

Practice Concepts and Policy Analysis

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Partners in Dementia Care: A Care Coordination Intervention for Individuals With Dementia and Their Family Caregivers

Katherine S. Judge, PhD,^{*,1,2} David M. Bass, PhD,² A. Lynn Snow, PhD,^{3,4}
Nancy L. Wilson, MSW,^{5,6} Robert Morgan, PhD,^{5,7} Wendy J. Looman, BA,²
Catherine McCarthy,² and Mark E. Kunik, MD, MPH^{5,6,8,9}

¹Department of Psychology, College of Health Sciences and Professions, Cleveland State University, Ohio.

²Margaret Blenkner Research Institute, Benjamin Rose Institute on Aging, Cleveland, Ohio.

³Center for Mental Health and Aging and Department of Psychology, University of Alabama.

⁴Veterans Affairs Medical Center, Tuscaloosa VA Medical Center.

⁵Houston Center for Quality of Care and Utilization Studies, Health Services Research and Development Service, Michael E. DeBakey Veterans Affairs, Houston, Texas.

⁶Department of Medicine and Huffington Center on Aging, Baylor College of Medicine, Houston, Texas.

⁷Division of Management, Policy, and Community Health, University of Texas School of Public Health, Houston, Texas.

⁸Menninger Department of Psychiatry and Behavioral Sciences and Department of Medicine, Baylor College of Medicine, Houston, Texas.

⁹Department of Veterans Affairs South Central Mental Illness Research, Education, and Clinical Center, Houston, Texas.

*Address correspondence to Katherine S. Judge, Department of Psychology, Cleveland State University, Cleveland, OH 44115-2214.
E-mail: k.judge46@csuohio.edu

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Purpose: This article provides a detailed description of a telephone-based care coordination intervention, Partners in Dementia Care (PDC), for veterans with dementia and their family caregivers. Essential features of PDC included (a) formal partnerships between Veterans Affairs (VA) medical centers and Alzheimer's Association Chapters; (b) a multidimensional assessment and treatment approach, (c) ongoing monitoring and long-term relationships with families, and (d) a computerized information system to guide service

delivery and fidelity monitoring. **Design and Methods:** Data illustrating the use of the intervention were displayed for 93 veterans and their caregivers after 12 months in PDC. Descriptive data were provided for each major component of the intervention protocol, including: initial assessment, goals, action steps, and on-going monitoring. Care coordinators completed a 12-item questionnaire ascertaining the acceptability and feasibility of implementing PDC. **Results:** Data from the assessments and

goals indicated areas of need were not limited to any one issue or subset of issues, but were widely distributed across a variety of domains. Findings for action steps suggested a primary focus on getting/giving information and action-oriented tasks to access services and programs. Most action steps were assigned and completed by veteran's spouses and the majority were successfully accomplished. On average, families had two contacts per month with care coordinators. Few barriers were indicated by care coordinators in implementing PDC, highlighting the acceptability and feasibility of the PDC protocol.

Implications: PDC addressed the diverse needs of individuals with dementia and their caregivers, including important non-medical care issues, such as understanding VA benefits, accessing community resources, and addressing caregiver strain. PDC proved to be a feasible model that was complementary to the existing programs of the 2 partnering organizations.

Key Words: Dementia, Caregiving, Intervention, Care coordination

Dementia affects the entire family by negatively impacting multiple domains including physical health, emotional health, social relationships, and legal and financial issues (Gurland, 1980; Kunik, Snow, et al, 2003; Schulz, Visintainer, & Williamson, 1990; Wright, Clipp, & George, 1993). Particularly challenging is accessing the range of services needed to address the care needs of both the individual with dementia and the primary family caregiver. Common issues include obtaining adequate diagnostic testing, understanding treatment options and medications, difficulties with memory and behavioral symptoms, and care- and illness-related strain (Mitnick, Leffler, & Hood, 2010). Additionally, many unmet care needs are the result of service fragmentation and inadequate communication among different medical providers, medical providers and consumers, and medical providers and community services (Reuben et al., 2009).

The Veterans Affairs (VA), the largest health care system in the United States, supports innovative approaches to comprehensive care for more than 570,000 veterans with dementia (Office of Assistant Deputy Under-Secretary for Health, 2004). Traditionally, care for veterans with dementia is managed by VA primary care clinicians who predominantly attend to diagnostic

assessment and medication management (Kunik, Walgama, et al., 2007). Less attention is given to care management for patients and their caregivers, with social work services referred to on an as-needed basis.

