

CCN/AD Interim Evaluation Findings November 2002

The Chronic Care Networks for Alzheimer's Disease (CCN/AD) initiative has reached several important milestones. Enrollment into the CCN/AD demonstration project has ended, and grant-funded project development efforts have concluded or are entering short extension periods. Surveys and data collection will continue for a few months, but most site-level project activities are completed.

The intent of CCN/AD was to develop practical, sustainable, and replicable approaches to dementia care through local partnerships of Alzheimer's Association chapters and healthcare systems and providers. As the CCN/AD national co-directors and national evaluation team are culling through the interim evaluation findings and initiative experience, we are finding the project results both positive and exciting. This is based on the interim evaluation findings described below, as well as on our observations of the changes in Alzheimer's and dementia awareness and care at the participating organizations in all the sites, the strength of the partnerships that have developed in most of the sites, and the qualitative responses of project enrollees and their family caregivers. Clearly, not all the project outcomes are as perfect as we might have imagined when we began CCN/AD in 1997. However, given the turbulence in the healthcare environment in the intervening years and the resulting changes in all project sites, our successes are very impressive.

Four "big" messages have emerged from the evaluation findings to date:

1. In the CCN/AD project, local partnerships of Alzheimer's Association chapters and healthcare systems and providers implemented the national model in different ways to fit their local situations; however, all sites brought chapters and providers together to improve dementia care. There are many possible ways to coordinate health care and supportive services for people with dementia and their family caregivers.
2. Training about dementia care is effective when it is provided in many different formats and repeated over time. Physicians, nurses, and other healthcare providers reported that their skills for dementia care increased through participation in CCN/AD.
3. Effective partnerships between Alzheimer's Association chapters and healthcare systems and providers take time and effort to build. Trust increases slowly, but the result of the partnerships is better, more coordinated care.
4. People with dementia and their family caregivers benefited from the services they received through the project. In particular, those who accessed information and support reported adequate help on important topics, greater satisfaction with care, and less strain in their relationships with other family members.

Throughout the project, we received requests from many healthcare systems and providers for information and advice about creating coordinated healthcare and supportive services for people with dementia and their families. We have shared the tools and materials that were

developed for CCN/AD, and we are seeing evidence that these tools and materials are being adopted, adapted, and used by many organizations. Now we also have site-specific tools and materials, including protocols, curricula, forms, communication approaches, and other practical aids to make available to organizations that want to change care for people with dementia in their own communities. We will document project activities that are sustained over time by the local partnerships and related activities that are initiated by healthcare systems, providers, and chapters in other communities.

The summary of interim evaluation findings that follows was prepared by the national evaluation team. This team includes more than a dozen research professionals and is headed by the lead evaluators, David Bass, Ph.D., Michael Luxenberg, Ph.D., and Connie Schmitz, Ph.D. The evaluation team's analysis continues, and final evaluation results will be disseminated in mid 2003.

Compilation of Interim Findings

The results below are derived from all four evaluation data sources (site visits, uniform database, provider survey, and patient and caregiver interviews). **These statements should be considered preliminary.** All could be qualified by additional information on such things as response rates, degree of completeness, and other details. We share these messages to try to understand the shape of the initiative as it nears the end of the third year.

Where We See Progress:

1. **Coordinating psychosocial and medical care for persons with dementia and their caregivers and managing care across provider, place, and time represented central goals of CCN/AD. Over the life of the project, there was slow but real progress towards these goals.**

In order to get to the stage where projects could define and implement a coordinated care model, they had to first develop their partnership, identify and educate providers, and enroll patients and caregivers. CCN/AD care models evolved at different rates across the six project sites [12 (sub)sites], but by Year 3, all projects were implementing elements of a coordinated care model. Some specific accomplishments reported by project participants:

- More Chapters were making proactive calls to enrollees in order to help coordinate their ongoing medical and/or psychosocial care at the end of the initiative than the beginning.
 - More managed care organization (MCO) case management personnel were helping to coordinate or manage the ongoing care of enrollees by the end of the initiative than at the beginning. (This is important if the care model is to survive without grant funding.)
 - The goal of providing dual track support—support for the person with dementia as well as the family caregiver(s)—was achieved at nearly every site.
 - The goal of providing medical and psychosocial support for patients and caregivers was achieved at nearly every site.
2. **Strengthening the linkage between MCOs and Chapters was a major goal of the initiative, and this was largely accomplished.**
 - By Year 3, sites had enrolled over 1,400 patients and nearly as many caregivers, and they had connected a large majority (80%) of them to Chapter services and other supports within six months of enrollment.
 - Some exploratory analysis of site characteristic data suggest that the more active the case management model and the closer MCOs were to Chapters in terms of

understanding their respective roles, the greater the use of Chapter services by patients and caregivers.

