



Research on Care Coordination for People with Dementia and Family Caregivers

Background Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

Introduction

More than 5 million Americans live with dementia, a disease that requires high levels of medical care and long-term services and supports (LTSS) (Bynum et al., 2004; Hebert et al., 2013). Most people with dementia also experience other chronic medical conditions, such as diabetes, hypertension, and congestive heart failure (Bunn et al., 2014). Even after taking these other conditions into account, health care use and costs are higher for people with dementia than for people without (Bynum et al., 2004; Lin et al., 2013). People with dementia have higher hospitalization rates, use more home health and nursing home care, experience more care transitions, and have higher health care expenditures (Daras et al., 2017; Feng et al., 2014; Marek et al., 2014; Reuben et al., 2013; Tan et al., 2014). The quality of care they receive is often suboptimal, with significant rates of potentially avoidable hospitalizations and emergency department visits (Daras et al., 2017; Feng et al., 2014; Lin et al., 2013).

The traditional health care system is not well suited to meeting the complex needs of people with dementia. Physicians lack the time and often the training to manage the ongoing care of patients with multiple chronic health conditions, including dementia (Boult & Wieland, 2010; Reuben et al., 2013). Typical fee-for-service reimbursement policies do not incentivize providers to coordinate medical care, and LTSS are not well integrated with health care delivery systems (Reuben et al., 2013). Some individuals with dementia are eligible for both Medicaid and Medicare (“dual-eligibles”), but historically providers within these two systems have not communicated about the patients they have in common, contributing to fragmented care (McGinn-Shapiro et al., 2015; Wiener et al., 2017). The sheer number of health and social service providers that serve this population, including physicians’ offices, outpatient clinics, emergency departments, hospitals, rehabilitation facilities, residential care facilities, adult day centers, home care, and community organizations, also makes coordinated communication challenging (Tan et al., 2014).

Care coordination seeks to improve the quality and efficiency of health care for people with chronic conditions such as dementia. The Agency for Healthcare Research and Quality (AHRQ) defines care coordination as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services... often managed by the exchange of information among participants responsible for different aspects of care” (Agency for Healthcare Research and Quality [AHRQ], 2007, p. 41). Care coordination and care management can take place within a single medical clinic or system or across health and community-based agencies. Although there is no consensus on the definition of care management and care coordination or even whether they are different, the term *care coordination* will be used in this paper to encompass both concepts (Lines et al., 2013).

This background paper examines select care coordination models that have been used with older adults, with a focus on those for people with dementia; describes challenges to implementing care coordination and the factors that may be important to successful implementation; reviews evidence about the effectiveness of care coordination models; and identifies areas where further research is needed.

Models of Care Coordination

Certain core elements are common to most models of care coordination, including dementia-specific models: (1) a social worker or nurse who serves as the service coordinator; (2) a multidisciplinary team made up of the coordinator and others, which may include primary care providers, occupational and other therapists, social workers, geriatricians, and LTSS and mental health providers; (3) a structured needs assessment to determine both the care receiver and caregiver's needs, often including health, home environment, and LTSS; (4) a care plan specifying planned services over time; (5) referrals or direct arrangements of care for health and LTSS services; and (6) ongoing monitoring and support to ensure that the plan is implemented (Lines et al., 2013). The multiple stakeholders and various processes involved in care coordination (e.g., assessment, care planning, transferring information, referrals, monitoring) make it a complex endeavor.

Within this framework, how care coordination services are delivered varies considerably. Eligible participants may be identified through medical records searches or through one-on-one assessments. Sometimes only high-risk individuals receive care coordination; sometimes everyone receives it. In some models, the intensity of coordination services varies with the severity of the patient's illness and functional impairment. A variety of assessment tools may be used, and the scope of services to which participants are connected varies greatly. In some cases, care coordination is limited to medical care, while in others, a whole range of services and supports is considered, such as home safety, behavioral health, advance planning, meal delivery, personal care, and other LTSS.

Care plans also vary in complexity and in the extent to which consumers and caregivers provide their input. Services may be provided for a limited time frame or be ongoing. Communication between coordinators and primary care physicians may occur regularly in a structured way or may be more sporadic. Levels of coordinator expertise and training differ among programs, as does the physical location in which they practice (Lines et al., 2013; Wiener et al., 2017).