This article describes an innovative care coordination intervention designed to address the unmet care needs of individuals with dementia and their family caregivers across all dementia stages. The intervention is being tested in Partners in Dementia Care (PDC), a project involving 508 veterans with dementia receiving primary care from the VA health care system and 486 of their informal family caregivers. The total sample includes both intervention and comparison participants. Twenty-two veterans did not have a primary family caregiver but still participated. Two communities are intervention sites, Boston, MA, and Houston, TX, and three are comparison sites, Providence, RI, Beaumont, TX, and Oklahoma City, OK. This article describes the PDC care coordination intervention and illustrates how the intervention was used by a subset of families who completed their 12 months in the study. Additionally, data from care coordinators describes the acceptability and feasibility of PDC.

PDC builds upon two previous studies: the Cleveland Alzheimer's Managed Care Demonstration (Bass, Clark, Looman, McCarthy, & Eckert, 2003) and the Chronic Care Networks for Alzheimer's Disease (CCN/AD, Maslow & Bass, 2003; Maslow & Selstad, 2001). The Cleveland Alzheimer's Managed Care Demonstration was a randomized controlled trial that confirmed the efficacy of an early version of the PDC intervention with families from one non-VA health care system and one Alzheimer's Association Chapter. CCN/AD confirmed the feasibility of the care coordination intervention in 10 sites, including five VA medical centers (Maslow & Selstad, 2001).

Conceptual Framework for the PDC Intervention

The PDC care coordination intervention is a telephone-based coaching program based on the Chronic Care Model, a widely used framework for developing successful and sustainable health care interventions (Bodenheimer, Wagner, & Grumbach, 2002a, 2002b). Components of the Chronic Care Model as implemented by PDC included (a) formal linkages between medical centers (the VA) and community agencies (the Alzheimer's Association), (b) organizational support from key leaders and

broad-based training about PDC, (c) delivery system redesign and decision support systems, (d) self-management of dementia as outlined by the PDC intervention protocol, and (e) the development of the PDC care coordination information system (CCIS) as the clinical information system.

Formal Linkages Between VA Medical Centers and Alzheimer's Association Chapters

PDC is implemented through formal partnerships between the VA and local Alzheimer's Association Chapters. The foundation for the partnerships are the complementary strengths of each organization: the VA's patient-focused diagnostic, disease, care management, and medical services and the Alzheimer's Association's supportive services and family caregiver-focused message of help and hope. Formal functioning of the partnership was facilitated by (a) support from organizational leaders; (b) establishment of site champions; (c) Memorandums of Understanding that described roles and responsibilities; (d) staff training within and across organizations; and (e) equity between the VA and Alzheimer's Association in grant funding, workload, and decision making for delivery of the intervention.

Organizational Support From Key Leaders and Broad-Based Training About PDC

Critical to the success of PDC was initial and ongoing support from key leaders and site champions at both organizations. Administrative and/or physician site champions at the VA and the Alzheimer's Association (AA) were selected and served as advocates for PDC. Leaders and champions assisted with identifying ways that PDC complements and supplements existing services; communicating and training VA physicians, nurses, social workers, and support staff; and encouraging referrals to PDC.

Initial and ongoing training was important in educating staff about PDC. Training focused on tools and protocols for diagnosing dementia, description of the PDC care coordination intervention, and procedures for referring patients. Additionally, training sessions allowed both partner organizations to receive and provide information about project roles and responsibilities, available services and resources, and procedures for sharing information and coordinating cases. Training was conducted in an ongoing fashion throughout the duration of the project and

consisted of biweekly conference calls that reviewed and allowed for discussion about the PDC protocol, case reviews, fidelity monitoring of the intervention, and troubleshooting implementation barriers.

Delivery System Redesign and Decision Support Systems

A key part of implementing health care interventions is changing internal organizational structures to facilitate and support the new program. In PDC, two key staff positions essential for implementing the intervention were added to the existing staff structure at each intervention site: the VA Dementia Care Coordinator (VA DCC) who worked in the VA, and the Alzheimer's Association Care Consultant (AA CC) who worked in the Alzheimer's Association Chapter. VA DCCs and AA CCs worked collaboratively with families; were bachelor or masters prepared social workers, nurses, or counselors; together comprised one full-time job equivalent; jointly maintained caseloads of 75–120 caregiving families; and had part-time administrative support. For the other portion of their work time, care coordinators worked on other grant-related activities at the VA or other service and support programs at the AA. VA DCCs primarily focused on veterans' medical and non-medical needs and assisted families with effectively using VA resources; AA CCs primarily focused on needs of informal caregivers such as care-related strain and accessing non-VA resources. To a lesser extent, AA CCs also addressed non-medical needs of veterans that were beyond the scope of VA resources.

