

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.