



A Chronic Care Networks for Alzheimer's Disease (CCN/AD) Project

**Final Report on an Innovative Partnership Between
Veterans Integrated Service Network 2 (VISN 2) &
Four Upstate New York Alzheimer's Association Chapters**

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Executive Summary

Partners in Dementia Care (PDC) was an innovative partnership of the U.S. Department of Veterans Affairs (VA) health care network in upstate New York (VISN 2) and four Alzheimer's Association chapters in the same area. From 1997-2003, these organizations worked together to improve care and outcomes for veterans with Alzheimer's disease and other dementias and their family caregivers.

The model of care used in the PDC project was intended to address four problems that are common in VA and non-VA health care settings: 1) underidentification of possible dementia, 2) lack of adequate diagnostic assessments, 3) lack of coordination between medical care and community services, and 4) lack of information and support for family caregivers. The model includes procedures and tools for early identification, assessment, care management, and family caregiver information and support.

PDC placed strong emphasis on training and conducted a wide array of formal and informal training activities throughout the project. A new VA position, Dementia Care Coordinator (DCC), was created for PDC, and one DCC was placed in each of VISN 2's five medical centers. The DCCs performed many functions related to planning, training, enrollment and assessment of veterans and their families, and ongoing care coordination within VA and between VA and chapters. The DCCs also functioned as a resource and team leader for the many VA physicians, nurses, and other staff who participated in PDC at each medical center. The four Alzheimer's Association chapters were involved in planning, decision-making, and PDC training activities. At enrollment, the DCCs obtained formal consent from veterans and families for the chapters to contact them to offer information, support, and other chapter services. DCCs and chapter staff also provided joint care management for some veterans and families.

PDC was intended not only to improve care for individual veterans and families but also to change the system of care for all veterans with dementia. Efforts were made to expand the project from the VA medical centers where it began to VA outpatient facilities and community centers and, within the VA medical centers, from specialty clinics to primary care. Efforts were also made to institutionalize aspects of the project, for example, by incorporating some of the project's early identification tools into VISN 2's computerized clinical reminder system.

Results. PDC identified, enrolled, and served more than 550 veterans and 500 family caregivers. An extensive evaluation conducted by an independent research team focused primarily on the feasibility of the intervention and its impact on veterans and their families. For various reasons, control groups were not used. Descriptive data were collected on the veterans and families who enrolled and their use of VA and chapter services. Three waves of mailed questionnaires and telephone interviews were used to obtain the perceptions of VA and chapter staff, veterans who were able to respond, and their families.

Evaluation findings show many positive outcomes. VA and chapter staff were enthusiastic about the model, the training, and the VA/Chapter partnership. They agreed on average that PDC improved quality of care and outcomes for veterans and families, increased their own ability to provide care, and gave them confidence that services needed by veterans diagnosed with dementia were available.

Almost all veterans who enrolled in PDC received the recommended diagnostic assessment, and more than half of the families chose to use chapter services. Veterans and caregivers who participated in the telephone interviews reported on average that they had received enough information or help with important areas of care, including treatment options, family concerns, daily living tasks, and legal and

financial issues. Veterans and caregivers who used chapter services were more likely to say they had enough information or help with these areas of care. Those who said they had enough information or help with particular areas of care were more likely to be satisfied and less likely to have symptoms of depression and other negative psychosocial outcomes.

Use of VA health care services changed very little between the 6 months before enrollment in PDC and 6 months after enrollment. Use of chapter services was associated with a higher likelihood that the veteran would have a VA primary care visit and, for veterans with mild memory impairment, a larger number of primary care visits. For veterans with moderate to severe memory impairment, use of chapter services was associated with a lower likelihood of having a specialty physician visit.

In addition to these findings, PDC data indicate many findings and associations that did not reach statistical significance but suggest important areas for future research.

Conclusions and Recommendations. The positive findings from PDC are encouraging. With funding from the Robert Wood Johnson Foundation, the PDC project team has used these findings and experiential learning from implementation in VISN 2 to refine the project model. The resulting best practice model is now ready for implementation in other VA health care systems and rigorous testing with a treatment/control group research design.

Conclusions about the impact of PDC on the use and cost of VA health care services for veterans with dementia must await the results of this research. In the meantime, some PDC procedures were clearly feasible and well accepted. These procedures could be incorporated in quality improvement projects in VA health care settings. They include: the early identification procedures and tools; involvement of nonphysician providers, including all clinic staff, in identifying people with possible dementia who need a diagnostic assessment; and the VA/Chapter partnership, including the consent process that allows chapters to initiate contact with families rather than waiting for families to call the chapter.

Anecdotal reports and previous research findings suggest that some physicians are reluctant to identify and diagnose dementia because they believe the condition is hopeless and there is “nothing to do” for the person or family. Although not provable with the existing data, it is likely that the VA/Chapter partnership in PDC and the resulting availability of information and support for veterans who received a diagnosis of dementia and their families increased physician willingness to make these diagnoses.

PDC findings indicate that the intervention worked less well for some subgroups of veterans and families. These subgroups include veterans who lived alone, veterans who had more co-existing medical conditions, family caregivers who lacked other relatives and friends to support them in caregiving, and family caregivers of veterans who needed more help with daily living tasks. The best practice model has been refined to address the needs of some of these subgroups, but further work will be needed, especially with respect to veterans who live alone.

VA estimates that in 2005, there are 142,000 veterans with dementia using VA services and about 400,000 additional individuals with dementia in the veteran population as a whole (Department, 2004). Better approaches to identification, assessment, medical and nonmedical care management, and family caregiver information and support are needed to serve this existing and potential patient population. PDC provides a feasible model and valuable findings and experiential learning to address this need.

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Appendix B: Statistical Tests for PDC Results – not included in this document

I. Introduction and Background

Partners in Dementia Care (PDC) was a joint project of the U.S. Department of Veterans Affairs (VA) Veterans Integrated Service Network in upstate New York (VISN 2) and four Alzheimer's Association chapters. Planning for the project began in 1997. The first veteran was enrolled in 2000, and the evaluation ended in 2004. The project goal was to improve care and outcomes for veterans with Alzheimer's disease and other dementias and their families through staff training, early identification and assessment, coordinated medical and non-medical care, and family information and support.

The Upstate New York site was one of six sites in the Chronic Care Networks for Alzheimer's Disease (CCN/AD) project, a national demonstration initiated by the Alzheimer's Association and the National Chronic Care Consortium (NCCC) (Maslow and Selstad, 2001).¹ Each CCN/AD site was a partnership of one or more Alzheimer's Association chapters and a health care system that was a member of NCCC. VISN 2 was the only VA network that participated in CCN/AD; it was eligible to participate because VA was a member of NCCC, and VISN 2 was its designated NCCC representative. VISN 2 and Alzheimer's Association chapter staff called their project "Partners in Dementia Care" to reflect the importance of partnership and the primary goal of the project.

CCN/AD used a "learning laboratory" approach to develop and implement a new model of coordinated dementia care. VISN 2 staff, their Alzheimer's Association chapter partners, and VA Central Office staff participated in developing the model and in numerous calls, meetings, and other activities intended to allow the six CCN/AD sites to learn from each other as they implemented the model. The learning laboratory approach was used in order to maximize the real world feasibility and relevance of the model. Although the model defined the basic components of coordinated dementia care, sites differed, as expected, in exactly how they implemented each of the components.

This report focuses on PDC, the Upstate New York site. It describes the partnering organizations and the way the CCN/AD model was implemented in that site. An extensive evaluation of the site was conducted by the same team of independent researchers that evaluated the CCN/AD project as a whole. This report describes the evaluation and presents the most important research findings for the Upstate New York site. A report on combined findings for all CCN/AD sites, including some comparisons between VA and non-VA sites, is being prepared and will be available in the fall 2005.

II. Methods

A. PDC Partnering Organizations

VISN 2 is an integrated health care delivery system composed of inpatient facilities, outpatient clinics, nursing homes, and home and community-based services. Acute inpatient and nursing home care are provided at five locations: Albany, Western NY (Buffalo and Batavia), Syracuse, Canandaigua, and Bath. Outpatient care is provided at 29 community-based outpatient clinics (CBOCs) throughout the network. With a service area of 42,925 square miles, VISN 2 encompasses 47 counties in New York State and two counties in northern Pennsylvania. In 2000, an estimated 574,000 veterans lived in this service area, and VISN 2 served about 18% of those veterans (VA Health Care Network, 2004).

