respiratory therapy, in-home and out-of-home respite, homemaking, personal care assistance, volunteer service, and psychiatric consultation. The intervention group received an average of 7.7 hours per month of care coordination services. The control group received an information packet on community resources. The primary outcome measures were caregiver burden and institutionalization.

The Lewisham Case Management Scheme in the United Kingdom, described by Challis et al. (2002), incorporated a care coordinator (social worker) into a mental health team of doctors, nurses, psychologists, and occupational therapists. The intervention was a 2-year program in which clinicians were responsible for managing acute care

needs and care coordinators were provided a budget to purchase LTSS for participants as needed. The limitations of this study arise from the observational design and the use of unmatched comparison groups for the evaluation of certain outcomes. The comparison group also had access to a mental health team, which may have attenuated the comparison.

Eloniemi-Sulkava et al. (2001) evaluated a home-based nurse care coordination program for persons with dementia in Finland. Participants were recruited through a national dementia registry and were randomized to either the care coordination program or usual care. The intervention consisted of a 2-year nurse-led care coordination program to assist patients with arrangements for social services and medical care.

Jansen et al. (2011) described a care coordination program led by senior nurses specializing in geriatric care in the Netherlands. The 1-year program targeted individuals with either early dementia or a greater than 50 percent risk of dementia based on common dementia measurement scales. Participants were randomized to either the intervention or usual care. The intervention consisted of geriatric nurses making home visits, writing a care plan (providing protocols for managing 30 problem areas), organizing family meetings, following up via telephone every 3 months, and referring families to other providers. Outcomes included a comparison between the two randomized groups on measures of care received, such as the number of home care hours per week and the number of respite care days.

Meeuwsen et al. (2012), another study from the Netherlands, compared care coordination by a memory clinic to coordination by a general practitioner who was given guidelines on dementia care. These clinics are designed for the diagnosis and treatment of memory-related conditions. Participants were diagnosed with dementia but had scores of anxiety and depression that were below levels of clinical depression or anxiety. Scores of participant cognition and quality of life were also high at baseline. Meeuwsen et al. (2012) cited biases caused by attrition in the control group as a possible limitation.

Finally, Nourhashemi et al. (2010) evaluated care coordination using a specific care plan in French memory clinics. The goal of the intervention was to incorporate biannual care coordination by the physicians in the memory clinics, with the main outcome measure being functional capacity of the patients; secondary outcomes included institutionalization rate and mortality. Participants with possible or probable Alzheimer's disease were selected based on standardized diagnostic criteria and an MMSE score of 12–26. They described selection biases, issues of contamination, and a government initiative which encouraged more care coordination in memory clinics as possible explanations for their results.

OUTCOMES

Utilization

Table 3 summarizes the effects of the interventions on medical and LTSS utilization. For most of the studies we reviewed, there were no significant changes in medical utilization (noted as NS). One study found a significant effect of care coordination on medical utilization: Callahan et al. (2006) reported fewer office visits in the intervention group.

Likewise, for most of the studies we reviewed, there were no significant changes in LTSS utilization. Two studies found lower nursing home placement rates in the intervention group. Results were mixed for home health and personal care services, respite and day care services, and other supports.

Costs

Three studies in this review evaluated costs. The MADDE demonstration resulted in reduced Medicare expenditures of \$500 on average, which did not offset the costs of the program (Fox et al., 2000). Participants had a 20 percent copayment, but there were no substantial cost containment incentives to encourage more efficient use of LTSS. The VA/Alzheimer's Association's PDC program found that there were no differences in VA health care expenditures between those in the program and those in the comparison group (AHRQ, 2012). However, there were reduced costs among a small number of outlying high-cost veterans. The other study that evaluated costs was the Lewisham, United Kingdom, study described by Challis et al. (2002). In that study, the intervention group spent more on social services and medical care compared to controls, but overall, there was no difference in costs to society between the two arms.