Features of decision support systems included procedures for referring patients to the study; promoting coordinated care involving physicians, nurses, social workers, and Alzheimer's Association staff; and protocols for implementing the care coordination intervention. These protocols included guidelines for frequency and timing of contacts with patients and caregivers and procedures for working collaboratively between organizations.

Self-Management of Dementia as Outlined by the PDC Intervention Protocol

Chronic illnesses present unique and complex issues that thwart an individual's ability to cope and manage symptoms and dementia is no exception. Based on the Chronic Care Model, self-management is an essential component in managing

Contact, Enrollment Information, and Socio-Demographics								
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Figure 1. Summary of data elements in the care consultation information system.

chronic illnesses. PDC had four primary ways of assisting patients and families: (a) providing disease-related education and information, (b) offering emotional support and coaching, (c) linking families to medical and non-medical services and resources, and (d) mobilizing and organizing the informal care network. The intervention protocol consisted of Assessment of Care Needs, Development of Care Goals, Development of Action Steps, and Ongoing Monitoring of Action Steps. All components used a consumer-driven philosophy, with care coordinators acting as advisors and coaches to empower dyads to manage their care. Although all veterans had diagnosed dementia, they were included in care planning and decision making whenever possible.

Because PDC was a research study, it was time limited with veterans and caregivers receiving the intervention for 12 months. Once completed, dyads received transition planning where they reviewed their progress, discussed current and

future goals, made a final Action Plan, and received contact information for the continuation of usual AA and the VA services and support.

Development of the PDC CCIS as the Clinical Information System

Clinical Information Systems are important for documenting and coordinating care across partner organizations. In PDC, the CCIS facilitated communication between VA DCCs and the AA CCs and functioned as a shared record, care planning tool, and fidelity monitoring tool. Developed in Excel, the CCIS was designed for easy use and was transferred between the two interventionists via encrypted e-mail in accord with VA approved business agreements. Figure 1 displays the data elements recorded in the CCIS organized by six categories: (a) contact, enrollment information, and sociodemographics; (b) assessment of care needs; (c) development of goals; (d) development

Table 1. Selected Characteristics of Patients and Caregivers

	Patient (<i>n</i> = 93)		Caregiver (<i>n</i> = 90)	
	Number	Mean or percent	Number	Mean or percent
Age (years)	—	80.0	—	69.2
White	79	84.9%	76	84.4%
Men	88	94.6%	7	7.8%
Education				
Eighth grade or less	14	15.1%	2	2.2%
Attended high school, did not graduate	13	14.0%	9	10.0%
Completed high school	22	23.6%	26	28.9%
Vocation training post high school	8	8.6%	5	5.5%
Attended college, did not graduate	11	11.8%	25	27.8%
College graduate	19	20.4%	16	17.8%
Graduate degree	6	6.5%	7	7.8%
Caregiver is next of kin	—	—	85	94.4%
Caregiver relationship to patient				
Wife	—	—	60	66.7%
Daughter	—	—	18	20.0%
Husband	—	—	2	2.2%
Son	—	—	3	3.3%
Other	—	—	7	7.8%

of action steps; (e) ongoing monitoring; and (f) information/education resources. Based on learnings from the Cleveland Alzheimer's Managed Care Demonstration and CCN/AD, care coordinators received specific training on how to use the CCIS along with how to develop and write goals and action steps. Goals and action steps were designed to match the priorities of the dyads and were customized based on dyad's particular care issues.

Implementation of the Care Coordination Intervention

CCIS data from a sample of 93 caregiving dyads that completed the 12-month intervention illustrated how the care coordination intervention was implemented and used. Data describe demographics and impairment, assessed care needs, goals, action steps, ongoing monitoring of action steps, and amount of interaction between dyads and care coordinators. The 93 families included in this analysis represented both intervention sites, with 43 from Houston and 50 from Boston. Selected data from the initial research interview, which is completed prior to beginning the intervention, showed no significant differences between these 93 cases and the full study sample for age of veterans and caregivers, relationship of veterans and caregivers, race of veterans, employment status of caregivers, method of referral to the study, and severity

of veterans' cognitive impairment based on the Blessed Orientation, Memory, and Concentration test (Katzman et al., 1983).

Recruitment and Characteristics of Veterans and Caregivers

Two methods were used to recruit veterans and their family caregivers: (a) direct referrals from physicians of veterans recently diagnosed with dementia and (b) search of VA electronic medical records for veterans with a dementia diagnosis given in the two years prior to beginning PDC.