¹ The other 5 sites were in San Francisco, Denver, Minneapolis/St. Paul, Philadelphia, and Troy/Albany, NY.

Four Alzheimer's Association chapters serve approximately the same geographic area (minus the two Pennsylvania counties). The chapters provide support and services for people with Alzheimer's disease and other dementias, their families, and other caregivers. Chapter services include information and referrals, family support groups and training programs, early stage support groups for people with dementia, care consultation, the Safe Return Program for wanderers, and training for service providers.

VA facilities have broad clinical expertise in diagnosing and managing medical disorders and provide a continuum of acute and chronic health care services. Alzheimer's Association Chapters have extensive experience in providing information and support for individuals with dementia and their caregivers. By working together, VISN 2 and the four chapters hoped to combine their expertise, experience, and services to provide better access to a wider array of services and coordinated medical and non-medical care for veterans with dementia. This common purpose and their geographic proximity facilitated the development of their working partnership.

B. Project Model

The CCN/AD model of coordinated dementia care was developed by health care and chapter representatives from the six CCN/AD sites, including the Upstate New York site. The model was intended to address problems with under-identification of dementia, frequent lack of standardized dementia diagnosis and assessment, fragmented service delivery, and insufficient information and support for family caregivers. Its four components are listed below and described in detail in a 40-page document that includes assessment instruments and other tools for implementation.²

- Early identification: the model uses two procedures: training for all staff about signs and symptoms of possible dementia and a brief family questionnaire.³
- Initial dementia assessment: the model uses assessment procedures divided into three categories: those that should be done for every person, those that should be done unless there is a good reason not to do them, and those that should only be done if there is a good reason to do them.⁴
- Care management: the model uses care blueprints that show desired outcomes, areas for assessment and goal formation, and possible interventions in six domains (medical treatment planning, patient functioning, patient nutrition, psychosocial care, caregiver support, and advance directives) for the early, middle, and late stages of dementia; the blueprints provide information sites can use to develop site-specific care protocols.
- Family caregiver information and support: the model uses grids with project objectives for family caregivers in six stages of caregiving (prediagnostic, diagnostic, role change, chronic caregiving, transition to alternative care, and end of life); the grids provide a tool sites can use to identify available programs and materials to achieve the objectives.

² *Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia* can be downloaded from the Alzheimer's Association website at www.alz.org/Resources/FactSheets/CCN-AD03.pdf.

³ Three sets of signs and symptoms, or "triggers," were used for identification of possible dementia: 1) the Alzheimer's Association's Ten Warning Signs (see *Tools*, p. 6, 2003); 2) a list of Behavior Triggers for Clinical Staff (see *Tools*, p.7, 2003); and 3) the Agency for Health Care Policy And Research (now AHRQ) "Symptoms That May Indicate Dementia" (Costa et al., 1996). The Family Questionnaire was developed for CCN/AD (see *Tools*, p. 9, 2003).

⁴ The assessment instruments included in the model are: the Mini-Mental State Examination (MMSE) (Folstein et al., 1975), Katz Activities of Daily Living (ADL) Scale (Katz et al., 1963); Functional Activities Questionnaire (FAQ) (Pfeffer et al., 1982); Geriatric Depression Scale (GDS) (Yesavage et al., 1983); Cognitive Incapacity & Problem Behaviors Assessment (Bass et al., 1994); and MBR Caregiver Strain Instrument (Bass et al., 1996).

C. Project Initiation, Organization, and Funding

VISN 2's network director made the initial decision to respond to a request for proposals for participation in CCN/AD. Once selected, the Upstate New York site was administered primarily through VISN 2's Geriatrics and Extended Care (GEC) Careline. A site coordinator was hired. Two project co-directors were named to represent VA and the chapters, respectively. When the VA co-director transitioned to become the project's clinical director, another VA co-director was named.

The Upstate New York site was more complex than the other five CCN/AD sites because it included five VA Medical Centers (VAMCs) and four Alzheimer's Association chapters. To facilitate planning and implementation, five subsites were identified, based on shared service area.⁵ A new VA position, Dementia Care Coordinator (DCC), was created and filled at each subsite.⁶ Over time, the DCC and primary chapter representative at each subsite became team leaders for the subsite. Each subsite also formed an advisory committee of VA and chapter staff to promote and guide project implementation.

Communication within the Upstate New York site and between the Upstate New York site and other CCN/AD sites took place through teleconferencing, email, and face-to-face meetings. VA videoconferencing facilities were used for monthly meetings of the Upstate New York site.

The Robert Wood Johnson Foundation made grants totaling \$809,507 to support the project in the Upstate New York site.⁷ The Alzheimer's Association made grants totaling \$198,250 to support the four chapters and the non-VA co-director. VISN 2's Educational Council and Eisai, Inc. made grants of \$27,400 and \$5,000 respectively for staff training. VISN 2 contributed an estimated \$1.9 million, including salary and benefits for the five DCCs and in-kind support for staff time, videoconferencing facilities, and meeting space. The four chapters contributed an estimated \$120,000 for staff time and other resources. The Alzheimer's Association, Retirement Research Foundation, and Schering Plough Foundation paid for independent evaluation of the CCN/AD project, including the Upstate New York site. In 2002, the Robert Wood Johnson Foundation made an additional grant of \$244,632 for further analysis of findings from PDC, development of a best practice model based on these findings, and preparation for implementation and rigorous evaluation of that model in other VA networks.

D. Training

The PDC project placed strong emphasis on training and conducted an array of broadly defined training activities intended to: increase awareness of dementia and the PDC project; familiarize VA and chapter staff with the procedures, care practices, and services provided by the other organization; and inform VA and chapter staff about their roles and specific tasks in implementing the project model. To increase awareness of dementia and the PDC project, information sessions were conducted at the VAMCs and chapters, and print materials with the PDC logo were distributed throughout the VAMCs and at local health fairs. Cross-organizational sessions were held to familiarize VA and chapter staff

⁵ The VAMC and chapter partners in the five subsites were as follows: 1) Albany VAMC and Northeastern NY Chapter; 2) Syracuse VAMC and Central NY Chapter; 3) Western NY VAMC and Western NY Chapter; 4) Canandaigua VAMC and Rochester Chapter and 5) Bath VAMC and Rochester Chapter. (The Rochester Chapter was a partner in two subsites.)

⁶ The five DCC positions were filled by a nurse practitioner, 3 nurses, and a social worker.

⁷ These funds paid for the site coordinator, research assistants at each subsite, chapter coordinators, the non-VA co-director, materials, meetings, and other project expenses.

and board members with each other's organization. A standardized curriculum was developed and presented at each VAMC early in the project. The curriculum described the project and the model of coordinated dementia care. It emphasized the importance of the VA/chapter partnership and described the roles and tasks of VA and chapter staff in implementing the project.

Training activities continued throughout the project. Multiple approaches were used, including formal lectures, train-the-trainer sessions, small discussion groups, videoconferencing, videotapes, computer learning, one-on-one instruction, and "lunch and learn," breakfast, and dinner meetings. Formal training sessions were evaluated, and VA staff who attended these sessions received CME credits.

E. Veteran Referral and Enrollment

Veterans with symptoms of possible dementia and/or a diagnosis of dementia could be referred to the project by many different sources. To encourage referrals, posters and brochures with information about symptoms of possible dementia and procedures for referring a veteran to the project were displayed in VAMC hallways, lobbies, and clinic waiting areas and distributed at employee and community health fairs. The Behavior Triggers for Clinical Staff (*Tools*, p. 7, 2003) were printed in prescription pad format for use in primary care clinics, where clerks, nurses, and other staff could check off symptoms and attach the form to the veteran's file to indicate a need for further evaluation and possible enrollment in the project. Family members and other caregivers who came in with an elderly veteran for a clinic visit were asked to complete the brief Family Questionnaire (*Tools*, p. 9, 2003) after the veteran gave verbal consent. Questionnaires with scores above a specified level were attached to the veteran's file to indicate a need for further evaluation and possible enrollment in the project. VA telecare nurses, adult day health care staff, and home-based primary care clinicians also referred veterans to the project. The Alzheimer's Association chapters revised the general scripts for their telephone information and referral Helplines to ask whether a caller was a veteran or calling about a veteran, and if so, whether he/she wanted to be referred to VA for possible services and enrollment in the PDC project. Callers who said yes were given the DCC's name and telephone number.