3. Educating primary care and other providers was a major goal of the initiative, and significant progress was made towards this goal.

By Year 2, every site was implementing multiple education strategies, including provider office visits, clinic meetings/presentations, formal and informal “one-on-one” meetings, large group presentations at grand rounds and conferences, written materials, and “informal advocacy” by key leaders. Provider education topics included information on the project partnership; dementia identification, assessment, and diagnosis; and ongoing care of patients and caregivers. Some specific successes:

- By Year 3, providers responding to the Time 2 Provider Survey who used the CCN/AD Early Identification Tools consistently reported greater improvement in their overall ability to care for dementia patients and caregivers, as well as greater improvement in care because of the partnership between health plans and Chapters.
- A large majority of responding providers said CCN/AD had improved their knowledge of dementia (75%), ability to use assessment tools (80%), and ability to care for patients and their family members (80%).
- Various ways of learning about the project, and especially formal presentations and “one-on-one” interactions, were associated with providers’ feelings that some aspects of care had improved in their setting and that their own personal ability to care for people with dementia and their families had improved.
- When Time 1 provider attitudes about the partnership between MCOs and Chapters were compared with Time 2 attitudes, there was a significant increase in trust and knowledge of the partner organizations.

4. A large majority of patients and caregivers reported having discussions with providers about important topics related to care.

In the interviews, patients and caregivers were asked if they had discussions about the following topics related to care: (1) accessing community services, (2) managing daily care tasks, (3) accessing support services (e.g., dementia support groups, education programs), (4) coordination of family and friend helpers, (5) treatment options, (6) assisting with legal and financial issues related to the illness, and (7) discussing nursing home placement.

- For five of the seven care topics, approximately two-thirds to three-quarters of caregivers reported extensive discussion. Most adequately discussed topics were daily task monitoring (84%) and support services (74%), followed by legal and financial information (71%), family and friend coordination (71%), community services (67%), and treatment options (67%).

5. **Satisfaction with care was positive.** On average, patients and caregivers were satisfied with the care they received from physicians, other providers, and especially Chapter personnel. They were also satisfied with their health plan.
6. **Assistance with certain aspects of care was related to better outcomes for patients and caregivers.**
 - More discussion with providers about *family and friend helpers* was associated with less relationship strain, health strain, and role captivity for caregivers. Greater discussion about *legal and financial topics* was also related to less relationship strain.
 - More discussion with providers about *treatment options* was associated with lower levels of relationship strain for patients, as well as less embarrassment about memory problems and less depression.
 - Higher levels of caregiver satisfaction with care were associated with more discussion of care dimension topics, especially with *managing daily care* and *treatment options*. Higher levels of patient satisfaction with care were associated with more discussion about coordinating *family and friend helpers*.

Limitations of CCN/AD Based on Current Findings

1. **Provider education is not finished.** Project personnel were asked during spring interviews to estimate the proportion of their targeted primary care providers who had received education on seven topics related to care and to qualify how fully covered were those seven topics.
 - Project personnel estimated reaching at least 50% of their targeted providers with information about pharmacologic treatments and provider roles and responsibilities (at 11 sites), dual track support (at 9 sites), dealing with problem behaviors and advanced directives (at 7 sites), and attending to comorbidities and tools/forms for managing ongoing care (at 6 sites). In each case, the remaining sites estimated reaching less than half of their targeted providers.
 - The most fully covered topics were pharmacologic treatments, dual track support, and provider roles and responsibilities. Eleven sites said they had covered those topics either moderately or fully. The least fully covered topics were attending to comorbidities (7 sites), and tools and forms for managing ongoing care (6 sites).
2. **A sizeable portion of providers did not complete the Provider Survey making it impossible to know their perceptions of the impact of the Initiative.** Approximately 60% of providers who continued working in the job that involved them in CCN/AD completed the Time 1 and Time 2 surveys, and 49% completed Time 1 through Time 3. Findings may not represent those who did not complete the surveys.