Other Outcomes

Below, we highlight the effects of care coordination on psychosocial outcomes. **Table 3** provides further details on each study's findings for caregivers and care recipients.

TABLE 3. Summary of Reported Effects of Care Coordination on Utilization

Author	Comparison	Medical Utilization			Long-Term Services and Supports			
		Inpatient Stays	Emergency Visits	Office Visits	Nursing Home Placements	Home Services	Respite/Day Care Services	Other Support Services
Randomized								
Bass et al.	Intervention vs. control at 12 months	Fewer (NS)	Fewer (NS)	More (NS)	Fewer ($p < 0.10$)	Fewer personal care, domestic, home health ($p < 0.10$)	---	Fewer counseling, legal assistance ($p < 0.05$)
Callahan et al.	Intervention vs. control at 12 months	Fewer (NS)	---	Fewer ($p = 0.03$)	Fewer (NS)	---	---	---
Chu et al.	Intervention vs. control at 18 months	---	---	More hours of nursing/social work/OT/PT/RT (NS)	Fewer (NS)	Fewer hours (NS)	Fewer hours (NS)	---
Eloniemi-Sulkava et al.	Intervention vs. control at 24 months	---	---	---	Fewer ($p = 0.042$)	---	---	---
Fox et al. Miller et al. Newcomer et al. Newcomer et al.	Intervention vs. control at 12 months	---	---	---	Same overall (NS), higher at 1 of 8 sites ($p = 0.043$)	More ($p < 0.01$)	More ($p < 0.05$)	---
Jansen et al.	Intervention vs. control at 12 months	---	---	More primary care, social worker, psychiatric/geriatric consults; fewer specialist visits (incl. psychologist) (NS)	---	More hours per week of home care, less dinner service days (NS)	More days of day care (NS)	---
Lam et al.	Intervention vs. control at 4 months (end of treatment) and 12 months	---	---	---	---	More paid helpers @ 12 months ($p < 0.05$), same home services (NS)	More day care at 4 & 12 months ($p < 0.01$), more respite @ 4 months (NS)	---
Meeuwsen et al.	Intervention vs. control at 6 & 12 months	---	---	---	---	---	---	---
Nourhashemi et al.	Pre-post at 12 & 24 months	---	---	---	More at both time points*	Less at both time points*	More at both time points*	---

TABLE 3 (*continued*)

Author	Comparison	Medical Utilization			Long-Term Services and Supports			
		Inpatient Stays	Emergency Visits	Office Visits	Nursing Home Placements	Home Services	Respite/Day Care Services	Other Support Services
<i>Observational</i>								
Challis et al.	Case vs. matched control	More (NS)	---	More primary care, fewer mental health or social worker (NS)	Fewer (NS)	More home care (NS); more days per year of home care ($p < 0.001$)	Fewer away, more at home respite (NS); Fewer day care (NS)	---
Judge et al. AHRQ	Intervention vs. usual care at 6 months	Fewer hospital readmissions, same inpatient stays*	Same*	More neurology, mental health, & telephone-based visits*	Fewer among the most impaired*	---	---	---
Specht et al.	Intervention vs. usual care at 3-6 months & 9-15 months	---	---	---	More*	---	---	---
Vickrey et al.	Intervention vs. usual care at 18 months	---	---	---	---	Less use of Meals on Wheels (NS); more home health ($p < 0.01$)	More use of respite ($p = 0.022$) & day care (NS)	More use of support groups (NS); more use of AA services ($p < 0.01$); more use of Caregiver Resource Center ($p = 0.002$)

* = Significance not reported; NS = Not significant; --- = indicates that outcome was not assessed/reported.

AA = Alzheimer's Association; ADLs = Activities of Daily Living; OT = occupational therapy; PT = physical therapy; RT = respiratory therapy.