Referrals from all these sources were received by the DCCs, who then did a preliminary verification of the veteran's eligibility for VA services, determined whether the veteran already had a dementia diagnosis, and referred veterans for further diagnostic evaluation, if needed. Veterans diagnosed with dementia and their family and other caregivers were asked by the DCC if they wanted to enroll in the project. If so, the DCC took them through the consent process approved by the VAMC Research and Development Committee for each subsite. The approved consent forms described the project and the exact information that would be released to the chapter⁸ and the national evaluation team.⁹

The Upstate NY site enrolled 574 veterans and 533 family and other caregivers in the period from early 2000 through the fall 2002. Only 50 veterans and 14 family caregivers disenrolled, and these disenrollments were due primarily to the veteran's death or relocation out of the network service area.

⁸ The only information released to the chapter was the name, address, and phone number of the veteran and/or family.

⁹ Each enrolled veteran was assigned a research number, and all project data released to the national evaluation team were identified by that number; no names or social security numbers were released to the national evaluation team.

F. Dementia Diagnosis and Assessment

When project enrollment began, diagnostic evaluations were conducted in the Memory Disorders Clinic at the three VAMCs that had such a clinic. Over time, routine diagnostic evaluations at these VAMCs were increasingly conducted in primary care, while the Memory Disorders Clinics continued to evaluate atypical and complex cases. At the two VAMCs that did not have a Memory Disorders Clinic, diagnostic evaluations were conducted in primary care or through referral to a VA specialist physician.¹⁰ As expected, the recommended instruments to assess veterans' functional status and caregiver perceptions and strain were usually completed by the DCC or other non-physician providers.

G. Care Management and Family Information and Support

The project model includes blueprints for medical and non-medical care in six domains for three time periods (*Tools*, pp. 24-30, 2003). As intended, VA and chapter staff used these blueprints to create subsite protocols for care. VA and chapter staff also completed the grids for identifying programs and materials needed to achieve the project's objectives for family caregivers. This activity helped to familiarize staff from each organization at a subsite with their partnering organization's programs and resources. It also helped to identify gaps in needed programs and materials. The completed tools were too cumbersome for daily practice, and more concise resource lists were used for this purpose.

Each VAMC created a resource room with informational materials for veterans, their families and other caregivers, and VA staff. Staff were informed about the resource rooms and encouraged to let veterans and their caregivers know about the materials available for their use.

Once veterans and their family and other caregivers were enrolled in the project, they were given a packet of information from the chapter. The DCC completed an initial care plan or referred them to the veteran's VA primary care case manager with suggestions for the care plan. The DCC notified the chapter of the enrollment and the names and phone numbers of the veteran and caregiver. The chapter then called the veteran and/or caregiver, described existing chapter services, and encouraged the veteran and/or caregiver to use any potentially helpful services. These proactive calls were possible because the consent forms obtained by the DCC at the time of enrollment included consent for the chapter to contact the veteran and/or family. Without such consent, chapters can only respond to calls they receive. Chapters' experience is that families often take years to follow through on a referral to the chapter, and some never contact the chapter. The proactive calls were intended to avoid these problems and allow chapters to reach veterans and their caregivers earlier with the offer of assistance.

The DCC and chapter care coordinator at each subsite communicated daily, weekly, or monthly, as needed, about veterans and families who were enrolled in the project. In this way, they attempted to coordinate the veteran's medical and non-medical care and provide consistent messages and support for the veteran and family. Communication was more frequent when a veteran and family were in crisis, and DCCs and chapter care coordinators occasionally made a joint home visit at such times.

Care management practices and communication between the DCC and chapter care coordinator differed across subsites and evolved over time. Frequent telephone and in-person meetings of the subsite teams allowed them to share information and learn from each other's experiences.

¹⁰ The recommended diagnostic procedures and assessment instruments were available on a VA intranet website.

H. Systems Change and Sustainability

More than just testing a new model of dementia care, the PDC project was intended to change the system of care, and efforts were made to transition project functions over time to achieve this objective. Although the components of the model were implemented entirely by project staff at the beginning, the effort over time was to have them implemented by regular (non-project) VA and chapter staff. Likewise, although training and implementation began in the five VAMCs, the effort over time was to train CBOC staff and support implementation in those sites. In the three VAMCs that had a Memory Disorders Clinic, the effort over time was to move project functions into primary care. Train-the-trainer programs provided by the chapters allowed VA staff in some subsites to take on training activities the chapters had performed early in the project. Similarly, VA staff in some subsites eventually took over running family support groups that chapters had initiated in the VAMCs.

Project leadership and staff hoped that these efforts to create systems change would make the new model of dementia care sustainable after outside funding and formal evaluation ended. In late 2002 and early 2003, the VAMCs and chapters in all five subsites signed memoranda of understanding (MOUs) that committed them to maintaining their working partnerships. Also in 2003, VISN 2 incorporated a modified version of the project's Behavior Triggers for Clinical Staff and Family Questionnaire into VISN 2' computerized clinical reminder system. This step was intended to institutionalize improvements in identification of possible dementia that had occurred in the project.

I. Dementia Diagnoses in VISN 2

At the beginning of the PDC project, VA staff believed that dementia was substantially under-identified and diagnosed. A small pilot study of veterans in a VISN 2 adult day health program found that only 35% of veterans with probable dementia had any indication in their medical record that dementia had even been considered, and none of the veterans had received an adequate diagnostic evaluation (Palumbo et al., 1999). VISN 2 and VA Central Office staff attempted to develop precise information about the number of veterans with a diagnosis of dementia who were being served by VISN 2, but lack of a uniform set of diagnostic codes to identify dementia interfered with this effort. Since then, a VA task force has developed a recommended set of dementia diagnostic codes for use throughout the VA system. Using 29 of these recommended ICD-9 codes for dementia, data were pulled from the VA Austin database for fiscal years 1998 through 2003 for all VISN 2 primary care patients who had a diagnosis of dementia among the first ten diagnoses listed for an encounter.¹¹

J. Operational Observations and Learning

In addition to the independent evaluation of PDC, VA and chapter staff generated many observations about their experiences with training, the VA/chapter partnership, and implementation of the project model. These observations were conveyed in qualitative interviews, discussions at project meetings, and informal feedback. The observations provide useful insights for understanding and replicating PDC, and some of the observations are included in the discussion section later in this report.

¹¹ The ICD 9 codes used in the analysis were: 0461, 0463, 2900, 29010, 29011, 29012, 29013, 29020, 29021, 2903, 29040, 29041, 29042, 29043, 2912, 2941, 2948, 2949, 3310, 3311, 3312, 3317, 33189, 3319, 3320, 3330, 3334, 29410, 29411.

K. Evaluation

Evaluation of the PDC project was conducted by the CCN/AD national evaluation team, composed of researchers and data analysts from three organizations: the Margaret Blenkner Research Institute, Professional Evaluation Services, Inc., and Professional Data Systems, Inc. The evaluation design was developed in collaboration with clinicians and project staff from all the CCN/AD sites. Due to strong interest in learning about the feasibility of the project model and the effectiveness of implementation procedures, the evaluation design included components to examine these issues. No control group was used. Instead, the evaluation focused on descriptive analyses of implementation fidelity and over-time changes in outcomes for veterans, family and other caregivers, and VA and chapter service providers.

1. Evaluation Questions: evaluation questions for PDC reflect a mix of descriptive and explanatory goals. The questions pertain to: characteristics of the veterans and caregivers who enrolled; implementation issues, e.g., training and provider attitudes about the model and the VA/chapter partnership; and the project's impact on veterans, caregivers, and use of VA and chapter services.