The following examples illustrate models of care coordination designed for older adults with complex health needs, including those with dementia:

- *Geriatric Resources for Assessment and Care of Elders (GRACE)*--GRACE was designed to improve care for low-income seniors with multiple diagnoses, including those with dementia. An interdisciplinary geriatrics team, led by an advance practice nurse and social worker, use in-home assessments and standard protocols to develop care plans, which are tracked through a central information technology system (Boult & Wieland, 2010; Counsell et al., 2007; McCarthy et al., 2015).
- *Program of All-Inclusive Care for the Elderly (PACE)*--PACE targets older adults eligible for Medicare and Medicaid who need a nursing home level of care with the goal of helping them remain in the community; almost half of PACE clients have dementia (National PACE Association, 2017). Clients receive most preventive, primary, acute, and LTSS and social services through their PACE adult day center. This centralization of services at an adult day center ensures frequent contact with participants. Payments are capitated (Boult & Wieland, 2010; McCarthy et al., 2015).
- *Transitional Care Model (TCM)*--In the TCM, advance practice nurses screen hospitalized older adults to determine who is at risk for poor outcomes and then work

with the hospital interdisciplinary care team to develop a comprehensive discharge plan. Follow-up occurs for 3 months postdischarge and includes frequent home visits and telephone calls. This model has been tested with patients who have cognitive impairment (McCarthy et al., 2015; Naylor et al., 2014).

- *Center for Medicare and Medicaid Innovation's Financial Alignment Initiative (FAI) Demonstrations*--The FAI Demonstrations seek to integrate medical, behavioral health, and LTSS care delivery for people dually eligible for Medicare and Medicaid. Two financial alignment models are being tested: a capitated model and a managed fee-for-service model in which states can benefit financially from generated cost savings that also improve quality. Care coordination is a centerpiece of these demonstrations (Wiener et al., 2017).

Although the initiatives described above include people with dementia, they are not focused on people with dementia. Examples of care coordination models developed specifically for people with dementia include the following:

- *Partners in Dementia Care*--This model features a partnership between Veterans Affairs Medical Centers and local Alzheimer's Association chapters, with care coordinators at the two locations working as a team using a shared electronic information system and regular meetings. The focus is on helping people with dementia and their caregivers navigate medical and social services, with at least one contact per month. Coordinators help clients develop simple action steps, with reassessment at least every 6 months (Bass et al., 2013, 2014).
- *Maximizing Independence (MIND) at Home*--In this model, noncredentialed memory care coordinators provide coordination with substantial involvement from a registered nurse and a geropsychiatrist. Beyond a comprehensive needs assessment, participants also receive dementia and skill-building training, linkage to services, and care monitoring. A key component of the program is the use of a computerized resource system that identifies needed resources to help people with dementia and caregivers cope with the illness. Most contact is by telephone, mail, and e-mail, with occasional in-person visits (Wiener et al., 2016).
- *Aging Brain Care Medical Home (ABC MedHome)*--In this model, a registered nurse coordinator and noncredentialed care coordinator assistants serve all patients diagnosed with dementia or depression within a health care system. An in-person assessment is followed by monthly contacts for the first 3 months and quarterly contacts thereafter. If hospitalization occurs, specific postdischarge protocols are used (Callahan et al., 2006; LaMantia et al., 2015; Wiener et al., 2016).
- *Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)*--Health care and community organizations collaborated with researchers to establish guidelines for quality of care for dementia patients and specific protocols for managing care. Health care and community service coordinators partnered to meet medical and support needs of people with dementia and caregivers. The program also provided dementia-related education to physicians. A web-based decision-support system was key to communication and efficiency (Lines et al., 2013; Rosalyn Carter Institute for Caregiving, 2017).

Challenges Associated with Care Coordination

The complexity of care coordination programs means that there are many potential obstacles to effective implementation (Khanassov et al., 2014). Inconsistent use of diagnosis codes and out-of-date contact information can make identifying and locating participants a challenge. Staff turnover, heavy caseloads, and unclear or overlapping role responsibilities with other members of the health care team may impact the effectiveness of care coordinators. The level of communication with patients and families and involvement of physicians varies considerably. The absence of effective electronic medical record systems is also a significant impediment for sharing medical information across providers (Khanassov et al., 2014; Reuben et al., 2013; Wiener et al., 2017). Lack of third-party coverage for LTSS needed by people with dementia is also a major problem.