3. **Changing “the system” of care was difficult.** While sites were successful in caring for individual patients and caregivers who were enrolled in the project, they were comparatively less successful in changing some of the MCO *systems* supporting early identification and care, as defined by the site visits and interviews with project personnel. For example, in Year 3:
- Significant financial disincentives for primary care providers to identify and diagnose dementia patients and lack of adequate reimbursement for care were reported by almost half (5 of the 12) sites.
 - Project personnel at 5 sites felt their MCO had no stated goals for meeting the needs of dementia patients.
 - Few sites said they had been able to incorporate a disease flag into the medical record or patient chart for dementia cases, establish a disease registry, or use the information system to track and report on the dementia population.
 - Few sites were able to “bundle” standard orders for assessment or care planning, incorporate clinical reminders, or implement dementia care guidelines in primary care.
 - Only one site felt that a majority of the targeted primary care providers had made dementia the “leading diagnosis” or “driver of care.”
4. **Care models varied in terms of achieving key characteristics.** Some sites were more successful than others at implementing different components of a coordinated care model. There was strong variation across sites *within* each of the four care components¹ (as defined by the site visits) *including* case management and caregiver support. In terms of one potential pattern, sites with “affiliated” MCOs² were more likely than “separate” and “independent” MCOs³ to achieve changes in the assessment and clinical/medical care site characteristics identified above and to build in mechanisms for provider education (i.e., orienting all new providers to dementia and ensuring that ongoing education would include dementia topics).
5. **Not all of the care topics identified in the patient and caregiver interviews were discussed, remembered, or found to be helpful.** Approximately one-third of caregivers reported less than adequate information about important care-related topics. Adequacy of information was related to a number of patient and caregiver characteristics, implying the site differences alone do not explain the extent of information adequacy.
6. **Sustainability is an issue, especially for projects with “independent” and “separate” MCOs.**

¹ As defined by Year 2 site visits, the four care model components are: clinical/medical care, case management (coordination of care over time and place), caregiver support, and communication and integration of care across providers.

² Affiliated MCOs = health plan and delivery system(s) are virtually, if not wholly aligned, and providers are employed full-time and paid as staff.

³ Separate MCOs = health plan and delivery system(s) are separate entities, but the providers targeted by the project are employed full-time and paid as staff. Independent MCOs = health plan and delivery system(s) are separate entities, and the providers targeted by the project are reimbursed as independent contractors in solo or group practices.

- In the spring of Year 3, only about one-quarter of MCO and Chapter staff were *sure* that referral to the Chapter would continue after the grant. Often, they were unsure because a key person who had been responsible for enrollment and referral was leaving or their status was not assured after the grant ended. For other sites, the end of the grant meant the end of a defined point of enrollment into the project, and staff could not predict what individual providers would do in the future when encountering a new case.
- Of the original seven project sites, one (Sacramento) dropped out in Year 2. Two others (Troy/Albany and Philadelphia) disbanded their partnership and/or staffing for the project as Year 3 was closing. It is unlikely that the Brown & Toland (sub)site from the San Francisco project will continue. Tremendous stress in the healthcare environment and turnovers in organizations have made it difficult for these sites to implement the project.
- Two other projects (Twin Cities and Denver) are continuing with positive momentum but expect changes in staffing and some key relationships. The two projects with the best prospects for sustaining their models are those with established healthcare systems where the health plan and provider groups are fully integrated, i.e., the Upstate New York project [with five VA (sub)sites] and San Francisco Kaiser. In both of these project sites, the key staff responsible for coordinating care (i.e., patient care coordinators and dementia care managers) are all employed with “hard” dollars, as opposed to grant dollars.

The National Evaluation Team will continue to collect information from sites that may further illuminate and possibly alter some of these interim findings. Still to come:

- Closing interviews with project leaders and key staff
- Further collection and analysis of MCO and Chapter service utilization
- Further analysis of Provider Survey data
- Further collection and analysis of Patient and Caregiver Interview data