2. Data Sources: Three data sources were used to address the evaluation questions:

- *Provider Survey.*- All types of VA and chapter providers were surveyed three times, using a self-administered questionnaire. Subsites sent the national evaluation team the names and contact information for about 400 providers who were trained or otherwise involved in PDC and consented to participate in the survey. Of the providers who received a questionnaire at Time 1 (T1), 62% completed it. Of those who completed a T1 questionnaire, 54% completed a Time 2 (T2) questionnaire, and 43% completed a Time 3 (T3) questionnaire. The T1 survey was completed an average of 9 months after initial provider training sessions. Time intervals between later waves of the survey also averaged 9 months.
- *Veteran and Family Caregiver Interviews.*- Veterans and their family or friend caregiver were interviewed three times by telephone. Interviews were conducted with veterans who were able and consented to participate and with caregivers who consented, regardless of whether the veteran with dementia was interviewed. Ninety-one veterans were interviewed at T1; of those, 80% were interviewed at T2, and 70% were interviewed at T3. Interviews were conducted with 271 caregivers at T1; of those, 84% were interviewed at T2, and 75% were interviewed at T3. T1 interviews were conducted an average of 8 months after PDC enrollment. T2 and T3 interviews were conducted 6 and 12 months later.
- *Uniform Database.*- Software was created by the national evaluation team to assure that uniform demographic, clinical, and service use data would be collected in all sites. Database information was collected on all veterans and family and friend caregivers who enrolled in PDC regardless of whether they participated in telephone interviews (see 2. above). Consent for collecting the information and using it for the evaluation was obtained at the time of enrollment. Uniform database information is available for 553 veterans and 513 caregivers.

3. Key Variables: A wide range of variables was used in testing the evaluation questions. Some of these variables are directly observable and are measured by single questions in the provider survey, telephone interviews, or uniform database. Examples are providers' discipline and work setting and veterans' and caregivers' age and living arrangements. Other variables are not directly observable but are represented by provider, veteran, or caregiver reports of attitudes and behaviors.

To increase reliability and validity, these variables combine responses to multiple questions into scales. All scales were constructed only after examining their psychometric properties using factor analysis, Cronbach's alpha reliability analysis, and correlation analysis.

4. Analytic Procedures: Various analytic approaches were used. Some evaluation questions required simple univariate or bivariate statistics, such as average, variance, range, paired t-tests, or correlations. Other evaluation questions required multivariate statistical procedures to estimate change over time or control for covariates or multiple characteristics that may affect an outcome. For questions that required more complex statistical tests, Ordinary Least Squares Multiple Regression and Multinomial Logistic Regression were the primary tests used.

III. Results

Only statistically significant findings are presented in this section. Footnotes indicate: 1) the tables in Appendix A that show the questions used to create particular variables, and 2) the tables in Appendix B that show the results of statistical procedures used to test relationships. Although T3 data were collected for the provider survey and veteran and caregiver interviews, only T1 and T2 data are presented. Analysis of T3 data is still in process, and combined T3 data for all CCN/AD sites will be included in the forthcoming report on the CCN/AD project as a whole. Preliminary analyses indicate that results for T3 are similar to those reported below for T1 and T2.

A. Characteristics of the Veterans Who Enrolled in PDC (n = 553)¹²

- Their average age was 77 years;
- 94% were male;
- 96% were white;
- 94% had a primary caregiver (either a spouse, other family member, or friend);
- 78% were married, and their spouse was their primary caregiver;
- 15% lived alone;
- they had an average score of 19.7 on a mental status test with a range of 0 (low) to 30 (high);
- they had an average of 4.6 co-existing chronic conditions;
- they had an average of 2.7 of 11 symptoms of depression; and
- they needed assistance from another person with an average of 2.7 of 12 daily living tasks.

B. Characteristics of the Caregivers Who Enrolled in PDC (n=513)¹³

- Their average age was 67 years;
- 96% were white;
- 78% were the veteran's spouse; 18% were other family members; and 4% were friends;
- 80% shared the same household with the veteran with dementia;
- 22% were employed full or part-time;
- they had an average of 4 family members or friends who supported them in caregiving; and
- they had an average score of 6.4 on a depression scale with a range of 0 (low) to 20 (high).

¹² The Upstate NY site enrolled a total of 574 veterans, but only 553 were enrolled by the time enrollment ended for purposes of the national evaluation.

¹³ The Upstate NY site enrolled a total of 533 family and other caregivers, but only 513 were enrolled by the time enrollment ended for purposes of the national evaluation.

C. Characteristics of Providers Who Completed the Provider Survey¹⁴

- 84% were from the VA, and 16% were from chapters;
- 8% were physicians; 47% were nurses; 15% were social workers; and 29% were other disciplines;¹⁵
- 47% worked in primary care;¹⁶
- they had worked for an average of 13.6 years with people with dementia and/or caregivers;
- they reported attending an average of 2.9 PDC training sessions before completing the T1 survey and an average of 2.5 PDC training sessions between the T1 and T2 surveys.

D. Use of the Recommended Procedures and Tools for Early Identification

- 53% of providers who completed the provider survey reported using the recommended procedures and tools for early identification of possible dementia; those who reported using the procedures and tools at T1 said they used them an average of 5 times; the remaining 47% said they did not use the procedures and tools.¹⁷
- Providers who completed the survey reported using the procedures and tools for early identification slightly less often at T2 than at T1.¹⁸
- Factors associated with more frequent reported use of the procedures and tools were:¹⁹
 - attendance at more PDC training sessions; and
 - more previous experience using these and similar procedures and tools.

E. Use of the Recommended Instruments for Initial Dementia Assessment

- Most veterans enrolled in PDC had completed assessments with the recommended instruments, including assessment of activities of daily living and functional status (ADL and FAQ) (99%), mental status (MMSE) (93%), depression (GDS) (86%), and caregiver attitudes and strain (90%).
- 69% of providers who completed the provider survey reported using these instruments; those who reported using the instruments at T1 said they used them an average of 5 times; the remaining 31% said they did not use the instruments.²⁰
- There was no significant change from T1 to T2 in reported use of the instruments.
- Factors associated with more frequent reported use of the instruments were:²¹
 - attendance at more PDC training sessions;
 - more previous experience using standardized dementia assessment instruments; and
 - being a physician vs. a nurse, social worker, or other provider.

¹⁴ The provider survey was completed by 249 providers at T1 and 134 providers at T2. The data presented here are for providers who completed the T1 survey.

¹⁵ Except for physicians, these provider disciplines, e.g., social work, included both VA and chapter staff.

¹⁶ 54% of VA providers (113 of the 209 VA providers) and 10% of the chapter providers (4 of the 40 chapter providers) worked in primary care.

¹⁷ Providers who said it was not part of their job to use these procedures and tools are not included in these figures.

¹⁸ See App. B, Table 2.

¹⁹ See App. B, Table 3.

²⁰ Providers who said it was not part of their job to use these instruments are not included in these figures.

²¹ See App. B, Table 3.

F. Providers' Attitudes About the Recommended Procedures, Tools, and Instruments for Early Identification and Initial Dementia Assessment

- On a 5-point scale from 0 (strongly disagree) to 4 (strongly agree), providers who completed the provider survey agreed that the procedures and tools for early identification and instruments for initial dementia assessment improved care outcomes for veterans and their families (average score=3) and were not burdensome for veterans and their families (average score=2.8).²²
- On a 4-point scale from 0 (strongly disagree) to 3 (strongly agree), providers who completed the survey agreed that use of these procedures, tools, and instruments increased their personal ability to care for veterans and their families (average score=2).²³
- Positive attitudes about the recommended procedures, tools, and instruments were associated with attendance at more PDC training sessions.²⁴
- Positive attitudes at T1 about the recommended procedures, tools, and instruments were associated with positive attitudes at T2.²⁵

G. Providers' Attitudes about the PDC Partnership

- On a 5-point scale from 0 (strongly disagree) to 4 (strongly agree), providers who completed the provider survey agreed that the partnership improved outcomes for veterans and their families (average score=2.9) and that the benefits of the partnership were not overshadowed by the challenges of inter-organizational collaboration (average score=2.8).²⁶
- On a 4-point scale from 0 (strongly disagree) to 3 (strongly agree), providers agreed that the partnership increased their own ability to care for veterans and families (average score= 2).²⁷
- On a 3-point scale from 0 (major difficulty) to 2 (no difficulty), providers agreed that issues of trust and knowledge of their partner organization were a “minor difficulty” (average score=1) at T1, and the reported level of difficulty was lower at T2 (average score=1.4).²⁸
- Factors associated with more positive attitudes about the partnership were:²⁹
 - attendance at more PDC training sessions; and
 - more frequent use of the recommended instruments for initial dementia assessment.
- Positive attitudes about the partnership at T1 were associated with positive attitudes at T2.³⁰
- Providers who were less concerned about the challenges of inter-organizational collaboration reported attending more PDC training sessions.