Care Receivers

- Bass et al. (2003) found that persons with dementia in the intervention group had less difficulty coping with memory problems.
- The program described by Callahan et al. (2006) showed a reduction in care receivers' behavioral and psychological symptoms at 12 months, which persisted 6 months after the intervention.
- In the Lewisham study, there were improvements associated with care receivers' ADLs, health, behavioral difficulties, and the environment. In addition, persons with dementia were more satisfied with their home environment 6 months into the study and showed improved social contacts (Challis et al., 2002).
- Judge et al. (2011) found an improvement in most psychological outcomes for persons with dementia and their caregivers. Six of eight psychosocial outcomes were better in the intervention patients than in the comparison group (AHRQ, 2012).
- The French study reported by Nourhashemi et al. (2010) found no significant differences between groups on patients' functional decline.
- Specht et al. (2009) reported an improvement in functional ability among persons with dementia 3-9 months into the program.
- Although Vickrey et al. (2006) observed a smaller decline in quality of life in the intervention arm, confidence in caregiving, caregiving mastery, and ratings of health care quality for persons with dementia were higher for participants in the intervention group.

Caregivers

- Bass et al. (2003) reported that caregivers who used other Alzheimer's Association services in combination with care coordination experienced reduced symptoms of depression, role captivity, and health deterioration. Role captivity was measured using survey items that measured feelings of being trapped, wishing to run away, and wanting to be free to lead [the caregiver's] own life. Similarly, health deterioration was measured with survey items which asked about getting sick more often, having worse physical health, having less energy, and being bothered by aches and pains.
- Callahan et al. (2006) reported that caregivers in the intervention group had reduced symptoms of distress at the end of the intervention and improvements in depression at the 6-month assessment.

- The Lewisham program (Challis et al., 2002) found that caregivers reduced their total caregiving hours and felt less burden and distress.
- Chu et al. (2000) reported that caregivers in this program experienced reduced burden and had fewer occurrences of disturbing behavior by persons with dementia.
- The MADDE demonstration resulted in improvements in caregiver stress and burden at some, but not all, sites (Newcomer et al., 1999). Caregivers in the care coordination program also reported fewer tasks with which they required assistance.
- Jansen et al. (2011) in the Netherlands reported no significant difference in caregiver quality of life, depressive symptoms, or burden between the intervention and control group.
- The other Dutch study, reported by Meeuwsen et al. (2012), found no significant difference in outcome measures (caregiver quality of life, burden, and sense of competence) across the two randomized sets of clinics.
- The PDC program in the VA found that eight of 11 psychosocial outcomes were better among caregiver participants than those in the comparison group (AHRQ, 2012).
- Specht et al. (2009) reported that caregivers had lower odds of both extensive and substantial stress at 3-9 months and extremely/compromised well-being at 9-15 months relative to those in the control group.

CONCLUSIONS

Although the results from a few of the programs appear promising, the evidence on the efficacy of care coordination for persons with Alzheimer's disease and their caregivers is still equivocal. The programs reporting the most success shared a few common characteristics. They coordinated both medical care and LTSS, and participants were in an integrated health care environment to which an LTSS coordination program was added. A larger, more integrated and coordinated system appeared to be the most effective in improving outcomes for individuals with Alzheimer's disease and their caregivers.

Many of these evaluations were susceptible to design constraints and limitations, such as small sample sizes, short follow-up periods, and unmatched comparison groups. The evaluations with positive results mainly evaluated outcomes such as caregiver strain, health status, adherence to dementia guidelines, and ADLs. For many of the common outcomes, there were either temporary improvements or no significant difference in outcome measures across the intervention and control groups. Few studies found significant results that persisted beyond the end of the program. The variability in results makes assessing the value of care coordination difficult.

Care coordination for people with Alzheimer's disease needs to be further explored. Future studies would benefit from larger sample sizes, longer time frames for follow-up and broader outcome measures. A number of studies in our analysis found improvements for a subset of persons with dementia, but these were not statistically significant. This may be a result of lack of statistical power or an insufficient time period to detect statistically significant differences. Larger sample sizes and longer timeframes would permit more rigorous analysis of subpopulations and could assist in tailoring future interventions.

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