Demographic characteristics of recruited veterans and caregivers are presented in Table 1. Nearly all veterans were men (94.6%) and nearly all caregivers were women (92.2%). The majority of veterans (70.9%) and caregivers (87.8%) completed high school and nearly 16% identified themselves as members of a minority group. On average, veterans received their diagnosis 2.39 years (*SD* = 2.01) prior to the study. As measured by the Functional Activities Questionnaire (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Personal Maintenance Scale (Lawton and Brody, 1969), 82.2% of veterans were experiencing moderate to severe difficulties with instrumental activities of daily living and 42% were experiencing moderate to severe difficulties with personal activities of daily living.

Table 2. Number and Percent of Triggered Assessment Domains ($n = 93$)

Assessment domains	Patient triggered domains		Caregiver triggered domains	
	Number	Percent	Number	Percent
Patient and caregiver				
Health information	10	10.8%	17	18.3%
Legal and financial planning	17	18.3%	27	29.0%
Understanding benefits	16	17.2%	21	22.6%
Financial concerns	6	6.5%	16	17.2%
Anxiety	20	21.5%	34	36.6%
Depression	23	24.7%	30	32.3%
Dyadic relationship strain	6	6.5%	19	20.4%
Informal support	11	11.8%	32	34.4%
Social isolation	17	18.3%	43	46.2%
Formal services	12	12.9%	25	26.9%
Emotional support	11	11.8%	27	29.0%
Sleep	22	23.7%	27	29.0%
Patient only				
Cognitive status	3	3.2%	—	—
Coexisting medical conditions	11	11.8%	—	—
Instrumental activities of daily living	27	29.0%	—	—
Personal care	32	34.4%	—	—
Medications	25	26.9%	—	—
Sensory issues	36	38.7%	—	—
Difficult behaviors	22	23.7%	—	—
Risk of falling	32	34.4%	—	—
Home safety	24	25.8%	—	—
Pain	23	24.7%	—	—
Nutritional status	11	11.8%	—	—
Caregiver only				
Physical and emotional strain	—	—	33	35.5%
Capacity to provide care	—	—	41	44.1%
Total number of triggered domains = 809				

Of the 55 veterans able to complete the short Blessed Orientation, Memory, and Concentration test (Katzman et al., 1983) by telephone, the mean number of errors was 12.80 ($SD = 6.77$), with 72.7% having 10 or more errors, a score consistent with dementia. Twenty-three veterans were too cognitively impaired to complete the Blessed, and nine had severe hearing or speech impairments. (Six veterans refused or had missing data.) Data for the Blessed highlighted the wide range of dementia symptoms experienced by veterans, although the majority had moderate to severe symptoms.

Assessment of Care Needs

The first step of care coordination was a multi-dimensional assessment that addressed 23 domains for veterans and 14 domains for caregivers. Designed for efficiency, assessment began with VA DCCs completing a set of structured trigger questions to screen for potential problems. Trigger questions were completed separately for veterans and care-

givers and were based on self-report information and care coordinator's clinical judgment. For veterans too impaired to provide self-report information, questions were administered to their caregivers. If a domain was "triggered," follow-up assessment questions were administered to collect more detailed information about the scope, severity, or urgency of the care issue. Assessment questions were based on standardized research and clinical tools (i.e., Center for Epidemiologic Studies Depression Scale, Radloff, 1977; relationship strain, Zarit, Reever, & Bach-Peterson, 1980). The decision about whether to use further assessment questions was based on care coordinator's judgment. VA DCCs took primary responsibility for administering assessment questions for veterans; AA CCs took primary responsibility for administering assessment questions for caregivers. Triggers and the optional assessment questions were completed within the first two to three telephone contacts.

CCIS data from the 93 caregiving dyads indicated 809 assessment domains triggered as potential

problems or concerns; an average of 8.7 domains per case ($SD = 5.5$). The median number of triggered domains was 8.0. This included an average of 4.5 for veterans ($SD = 3.5$) and 4.2 for caregivers ($SD = 3.1$). Table 2 presents the number and percent of triggered assessment domains.

The most commonly triggered domains pertained to approximately one third of veterans and were concerns about sensory issues, that is problems with vision, speech, or hearing (38.7%), personal care (34.4%), instrumental task assistance (29%), and falling (34.4%). About one fourth of veterans triggered: medications (26.9%), home safety (25.8%), problems with pain (24.7%), depression (24.7%), sleep problems (23.7%), difficult behaviors (23.7%), and symptoms of anxiety (21.5%). The least commonly triggered domains were cognitive impairment (3.2%), dyadic relationship strain (6.5%), financial concerns (6.5%), and health information (10.8%).

For caregivers, the most commonly triggered domains were social isolation (46.2%) and capacity to provide care (44.1%), followed by anxiety (36.6%), physical and emotional strain (35.5%), need for informal support (34.4%), and depression (32.3%). A wide variety of other domains triggered for approximately one fourth of caregivers and included legal and financial planning (29%), sleep problems (29%), emotional support (29%), need for formal services (26.9%), understanding benefits (22.6%), and dyadic relationship strain (20.4%).