H. Use of VA Health Care Services

- During months 2-6 after enrolling in PDC, 57% of veterans had at least one primary care visit, with an average of 1.15 visits; 67% of veterans had at least one specialty physician visit, with an average of 2 visits; 7% of veterans had at least one hospital stay; and 9% of veterans had at least one nursing home stay.³¹

²² See App. A, Table 1 for items in these variables and App. B, Table 2 for statistical tests.

²³ See App. A, Table 1 for items in this variable and App. B, Table 2 for statistical tests.

²⁴ See App. B, Table 4.

²⁵ See App. B, Table 4.

²⁶ See App. A, Table 2 for items in these variables and App. B, Table 5 for statistical tests.

²⁷ See App. A, Table 2 for items in this variable and App. B, Table 5 for statistical tests.

²⁸ See App. A, Table 2 for items in this variable and App. B, Table 5, for statistical tests.

²⁹ See App. B, Tables 6 and 7.

³⁰ See App. B, Table 7.

³¹ See App. B, Table 8. VA services used in the month immediately after PDC enrollment are not included because of the likelihood that visits associated with enrollment could erroneously increase apparent service use.

- Comparing use of each type of VA health care service in the 6 months before enrollment in PDC and months 2-6 after enrollment, there was no significant change in the proportion of veterans who had at least one primary care visit, hospital stay, or nursing home stay; however, the proportion of veterans with at least one specialty physician visit was higher in months 2-6 after enrollment (67% after enrollment vs. 60% before enrollment).³²

I. Use of Alzheimer’s Association Chapter Services

- In the 6 months after enrollment in PDC, 57% of veterans and/or their family or friend caregivers used chapter information and education services, with an average of one such service for all enrollees; 12% used a support group; and 6% used chapter care consultation.³³
- The chapters reported that none of the veterans or family or friend caregivers who enrolled in PDC had used chapter services before enrolling in the project.

J. Relationship Between Use of Chapter Services and Use of VA Health Care Services

- Overall use of chapter services was not associated with any significant change in the proportion of veterans who used VA health care services.
- Use of one type of chapter services, information and education, was associated with an increase in the *proportion* of veterans who had at least one primary care visit.³⁴
- For a subgroup of veterans who had mild memory impairment, use of chapter information and education services was associated with an increase in the *number* of primary care visits.
- For a subgroup of veterans who had moderate or severe memory impairment, use of chapter care consultation was associated with a decrease in the *number* of specialty physician visits.

K. Veterans’ Perceptions of the Types and Adequacy of Help They Received from PDC

Veterans who were able to participate in the telephone interviews (n=91 at T1; 73 at T2) were asked whether a provider had talked with them since they enrolled in PDC about several issues in four general areas of care: 1) daily living tasks, 2) legal issues, 3) family concerns, and 4) treatment options. They were also asked whether they had enough information or help with these issues. In the area of treatment options, for example, veterans were asked whether a provider had talked with them about tests for diagnosing memory problems, causes of their memory problems, and medications that help memory problems.³⁵

- 51% of veterans reported that a provider had talked with them about treatment options; smaller proportions reported that a provider had talked with them about daily living tasks (17%), legal issues (27%), and family concerns (7%).
- 60% of veterans reported that they had enough information or help with treatment options; larger proportions reported that they had enough information or help with daily living tasks (93%), legal issues (82%), and family concerns (85%).
- Veterans who reported that a provider had talked with them about treatment options were more likely to report that they had enough information or help with this area of care.³⁶

³² See App. B, Table 9.

³³ See App. B, Table 8.

³⁴ See App. B, Table 27. These findings pertain to use of chapter services in the 6 months after enrollment in PDC and use of VA services 6 months before and 2-6 months after enrollment in PDC. The regression equations in Table 27 control for veterans’ use of VA services in the 6 months before enrollment in PDC.

³⁵ See App. A, Table 3 for the issues included in the other three general areas of care.

³⁶ See App. B, Tables 10-13.

- Veterans who received more chapter services in the 6 months after enrollment were more likely to report that a provider had talked with them about treatment options and daily living tasks and that they had enough information or help with daily living tasks and legal issues at T1.
- Veterans with more co-existing medical conditions were less likely to report that a provider had talked with them about daily living tasks; they were also less likely to report that they had enough information or help with daily living tasks and treatment options at T1.

L. Veterans' Satisfaction with the Care They Received from PDC

In the telephone interviews, veterans were asked to agree or disagree with 12 statements about their satisfaction with the care and services they received from physicians and other service providers.³⁷

- On average, veterans agreed with more than 10 of the 12 statements (10.3 at T1; 10.4 at T2).³⁸
- Veterans' satisfaction scores show a few statistically significant relationships with their reports about the types and adequacy of information and help they received:³⁹
 - veterans who reported that providers had talked with them about daily living tasks at T1 were more satisfied with the care they received.
 - veterans who reported that they received enough information or help with treatment options at T1 were more satisfied with the care they received.
- At T1, veterans who lived alone were less satisfied with the care they received than veterans who lived with someone else.
- Veterans who were more satisfied with the care they received at T1 were also more satisfied at T2.

M. Relationship of PDC to Psychosocial Outcomes for Veterans

- Veterans who participated in telephone interviews and reported receiving enough information or help with family concerns at T1 had less relationship strain with their caregiver at T1.⁴⁰
- At T1, veterans who reported receiving enough information or help with treatment options had less emotional strain.
- At T2, veterans who reported receiving enough information or help with family concerns had fewer symptoms of depression and less emotional strain and relationship strain.⁴¹
- At T2, veterans who reported receiving enough information or help with daily living tasks had less relationship strain.
- Levels of depression, emotional strain, and relationship strain at T1 were positively associated with levels of these psychosocial outcomes at T2.

N. Caregivers' Perceptions of the Type and Adequacy of Help They Received from PDC

Family and friend caregivers who participated in the telephone interviews (n=271 at T1; 227 at T2)⁴² were asked whether a provider had talked with them since they enrolled in PDC about several issues in six general areas of care: 1) daily living tasks, 2) home care services, 3) legal and

³⁷ See App. A, Table 6 for the 12 statements.

³⁸ See App. B, Table 18.

³⁹ See App. B, Table 19.

⁴⁰ See App. A, Tables 7 and 8 for these variables (depression, emotional strain, and relationship strain). See App. B, Table 23 for statistical tests.

⁴¹ See App. B, Table 24 for statistical tests.

⁴²The 271 caregivers interviewed at T1 were spouses (78%), other family members (17%), and friends (5%).

financial issues, 4) support services, 5) family concerns, and 6) treatment options.⁴³ They were also asked whether they had enough information or help with these issues.

- 59% of caregivers reported that a provider had talked with them about treatment options; smaller proportions reported that a provider had talked with them about daily living tasks (33%), home care services (40%), legal and financial issues (40%), support services (51%), and family concerns (17%).
- On average, caregivers reported that they had enough information or help with at least two-thirds of the issues in each of the six general areas of care, with the proportion ranging from 86% for daily living tasks to 67% for support services.
- Caregivers who reported that a provider had talked with them about the general areas of care:⁴⁴
 - had used more chapter services at T1 and T2;
 - were caring for a veteran with more co-existing chronic conditions at T1; and
 - reported at T1 that they had a larger number of family members and friends who supported them in caregiving.
- Caregivers who reported that a provider had talked with them about the six general areas of care at T1 and T2 were more likely to report that they had enough information or help with these areas of care at T1 and T2.⁴⁵

O. Caregivers' Satisfaction with PDC Care

In the telephone interviews, family and friend caregivers were asked about their satisfaction with four types of care: 1) care from physicians, 2) care from other providers, 3) types of help available, and 4) VA care in general.⁴⁶

- On a 4-point scale from 0 (strongly disagree) to 3 (strongly agree), caregivers agreed that they were satisfied with all four types of care. Average scores ranged from 1.8 for types of help available to 2.2 for VA care in general.⁴⁷
- Caregivers who reported that a provider had talked with them about treatment options and those who reported that they had enough information or help with treatment options were more satisfied with care from physicians at T1 and more satisfied with all four types of care at T2.⁴⁸
- Caregivers who had a larger number of family members and friends who supported them in caregiving reported higher satisfaction with all four types of care at T1.
- Caregivers who reported that they had enough information or help with family concerns reported higher satisfaction with the types of help available at T1.
- Caregivers who reported that they had enough information or help with daily living tasks reported higher satisfaction with VA care in general at T1.