Reimbursement structure also plays a significant role in how easily care coordination is integrated into existing operations (Boult et al., 2009; Sanna & Reuben, 2013). New Medicare rules provide reimbursement for certain care coordination services provided to patients with chronic illnesses (Center for Medicare & Medicaid Services, 2016). However, the incentive to bill for more care under a fee-for-service structure is in direct contradiction to the goal of care coordination in reducing unnecessary and costly procedures (McCarthy et al., 2015). Managed care systems, which emphasize prevention and cost savings and pay per patient rather than by procedure, may be better positioned to implement, sustain, and demonstrate benefits from care coordination efforts (Sanna & Reuben, 2013).

Effectiveness of Care Coordination

Reviews of research on general care coordination have examined outcomes for older patients with complex health care needs and their caregivers, including measures of health, quality of care, and service usage and costs. Strong evidence indicates that care coordination for older people can improve quality of care and quality of life (Boult et al., 2009; Hickam et al., 2013). The impact on hospitalization rates, emergency department use, and health care costs is unclear but may be greater for people who are sicker or who receive more contact from their coordinators (Boult et al., 2009; Hickam et al., 2013; Krause, 2005). Care transitions programs like the TCM do appear to reduce preventable hospitalization readmissions (Hickam et al., 2013; Nelson, 2012).

Less research has been done on dementia-specific programs. Some studies have reported positive outcomes that failed to achieve statistical significance, which may be attributable to small sample sizes or because subjects were not followed for a long enough period (Lines et al., 2013). Care coordination does appear promising in its ability to reduce caregiver depression, burden, and unmet needs while enhancing quality of life and quality of care for people with dementia (AHRQ, 2007; Khanassov et al., 2014; Lines et al., 2013; Samus et al., 2014). Evidence of an impact on behavioral symptoms of dementia is mixed (Khanassov et al., 2014; Samus et al., 2014), as are reductions in hospital admissions, length of stays, and delayed institutionalization (Khanassov et al., 2014; Samus et al., 2014). More research is needed to support these tentative findings and to learn more about which approaches are most effective for dementia.

The specifics of how care is coordinated are important; when it is implemented well, better outcomes may follow (Khanassov et al., 2014). Differences in implementation may account for the mixed evidence of its effectiveness. Meta-analyses of existing studies have identified the following factors as improving outcomes:

- more in-person interaction and engagement between patients and coordinators (AHRQ, 2007; Hong et al., 2014; Marek et al., 2014; McCarthy et al., 2015; Nelson, 2012);
- selecting the right participants, particularly through the use of assessment rather than database searches (AHRQ, 2007; Hong et al., 2014; Marek et al., 2014; McCarthy et al., 2015);
- substantial and regular interaction between the coordinator and the primary care provider (Hong et al., 2014; Nelson, 2012);
- limited caseloads and routine monitoring (McCarthy et al., 2015); and
- appropriate technology that facilitates communication among team members and enables real-time updates, decision support, and analytics (Hong et al., 2014; McCarthy et al., 2015).

All of the factors listed above require greater investment of time and resources, but it may be only through this investment that desired outcomes will be achieved. This may be particularly true for programs serving people with dementia (Naylor et al., 2014).

Gaps in Research

Further research is needed to better understand the science of care coordination (Hong, 2014; Lines et al., 2013; McCarthy et al., 2015). More needs to be known about which factors are important to care coordination outcomes and whether these factors differ for people with dementia. Researchers can help answer these questions by collecting data on the scope of services provided; coordinator experience and training; coordinator role; mode and frequency of contact with clients; mode and frequency of contact with physicians; coordinator caseload; use of specific protocols or guidelines; criteria and process for identifying participants; assessment tools; reimbursement model; information technology; and population characteristics, including risk factors, health care utilization, social support, and living situation (AHRQ, 2007; Hong et al., 2014; McCarthy et al., 2015; Nelson, 2012).

Another key issue is whether care coordination processes are being delivered as intended, and if not, why not (Khanassov et al., 2014; McCarthy et al., 2015; Samus et al., 2014). Research also is needed to address how care coordination can best help people with dementia manage transitions in care and how care coordination intersects with other health care models and systems such as Accountable Care Organizations (Fortinsky & Downs, 2014; Naylor et al., 2014).

Conclusion

Care coordination has the potential to help older adults with chronic illness, including those with dementia, by addressing sources of fragmentation and inefficiency in health care systems, improving care quality and health outcomes for people with dementia and their caregivers, and limiting health care costs. Evidence to date suggests that many models of care coordination can improve care quality and at least some health outcomes; the impact on costs is less clear.

Additional research is needed to better understand the features of care coordination that affect success and to understand which patients are most likely to benefit from which types of coordination.

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