Figures in Table 2 highlight the diversity of care needs, as triggered concerns were not dominated by a small subset of domains. The breadth of triggered domains reinforced the importance of the care coordination intervention's attention to a wide range of medical and non-medical issues. Interventions focusing on a narrow range of topics would have missed many salient problems and concerns.

Once the assessment was completed, care coordinators held a telephone or, on rare occasion, in-person conference to review and discuss results, prioritize needs, and determine who would serve as the "primary" care coordinator. The VA CC was primary when veterans' needs were of greatest urgency; the AA CC was primary when caregivers' needs were the most urgent. The primary coordinator initiated contact with dyads within one week of the case conference. The timing and amount of contact from the secondary coordinator depended on the type and intensity of problems and concerns. Designation of primary coordinator could change as dyad's needs changed.

Development of Goals

Once the assessment was completed, care coordinators and dyads developed specific goals. Consistent with the intervention's consumer-driven philosophy, goals matched the priorities of veterans and caregivers, unless there were concerns about abuse, neglect, exploitation, or safety. This means not all triggered assessment domains translated into goals.

There were a total of 488 goals for the 93 caregiving dyads, with an average of 5.2 goals per case ($SD = 2.8$); the median was 5. Table 3 displays the number and percent of goals corresponding to each assessment domain. Figures indicated that goals did not cluster on one domain or even a small subset of domains. The diversity of domains associated with goals was consistent with the broad range of triggered assessment domains.

For veterans, domains most likely to have goals were sensory issues (17.2%), preventing falls (17.2%), personal care (17.2%), legal and financial planning (15.1%), and home safety (15.1%). Goals for dyadic relationship strain (1.1%), financial concerns (3.2%), instrumental daily activities (3.2%), and pain (4.3%) were rare. For caregivers, assessment domains most likely to have goals were accessing formal services (28%), getting emotional support (22.6%), improving the capacity to provide care (18.3%), and understanding benefits (17.2%). Domains least likely to have goals were sleep (2.2%), financial concerns (4.3%), and depression (5.4%).

For two domains that applied to both care partners, accessing formal services and emotional support, there was considerable disparity in goals for caregivers compared with goals for veterans. Approximately one fourth of caregivers had goals for these two domain (28% accessing formal services, 22.6% emotional support), whereas veterans rarely had goals for these two domains (6.5% and 8.6%, respectively).

Table 4 lists the number and percent of goals developed jointly by the care coordinators and caregiving dyads according to 13 predetermined content areas. Nearly all goals (92.2%) fit into a single content area, with a small portion (7.8%) being multifaceted and falling into two or three categories. The 13 categories correspond to the 4 major ways the intervention assisted families (i.e., providing disease-related education and information, offering emotional support and coaching, linking families to medical and non-medical

Table 3. Number and Percent of Patients and Caregivers With Goals for Assessment Domains ($n = 93$)

Assessment domains	Patient goals		Caregiver goals	
	Number	Percent	Number	Percent
Patient and caregiver				
Health information	6	6.5%	8	8.6%
Legal and financial planning	14	15.1%	7	7.5%
Understanding benefits	8	8.6%	16	17.2%
Financial concerns	3	3.2%	4	4.3%
Anxiety	9	9.7%	9	9.7%
Depression	10	10.8%	5	5.4%
Dyadic relationship strain	1	1.1%	7	7.5%
Informal support	5	5.4%	8	8.6%
Social isolation	5	5.4%	11	11.8%
Formal services	6	6.5%	26	28.0%
Emotional support	8	8.6%	21	22.6%
Sleep	6	6.5%	2	2.2%
Patient only				
Cognitive status	5	5.4%	—	—
Coexisting medical conditions	5	5.4%	—	—
Instrumental activities of daily living	3	3.2%	—	—
Personal care	16	17.2%	—	—
Medications	4	4.3%	—	—
Sensory issues	16	17.2%	—	—
Difficult behaviors	11	11.8%	—	—
Risk of falling	16	17.2%	—	—
Home safety	14	15.1%	—	—
Pain	4	4.3%	—	—
Nutritional status	5	5.4%	—	—
Caregiver only				
Physical and emotional strain	—	—	10	10.8%
Capacity to provide care	—	—	17	18.3%
Total number of developed goals = 488				

services and resources, and mobilizing and organizing the informal care network) supplemented by the most frequently reported unmet needs by families who participated in the CCN/AD initiative (Maslow & Bass, 2003). Interrater reliability between two independent raters was tested for one

third of the sample ($n = 31$ cases) and was established at 91% agreement.