P. Relationship of PDC to Psychosocial Outcomes for Caregivers

- Family and friend caregivers who participated in telephone interviews and reported receiving enough information or help with legal and financial issues at T1 had fewer symptoms of depression and less emotional strain, physical health strain, and relationship strain at T1.⁴⁹

⁴³ See App. A, Table 4, for the issues included in these general areas of care.

⁴⁴ See App. B, Tables 14 and 16 for statistical tests.

⁴⁵ See App. B, Tables 15 and 17 for statistical tests.

⁴⁶ See App. A, Table 5 for the issues included in these types of care.

⁴⁷ See App. B, Table 20 for statistical tests.

⁴⁸ See App. B, Tables 21 and 22 for statistical tests.

⁴⁹ See App. A, Tables 9 and 10 for these variables (family caregiver depression, emotional strain, physical health strain, and relationship strain). See App. B, Table 25 for statistical tests.

- At T2, caregivers who reported receiving enough information or help with daily living tasks had fewer symptoms of depression and less physical health strain.⁵⁰
- At T2, caregivers who reported receiving enough information or help with family concerns had less emotional strain and less relationship strain.
- Caregivers who reported that their care recipient was dependent in more activities of daily living (ADLs) had more emotional strain, physical health strain, and relationship strain at T1 and more symptoms of depression at T1 and T2.
- Caregivers who lived with the veteran had more symptoms of depression and more relationship strain at T1 and T2, more physical health strain at T1, and more emotional strain at T2.

Q. Dementia Diagnoses Over Time in VISN 2

From 1998 to 2003, the primary care outpatient population in VISN 2 increased 34% from 95,260 to 127,399 individuals. During this period, the number of veterans with recorded dementia diagnoses increased 53% from 1,903 to 2,974 individuals.⁵¹

IV. Discussion

PDC was an ambitious project that involved a large number of VA and Alzheimer's Association chapter staff and attempted to change many aspects of the care provided for veterans with dementia. Over time, project implementation expanded from the Syracuse VAMC to the other four VISN 2 medical centers and several CBOCs. In the three VAMCs that had a Memory Disorders Clinic, implementation also expanded from these specialty clinics to primary care.

The evaluation of PDC shows many positive outcomes. VA and chapter staff were generally enthusiastic about the project model and the VA/Chapter partnership. Those who completed the provider survey agreed on average that PDC improved quality of care overall and increased their own ability to care for veterans with dementia. Veterans and their caregivers who participated in telephone interviews reported on average that they had received enough information or help with important areas of care. Moreover, those who said they had received enough help with certain areas of care were significantly less likely to have symptoms of depression and other negative psychosocial outcomes.

Since the evaluation of PDC did not include a control group, it is not possible to determine with certainty that these positive outcomes are a result of the project intervention. The decision not to use control groups in the CCN/AD project (and therefore, in PDC) was a difficult one. CCN/AD project leaders weighed the value of results based on a treatment/control group research design versus the project goal to change systems of care. Specifically, they worried that concerns about contamination of control groups within the participating health systems would limit CCN/AD sites' efforts to expand training and other parts of the intervention as widely as possible within those systems. The alternative of using control groups in other health care systems was also problematic. In 1998, when the CCN/AD evaluation was designed, little research had been conducted on dementia care in health care settings, and project leaders believed it would be very difficult to determine which characteristics of the

⁵⁰ See App. A, Tables 9 and 10 for these variables. See App. B, Table 26 for statistical tests.

⁵¹ These figures for the number of veterans with recorded dementia diagnoses do not include veterans with Parkinson's disease. If these veterans are included as veterans with a recorded dementia diagnosis, the number of such veterans increased 54% (from 2,526 to 3,887) in the period from 1998-2003.

participating health care systems would have to be matched to create comparable control sites. In addition, since people with dementia frequently are not identified in health care settings, CCN/AD project leaders believed that it would be difficult to create comparable samples of people with dementia in the control sites without using the same identification procedures that were a major component of the project model being tested in the treatment sites. Lastly, project leaders were committed to a “learning laboratory” approach that would allow adjustments to the model in response to site-level experiences with implementation. Although the “learning laboratory” approach was appropriate for the state of this kind of research at the time, it would have been difficult to reconcile with a treatment/control group research design

Given the evaluation findings presented in this report and experiential learning from implementation of the CCN/AD model in the Upstate New York/VISN 2 site, PDC is now ready for replication and testing with a treatment/control group research design. As noted earlier, the Robert Wood Johnson Foundation provided funding in 2002 for in-depth analyses of PDC data. These analyses and the observations of VA and chapter staff about their experiences with implementation have contributed to better understanding about how the model worked in VISN 2. With this understanding, the model has been refined to strengthen it and make it more suitable for VA health care systems. The resulting best practice model should be replicated and tested in other VA networks with a rigorous, treatment/control group research design.

The following discussion focuses on evaluation findings and observations of PDC project leaders and VA and chapter staff about issues that are important for replication and future research. These issues include training, the VA/Chapter partnership, case finding, the importance to veterans and families of particular areas of care, physician willingness to diagnose dementia, and the roles of other providers, chapters, and DCCs. Questions about cost and sustainability are also discussed.

Training.- PDC training was well attended and had positive effects on provider behavior and attitudes. VA and chapter staff who completed the provider survey reported attending an average of more than five training sessions in the first 18 months of the project. Providers who attended more training sessions were significantly more likely to use and to have positive attitudes about the recommended procedures for early identification and initial dementia assessment. They were also significantly more likely to have positive attitudes about the VA/chapter partnership. No data are available on the unduplicated number of VA staff members who received training, but project leaders estimate that more than 1,000 staff members received PDC training.

Observations of PDC project leaders and staff support the importance of providing formal training based on a standardized curriculum at the beginning of the project. PDC leaders and staff noted that after this initial training, staff in the VAMCs and CBOCs requested additional training and identified desired topics. Formal training about these and other topics were provided throughout the project. The DCCs also took advantage of opportunities for informal training, for example, impromptu, one-on-one discussions with another VA staff member about approaches for addressing the needs of an individual veteran or family. The DCCs observed that informal training became more common than formal training as the project evolved.

VA/Chapter Partnership.- PDC placed strong emphasis on partnership, with the belief that the combined expertise, experience, and services of VA and the chapters would result in better care for veterans with dementia. VA and chapter staff who completed the provider survey generally agreed that the

partnership improved outcomes and increased their own ability to provide care for veterans and their families. They also agreed that the challenges of collaboration were minor at first and lessened over time as they gained more experience working together.

Partnerships between health care organizations and community agencies are often proposed as a way to overcome fragmentation of care for people with various chronic diseases and conditions. Although some successful partnerships have been developed in VA and other settings, the VA/Chapter partnership in PDC probably went beyond what has been achieved in other partnership efforts in dementia care. VA and chapter staff participated in joint training, joint decision-making about project implementation, joint efforts to create services to meet veterans' and caregivers' needs, and even joint care management for some veterans and families.

Developing and maintaining this working VA/Chapter partnership was not easy. PDC project leaders and staff observed that the two organizations knew little about each other at the start of the project. They learned more as they worked together to plan training events and prepare site protocols and materials. Lack of trust was also a challenge at the start. Staff in both organizations wondered whether "their" patients would be well cared for by the other organization. Later challenges related to turf. Staff in both organizations sometimes reacted negatively when they perceived that the other organization was doing something they considered their job or getting credit for services they provided. While understandable, such reactions could undermine efforts to provide care that appears seamless to the veteran and family. In the PDC project, turf issues were most often resolved through discussion and compromise based on the shared goal of improving care for veterans and their families.