As presented in Table 4, approximately one fifth of goals focused on providing educational information (21.3%) or accessing non-VA and non-Alzheimer's Association services (16.8%). Approximately 10% of goals pertained to: accessing Alzheimer's services (12.7%), accessing VA benefits and services (10.2%), and coping and providing support (8.4%). The least commonly developed goals related to interacting with health care providers (2.9%), managing medications (2.5%), and altering living arrangements (2.0%). The vast majority of goals corresponded to the four main functions of the PDC care coordination: education, support, accessing formal services, and mobilizing the informal care network.

Development of Action Steps

Action steps were concrete behavioral tasks intended to help families move toward goal

Table 4. Content of Goals ($n = 488$)

Content areas	Number	Percent
Get or give information	104	21.3%
Access other services (non-VA and non-Alzheimer's association)	82	16.8%
Access Alzheimer's services	62	12.7%
Access VA benefits and services	50	10.2%
Help cope and provide informal support	41	8.4%
Safety	33	6.8%
Manage coexisting medical conditions	25	5.1%
Manage symptoms	22	4.5%
Assess problems	17	3.5%
Access non-VA benefits	16	3.3%
Interact with health care providers	14	2.9%
Manage medications	12	2.5%
Alter living arrangement	10	2.0%

Table 5. Content of Action Steps ($n = 689$)

Content areas	Number	Percent
Get or give information	307	44.6%
Access VA benefits and services	98	14.2%
Access Alzheimer's services	87	12.6%
Access other services (non-VA and non-Alzheimer's association)	70	10.2%
Interact with health care providers	29	4.2%
Help cope and provide informal support	28	4.1%
Safety	27	3.9%
Manage symptoms	15	2.2%
Assess problems	8	1.2%
Alter living arrangement	7	1.0%
Access non-VA benefits	5	0.7%
Manage medications	4	0.6%
Manage coexisting medical conditions	4	0.6%

achievement and included the person responsible for completing each task, an expected completion date, and, if relevant, the names of agencies and/or professionals who needed to be contacted. Once the initial set of action steps was completed, a written Individual Action Plan was mailed to families. Action steps were continually added and updated.

On average, 3.3 action steps (median = 3) were implemented per case ($SD = 2.39$) during the 12-month study. Table 5 lists the number and percent of action steps developed jointly by the care coordinators and caregiving dyads according to the same 13 categories used for coding goals. Inter rater reliability for one third of cases resulted in a 93% agreement in coding content of action steps. The most common content of action steps was getting/giving information (44.6%). Collectively, the remaining action steps (55.4%) pertained to action-based tasks that involved care coordinators coaching and working with dyads to "take action" across a wide range of care issues. The most common pertained to accessing VA benefits and services (14.2%), accessing Alzheimer's services (12.6%), and accessing other services (10.2%).

The greatest proportion of action steps was assigned to veteran's spouses (41.9%), which were primarily wife caregivers. This finding highlights the primarily all-male veteran sample (94.6%) and the critical role their wives play in their care. VA DCCs and AA CCs shared an approximately equal number of assigned action steps 14.7% and 16.9% respectively. The even distribution of action steps reinforced the importance of the VA and Alzheimer's Association partnership, as both coordinators were equally involved in assisting with action steps. Remaining action steps were distributed

across a wide range of other individuals including patients themselves (10.5%) and daughters (8%). Very few action steps were assigned to more distant relatives, friends, or service providers (7.9%). Overall, action steps appeared to be dominated by only a few individuals involved in veterans' informal and formal helping networks.

Ongoing Monitoring of Action Steps

Care coordinators monitored the status of action steps on a regular basis to ensure timely completion of tasks, address potential barriers, modify or add action steps, and identify new goals. Depending on the action step, on-going monitoring was completed by the primary, secondary, or both care coordinators. The timeframe for scheduling monitoring calls was dependent upon the care goals and on the intensity of support required. Unless more contact was required, families were contacted minimally on a biweekly basis for the first three months and on a monthly basis after the first three months. Care coordinators met on a weekly basis either by telephone or in person for a minimum of 1 hr per week to review and discuss all active cases. A brief synopsis of the veteran's care plan goals and progress was integrated into their VA electronic medical records. The following CCIS data reflected key components of ongoing monitoring: final disposition, number and length of contacts, and who initiated and received contacts.

The disposition of action steps was coded as: "accomplished," "still in progress after study period," "not accomplished," and "not relevant." The majority of action steps (59%) were successfully accomplished during the 12-month study period. However, a substantial number (41%) of action steps were either not accomplished (20.6%), were still in progress at the end of the 12-month study period (17.3%), or became irrelevant after being established (3.1%). Reasons for not accomplishing action steps included too costly, not perceived as needed/wanted, logistically not feasible, not eligible, or application pending/on waiting list. A large number of action steps ($n = 147$, nearly 26%) did not have disposition codes recorded in the CCIS by clinical staff. This appeared to be the result of random missing information.

On average, care coordinators and dyads had 24.6 contacts during the 12-month study period ($SD = 15.4$) or approximately 2 contacts per month. The median number of contacts was 23. As planned in the PDC protocol, the vast majority (84%) of

Table 6. Number and Percent of Contacts by Initiator and Recipient

Relationship to patient	Contact initiator (<i>n</i> = 2,269)		Contact recipient (<i>n</i> = 2,102)	
	Number	Percent	Number	Percent
VA DCC	1,083	47.7%	231	11.0%
Alzheimer's association care coordinator	884	39.0%	108	5.1%
Spouse	151	6.7%	957	45.5%
Patient/self	5	0.2%	205	9.8%
Other relative	2	0.1%	86	4.1%
Daughter	56	2.5%	293	13.9%
Friend	0	0.0%	18	0.9%
Son	12	0.5%	60	2.9%
Service provider	30	1.3%	134	6.4%
Other	46	2.0%	10	0.5%

Note: Information on the relationship of the person initiating contact is not recorded in the care coordination information system for 19 contacts; information on the person who is the recipient of contacts is not recorded for 186 contacts. VA DCC = VA Dementia Care Coordinator.

contacts were by telephone. On average, telephone contacts between care coordinators and dyads lasted 14 min (*SD* = 5.5), with 28% of calls less than 10 min, 60% of calls between 11 and 20 min, and 12% between 21 and 33 min.

Table 6 presents the number and percent of contacts by the initiator and the recipient. The majority of contacts were initiated by the VA DCC (47.7%) and the AA CC (39%) and were received by veterans' spouses (45.5%) or daughters (13.9%). Nearly equal numbers of contacts were initiated by the VA DCC and AA CC, which underscores the importance of the partnership. Interestingly, only a small number of contacts (16.1%) were initiated by the dyad or someone from their informal network to the VA DCC or AA CC. The relatively low percentage of calls to care coordinators was consistent with the protocol's recommendation that care coordinators schedule and make ongoing follow-up calls. It also suggests it was rare for dyads to contact care coordinators, despite the consumer-driven philosophy.

Acceptability and Feasibility of PDC

Acceptability and feasibility of the care coordination intervention were assessed by surveying six care coordinators (three VA DCCs and three AA CCs) after they had extensive experience working with veterans and caregivers in PDC. The survey was designed to understand care coordinators'

perceptions of barriers to implementing PDC within their communities and respective organizations. Surveyed care coordinators delivered the intervention for a minimum of nine months, with four involved for the entire study period.

Based on measures developed for the provider evaluation of the CCN/AD intervention, the survey included 12-items focused on 3 domains: (a) acceptance and use of PDC by patients and families, (b) physician participation, and (c) organizational partnership barriers. Care coordinators rated each item for how much difficulty ("not a difficulty = 0," "minor difficulty = 1," "major difficulty = 2") it was in implementing PDC.

Two questions measured acceptance and use of PDC by patients and families. Questions asked about patients' and family members' reluctance to accept the dementia diagnosis and willingness to use Alzheimer's Association services. Three questions comprised physician participation domain, including physicians' willingness to recognize dementia, physicians' reluctance to give a dementia diagnosis, and whether physicians viewed dementia as important as other health conditions. Six items represented organizational barriers to PDC including perceptions of problems with the quality of Alzheimer's Association services, problems with the quality of VA services, lack of knowledge of the Alzheimer's Association services, lack of knowledge of the VA services, organizational financial problems limiting the success of PDC, the ability to share patient/family information between partner organizations, and overall challenges in collaboration between organizations.

For the acceptance and use of PDC by patients and families, care coordinators' mean rating was 1.33 (*SD* = 0.41), indicating this was a minor difficulty for implementing PDC. For physician's participation, the mean was 0.58 (*SD* = 0.80), indicating this was not a difficulty or a very minor difficulty. The mean rating for organizational partnership barriers was 0.88 (*SD* = 0.51), indicating these issues also were minor difficulties.

Based on perceptions of care coordinators who were most familiar with PDC, results suggest only minor barriers to implementation. Overall, results reinforce the acceptability and feasibility of the PDC care coordination.

Discussion

PDC incorporated several unique features, distinguishing it from most other services and

programs for dementia caregiving dyads. One unique feature was delivery of the intervention through formal partnerships between VA medical centers and local Alzheimer's Association Chapters. Despite wide differences in the structure and function of these two organizations, one a large bureaucracy dominated by the medical model and the other mission driven with a small professional staff and a large cadre of volunteers, the PDC partnership was feasible and successfully implemented. The equal distributions of action steps and contacts involving VA DCCs and AA CCs highlighted the benefits of combining the strengths and resources of two complimentary organizations.