Case Finding.- In 1996, prior to the development of the CCN/AD model, a government-appointed expert panel published guidelines for identifying people with possible dementia (Costa et al., 1996). The panel recommended against screening with brief mental status tests and in favor of training all health care providers to recognize signs and symptoms of possible dementia. The CCN/AD model follows this recommendation, which has since been confirmed by three other expert groups (Brodaty et al., 1998; Patterson et al., 2001; U.S. Preventive Services Task Force, 2003). The first component of the model includes training for all staff, using the signs and symptoms of possible dementia from the 1996 report and two other lists of signs and symptoms. The four expert groups also recommended that health care providers follow up on family or other informant perceptions that a person has symptoms of possible dementia. The brief Family Questionnaire is intended to elicit these perceptions.

No data are available on exactly how the lists of signs and symptoms of possible dementia were used. Most providers who completed the provider survey responded positively to questions about this component of the model, agreeing, for example, that the early identification procedures reduced the number of times dementia was overlooked by clinicians. One of the three lists of signs and symptoms was incorporated into a VISN-wide computerized clinical reminder system. PDC project leaders and staff observed that the lists were well received and noted that different provider disciplines preferred different lists. They recommended that all three lists be retained in replication efforts.

A preliminary analysis of data on responses to the Family Questionnaire by caregivers enrolled in the Syracuse subsite suggest that it may be more sensitive than brief mental status tests, such as the MMSE and FAQ, in identifying people with possible dementia (Judge et al., 2004). PDC project leaders and staff observed that the Family Questionnaire was well accepted, and it was also incorporated into the VISN-wide computerized clinical reminder system.

Overall, the CCN/AD procedures for early identification of possible dementia seemed to work. Identification and enrollment of veterans with dementia was slow at first but became easier as the project evolved. From 1998 – 2003, the number of veterans with a dementia diagnosis in VISN 2 increased 53%, while the total number of veterans served in the network increased 34%. The extent to which this increase is attributable to PDC or other factors is unclear.

Many VA and nonVA clinicians and others wish there were a quick test to screen for dementia. The main reason for the expert groups' recommendations against screening for dementia with brief mental status tests is the likelihood of many false positives, that is, scores that indicate a person has dementia when he or she does not. False positives are especially likely for people from some ethnic minority groups and people with low educational background and other characteristics that cause them to do poorly on the tests even though they do not have dementia. Some VA clinics serve many veterans with such characteristics. False positives result in unnecessary anxiety for patients and families and unnecessary use of costly health care resources for further evaluation. False positives may also discourage physicians and others from trying to identify dementia in their patients. The PDC evaluation did not measure the number of false positives. Nor did it measure the number of false negatives, that is, veterans with dementia who were missed by the early identification procedures. These are important issues for future studies. At present, however, the findings and experience in PDC support the feasibility and usefulness of the CCN/AD approach to identification of possible dementia.

Importance to Veterans and Caregivers of Help with Particular Areas of Care.- As noted earlier, veterans and family and friend caregivers who reported that they had received enough information or help with particular areas of care were significantly more likely than other veterans and caregivers to be satisfied and significantly less likely to have negative psychosocial outcomes. For veterans, the most important area of care in this regard was family concerns: veterans who said they had enough information or help with family concerns had fewer symptoms of depression and less emotional strain and relationship strain with their caregiver. Treatment options was another important area: those who said they had enough information or help with treatment options were more satisfied with their care and had less emotional strain. Veterans who said a provider had talked with them about daily living tasks were also more satisfied with their care and had less relationship strain.

For caregivers, the area of care that was most important in terms of satisfaction was treatment options: caregivers who said they had enough information or help with treatment options were more satisfied with all aspects of the veteran's care. Caregivers who said they had enough information or help with family concerns were more satisfied with the types of help available to them, and caregivers who said they had enough information and help with daily living tasks were more satisfied with VA in general. For psychosocial outcomes, the most important area of care was legal and financial issues: caregivers who said they had enough information and help with legal and financial issues had fewer symptoms of depression and less emotional strain, physical health strain, and relationship strain. Having enough information or help with daily living tasks was also associated with lower levels of caregiver depression and physical health strain, and having enough information and help with family concerns was associated with lower levels of emotional strain and relationship strain.

Caregivers who said a provider had talked with them about the six general areas of care also said they had enough information or help with these areas of care. Veterans who said a provider had talked with them about treatment options also said they had enough information or help with this area of care.

These findings are instructive from a clinical perspective. They point to particular areas of care that are important to veterans and their caregivers. The statistically significant associations between the two sets of variables -- having enough information or help with an area of care and lower levels of depression and other negative psychosocial outcomes -- suggest causal relationships. Future studies should be conducted to test these relationships. In the meantime, VA and chapter staff should be aware of the apparent value to veterans and their caregivers of having a provider talk with them about treatment options, family concerns, daily living tasks, and, for caregivers, legal and financial issues.

The PDC findings about areas of care that are important for veterans with dementia are available because the evaluation included interviews with them. Only a small proportion of veterans who enrolled in PDC (16%) were able to participate in these interviews, but their responses provide a unique perspective on the effectiveness of the intervention. Research on dementia care is slowly beginning to include interviews with people who have the condition. Future studies should include such interviews. As in PDC, interview questions and response categories should be simplified to make it easier for people with dementia to respond.

PDC findings about the impact of information and help with particular areas of care also point to subgroups of veterans and families who were less likely to be helped by the intervention. These subgroups include:

- veterans who lived alone;
- veterans who had more co-existing medical conditions;
- caregivers who lacked other relatives and friends to support them in caregiving; and
- caregivers of veterans who needed more help with daily living tasks.

The needs of people in these subgroups for more or different kinds of information and help should be addressed in replication efforts and future dementia care research.

Physicians' Willingness To Diagnose Dementia. Anecdotal reports and research findings from physician interviews (Boise et al, 1999) suggest that some physicians are reluctant to identify and diagnose dementia because they believe the condition is hopeless and there is "nothing to do" for the person or family. PDC was intended to counter these beliefs by assuring that there would be "something to do" for veterans diagnosed with dementia. Most providers who completed the provider survey responded positively to questions about this issue, agreeing, for example, that the project increased their confidence that care and services needed by veterans and families were available.

PDC project leaders and staff noted that as the project went on, they heard fewer physicians say or imply that there is no reason to diagnose dementia because there is "nothing to do" for people with the condition. They also observed that VA physicians and other primary care providers were more enthusiastic about training and the CCN/AD procedures for early identification and diagnosis when they understood that VA and chapter resources would be available for veterans who were diagnosed. These observations and survey responses suggest that physicians may be more willing to identify and diagnose dementia if they believe resources are available to help. The observations and survey responses also suggest that providing training and tools for identification and diagnosis without also providing resources to respond to the needs of veterans who are diagnosed will be less effective.

Role of Nonphysician Providers.- The CCN/AD model was designed to encourage nonphysician providers, including all clinic staff, to identify veterans with possible dementia and participate, as

appropriate, in other project functions related to assessment and ongoing care management. This aspect of PDC worked well and should be retained in replication efforts. It is not clear exactly what or how much of the information obtained by nonphysician providers is needed by physicians and how this information should be communicated. These are questions for future studies.

Role of Alzheimer's Association Chapters.- The four Alzheimer's Association chapters that partnered with VA were involved in many project activities, ranging from planning and protocol development to ongoing provision of information and supportive services for veterans and their caregivers. No data are available to measure the impact of chapter involvement in most of these activities. PDC leaders and project staff observed that chapters contributed valuable knowledge about dementia care and a wide array of print and other informational materials for veterans, families, and staff. They speculated that chapter involvement in PDC probably increased the project's focus on families and other caregivers. VA is also committed to supporting family caregivers, but VA's primary client is the veteran, whereas chapters have historically focused more on families. Although not provable, it is also likely that the involvement of two partners, VA and chapters, helped to promote and sustain the project, especially at times when one or the other partner faced internal obstacles to implementation.

PDC findings show that veterans who used chapter services were significantly more likely to report that a provider had talked with them about treatment options and daily living tasks and that they had enough information or help with daily living tasks and legal issues. Likewise, caregivers who used chapter services were significantly more likely to report that a provider had talked with them about the six general areas of care. Further research is needed to clarify the relationship between these variables and psychosocial outcomes. It is likely, however, that use of chapter services resulted in better psychosocial outcomes for some, and perhaps many, veterans and caregivers.

Veterans and caregivers can only benefit from chapter services if they are linked to the chapter and decide to use services. As described earlier, initial linkage to the chapters was facilitated by the use of signed consent forms that were faxed by the DCC to the chapters. These forms allowed chapters to contact the family to offer services. Without this consent process, chapters can only respond to contacts initiated by the family, which may take years. Not all families who were contacted by the chapter decided to use services, but more than half did, and chapters reported that none of these families had been previously connected to the chapter. The faxed consent process clearly worked and should be used in future efforts to increase access to chapter services for veterans with dementia.

Late in the PDC project, as VA responded to new privacy requirements mandated by the Health Insurance Portability and Accountability Act (HIPAA), concerns arose about releasing any information about veterans to the chapters. HIPAA requirements were not well understood, and VA staff wondered whether the faxed consent process could still be used and whether the DCCs and other VA clinicians could continue to exchange information with chapters about individual veterans and families for whom they were providing joint care management. VA has a "Consent to Release Information" form that veterans and caregivers can sign to allow the release of limited information to community agencies, and this form was used to address concerns about HIPAA. Given the apparent value of chapter services to veterans and caregivers and the likely benefit of care coordination, it is important for VA to clarify and affirm the allowable procedures for the exchange of information for this purpose.

Role of the DCCs.- Like chapters, the DCCs played many roles in PDC, ranging from planning and protocol development to direct services, including care management, for veterans. They functioned as

subsite leaders, arranged and participated in formal training events, and provided informal training for VA staff. In addition, the DCCs functioned as agents of change: they identified ways the project could be expanded in their subsites and worked to implement the expansions; they also identified ways that components of the model could be institutionalized in VISN 2 and worked to make this happen.

The DCC position was created for PDC, and the functions associated with the position were not fully defined at the start of the project. This created challenges for the individuals who took the positions and had to juggle multiple functions and help to define their own roles as the project evolved. In retrospect, some of the DCCs felt that functions related to project management and direct services for veterans should have been assigned to different positions. Other DCCs were not sure and commented that responsibility for ongoing care management and other direct services for veterans usually was and should be transitioned to VA nurses, social workers, and other clinicians who provide these services in primary care and other VA clinics. Separation of project management and direct care functions also would not accommodate the important DCC functions with respect to training and systems change.

The PDC experience is useful in thinking about how functions performed by DCCs in PDC should be allocated in future replications. It is possible that the most effective allocation of functions may differ in different VA settings. Regardless of this decision, however, PDC leaders and staff recommend that referrals to chapters should come not only from DCCs, as they did in PDC, but also from other VA nurses, social workers, and clinicians. Moreover, these clinicians should engage in joint VA/chapter care management when a veteran and caregiver situation indicates that this approach will be helpful.

Questions about the Cost and Sustainability of PDC. - The overall cost of PDC includes the cost of new functions and services and the cost of existing functions and services that were incorporated into the project. For VA, the major new cost was the DCCs. As noted earlier, DCCs' functions changed over time, and it is difficult to separate functions associated with starting a new project from functions needed for ongoing implementation. It is also difficult to determine the extent to which DCC functions replace or are in addition to existing functions of other VA clinicians. Development of a meaningful cost figure for the intervention as a whole will require more information about the cost of each function and service once implementation has reached a steady state.

For sustainability, the most important aspect of an intervention like PDC is probably its effect on veterans' use of other VA health care services. Research on Medicare health care services shows that the use and cost of these services are two to three times higher for beneficiaries with dementia than for other Medicare beneficiaries, and hospital costs account for more than half of total costs (Bynum et al., 2002; Hill et al, 2002). Better identification of dementia could result in increased use of health care services because of newly recognized health care needs. Alternatively, better identification could result in more focused medical management which, in turn, could reduce use of health care services. Chapter services could also affect use of health care services. One study of Medicare beneficiaries with dementia found, for example, that among beneficiaries with moderate to severe memory impairment, those who used chapter services had a statistically significant reduction in hospital admission rates compared with those who did not use chapter services (Clark et al., 2002).

PDC data show little change in veterans' use of most VA health care services from six months before to six months after enrollment. In general, the use of health care services is expected to increase over time for people with dementia, as their condition worsens, but the time period for which PDC service use data are available may have been too short to see the effects of disease progression. Credible

conclusions about the effect of the intervention on veterans' use of VA health care services will require replication with a longer period of observation and a treatment/control group research design.

Even without such a research design, PDC data provide some information about the relationship between use of chapter services and use of VA health care services, because some veterans and their caregivers used chapter services and others did not. The data show that use of chapter information and education services was associated with greater likelihood that the veteran would have a VA primary care visit and, for veterans with mild memory impairment, a higher number of primary care visits. For veterans with moderate to severe memory impairment, use of chapter care consultation was associated with a smaller likelihood that the veteran would have a VA specialty physician visit.

Experiential Learning From PDC.- Some of the experiential learning from PDC has been noted in the discussion above. A forthcoming project manual will summarize additional learning from PDC. The manual will be directed to VA and chapter clinicians and administrators who are interested in replicating parts or all of the intervention. It will describe approaches for developing strong VA/chapter partnerships and VAMC planning and implementation committees to guide and monitor implementation of the intervention. The manual will include flowcharts, position descriptions, and a standardized curriculum for staff training. It will also describe the best practice model that has been developed from the findings and experience with PDC.

VA health care systems and medical centers are complex organizations with large numbers of staff and patients and numerous obligations and goals that are not related or only marginally related to dementia care. In VISN 2, the five subsites differed in many ways that affected the way they implemented the PDC intervention, e.g., rural vs. urban location, geographic distance between the medical center and chapter, and whether the subsite had a memory disorders clinics. The fact that the intervention was implemented successfully in all five subsites suggests that it is feasible for many VA health care settings. Experiential learning from PDC indicates, however, that the flexibility that was built into CCN/AD and PDC from the start was essential for this project and will be essential in any future replication. This flexibility allows local staff to fit the intervention into their complex organizations and probably also increases administrative and staff buy-in for the project goal, model, and procedures.

Lastly, at the time the PDC project was implemented, VISN 2 functioned with an administrative structure in which different "Carelines" controlled their own budgets. Experiential learning from PDC suggests that this administrative structure contributed to successful multi-site implementation in the network's large geographic area. On the other hand, the "Careline" structure meant that effective implementation in each medical center required buy-in from staff in the various carelines in that center. Future replications in VA networks with a different administrative structure may be most effective if they focus at least initially on implementation at the medical center rather than the network level.

V. Conclusions

PDC accomplished its goal to improve care and outcomes for veterans with Alzheimer's disease and other dementias and their families and other caregivers. The intervention, including the VA/chapter partnership, was well accepted by VA and chapter clinicians and administrators. More than 550 veterans and 500 caregivers were enrolled and served by the project. Veterans and their caregivers reported that they had received help with important areas of care, and the receipt of help and its perceived adequacy was associated with higher levels of satisfaction and lower levels of depression and other nega-

tive psychosocial outcomes. Rigorous evaluation with a treatment/control group research design will be needed to further investigate these relationships and the effect of the intervention on the use and cost of VA and chapter services.

VA estimates that in 2005, there are about 142,000 veterans with dementia using VA services and about 400,000 additional individuals with dementia in the veteran population as a whole (Department, 2004). Better approaches to case finding and medical and nonmedical care management are needed to serve this existing and potential patient population. PDC provides useful findings and experiential learning for this purpose. It also fits well with VA's current focus on care coordination.

During the time period of the PDC project, considerable interest was expressed in the project goal, intervention, and preliminary findings. Information about the project was presented in three congressional hearings (Alzheimer's Association, 2003; Hemmings, 2002; Sabo, 2004) and numerous national and regional VA and nonVA meetings. PDC findings and experiential learning should now be disseminated to VA clinicians and administrators. Use of PDC procedures and tools should be encouraged, where appropriate for quality improvement purposes, and the best practice model should be implemented and tested in a controlled research trial that can provide greater understanding of the intervention's impact on veterans, their families, and their use of VA and chapter services.

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