Inclusion of family caregivers was another unique characteristic. In medical care environments, the needs of informal caregivers are rarely attended to and included in the treatment plan (Reuben et al., 2009). This omission was highlighted by findings in the assessment that showed caregivers had an average of 4.2 problems or concerns pertaining to their ability to provide care and/or cope with their role. Additionally, as evidenced by the high percentage (41.9%) of assigned action steps, patients' spouses played an integral role in managing illness-related symptoms. These findings pointed to the importance of addressing caregivers' needs, which if ignored place individuals at high risk for negative caregiving consequences and jeopardize the home care situation.

A third feature was the breadth of issues addressed for veterans and caregivers. Problems were widely distributed across 25 potential areas of need, with no one need or small group of needs dominating the intervention and was reinforced by variation in the content of goals, as well as differences between veterans' needs and caregivers' needs. These findings suggest that broad-based interventions may be more effective in addressing the myriad issues faced by families across the continuum of the illness.

A fourth important feature of PDC was the use of a consumer-directed philosophy that enabled dyads to actively engage in their care, which also is consistent with the recommendations put forth by the Institute of Medicine (2008). The consumer-directed philosophy distinguished care coordination from case management, counseling, and other in-person programs and services. It also enabled care coordinators to serve a large number of families in a cost-efficient way because veterans and families were taking action on their own with support and guidance from VA DCCs and AA CCs.

Interestingly, few caregivers initiated contact with care coordinators. This finding was somewhat surprising given the consumer-directed philosophy of PDC. However, caregivers may have been less likely to proactively contact care coordinators because they were receiving regularly scheduled phone calls as outlined in the PDC protocol for ongoing monitoring. Therefore, caregivers may have been comfortable with the amount of contact they received and did not experience a need for further contact. These results highlight the importance of ongoing monitoring and the essential role of including the caregiver, as most individuals with dementia would be less likely to contact a service provider on their own and for some, actively participate in the on-going monitoring phone calls.

A final feature was the telephone-based method for delivering the intervention, which enabled maintenance of long-term relationships in a time- and cost-efficient way. Communication with families occurred, on average, twice a month. Regular scheduled follow-up calls enabled the Action Plan to be updated and modified, thereby resulting in potentially fewer adverse events and crises. Additionally, the telephone format was appropriate for families who lived in rural areas that are often underserved, and families who have difficulty with transportation to appointments. The vast majority of calls (88%) were not overly time consuming (i.e., ≤ 20 min), which was a benefit for time-pressured family members and clinicians.

Implementation is a challenge for any intervention and PDC was no exception. Initial implementation challenges included establishing protocols for sharing client information between partner organizations that were compliant with rules of confidentiality. To date, lessons learned underscored the importance of having knowledgeable and supportive site champions, leaders, and staff along with dedicated time and support from each organization. Foreseeable challenges related to implementation include reconciling community and organizational characteristics across sites; streamlining processes for monitoring intervention fidelity; ongoing staff and training issues; and marketing, cost, and payment sources (Bass and Judge, 2010).

Another challenge for any new intervention program is long-term sustainability. PDC is sustainable because it is consistent with several policy mandates within the VA health care system and broader changes in health care throughout the United States, including the Millennium Act

(1999), the VA Geriatric and Extended Care Strategic Plan (2008), the Olmstead Act (1999), and a number of provisions of the recently passed health care reform bill that involve care coordination (Lind, 2010). These mandates recognize the importance of addressing caregiver needs and supporting veterans living in the community through coordinated services. PDC addressed these issues by (a) decreasing fragmented services by coordinating care through formal VA-AA partnerships, (b) including the family caregiver as an active participant in the treatment of dementia, and (c) assessing and treating a wide range of medical and non-medical care needs for patients and caregivers.

The PDC care coordination intervention was designed to address the myriad care needs of caregiving dyads across the severity of dementia symptoms. Although care coordinators found PDC to be an acceptable and feasible approach, one limitation of the current study was the lack of data to examine whether veterans' and their family caregivers' were satisfied with the PDC protocol. Including such data would have provided valuable information on the acceptability and feasibility of this type of intervention program for caregiving dyads with dementia. Next steps will be to examine the impact of PDC on various psychosocial and service utilization outcomes. Hypotheses posit the intervention will reduce depression, care-related strains, unmet needs, and excess health care costs and service use. If successful, broader implementation of PDC will be explored within the VA and Alzheimer's Association.

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