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Trying Out a New Model of Caring for People with Dementia

Implementing the Chronic Care Networks for Alzheimer's Disease and planning for the Veterans Affairs' Partnership for Dementia Care

SUMMARY

Beginning in 1996, the Alzheimer's Association and the National Chronic Care Consortium partnered to develop and demonstrate a model of integrated health care and supportive services—Chronic Care Networks for Alzheimer's Disease—for people with Alzheimer's disease and dementia. Eight sites participated in developing the model, and six sites continued on to implement the model.

From September 1999 through October 2004, the Robert Wood Johnson Foundation (RWJF) supported three of the implementation sites — Minneapolis/St. Paul, Minn., Philadelphia, and upstate New York. In addition, RWJF made two grants to the Benjamin Rose Institute to support an evaluation of the project and to develop a proposal to further test the model.

Key Results

Project staff from the Alzheimer's Association, the Benjamin Rose Institute, and the Veteran's Administration reported the following key results:

- Minneapolis/St. Paul, Minn., Philadelphia, and Upstate New York (which called its project Partners in Dementia Care) enrolled 835 people with dementia and 773 caregivers in Chronic Care Networks for Alzheimer's Disease.
- Each site:
  - Identified and assessed people with dementia
  - Provided information, support, care consultation, and community referrals to the enrollees and their caregivers
  - Coordinated care provided to enrollees and their families by the partnering organizations within each site. Each site was a partnership of managed care

organizations, health care systems, Alzheimer's Association chapters, and other community agencies.

- Project staff from the Benjamin Rose Institute, in collaboration with the Alzheimer's Association and the Veteran's Administration, prepared a proposal for a controlled clinical trial of the Upstate New York intervention, Partners in Dementia Care, for veterans and their caregivers. In October 2005, the Veterans Administration approved the proposal.

  (The five-year controlled research study of Partners in Dementia Care concluded in 2011. See the Program Results Report for results and findings from the study.)

Key Evaluation Findings

Researchers from the Benjamin Rose Institute reported the following key evaluation findings:

- At the initial interview, caregivers most frequently reported receiving help with support services (87.3%) and treatment options (86.0%).
- At the initial interview, patients most frequently reported receiving assistance with treatment options (61.9%), followed by legal issues (38.4%), and daily living tasks (32.7%). Family issues received the least attention (20.7%).
- The amount of assistance both caregivers and patients reported receiving decreased over the study period, with most of the decrease occurring during the six months between the first and second interviews.

Funding

Between September 1999 and October 2004, RWJF provided four grants totaling $2.53 million for this unsolicited project (two grants totaling $1.54 million to the Alzheimer's Association[1] and two grants totaling $989,187 to the Benjamin Rose Institute[2]).

CONTEXT

In the late 1990s, estimates of the number of older Americans with Alzheimer's disease ranged from 2.3 to 4.5 million, not including the many older people with other types of dementia, according to the Alzheimer's Association and the National Chronic Care Consortium. By 2050, the number of older Americans with Alzheimer's disease is expected to grow to between 9 and 14 million. The Alzheimer's Association is a Chicago-based health organization devoted to Alzheimer's research and support. The National Chronic Care Consortium was a Minnesota-based association of health care

[1] ID#s 37013 and 37913.

[2] ID#s 40335 and 46763.

organizations that was involved in chronic care from 1991 to 2003. Although no longer active, its website still contains resources.

From the mid 1980s to the late 1990s, considerable progress was made in developing home and community-based care and supportive services for people with Alzheimer's disease; however, improvements were needed in acute and primary medical care and in integrating medical care with home and community-based care. Experts believed that managed care and integrated health care delivery systems offered new ways to address these problems and to improve care for people with dementia and/or other chronic illnesses.

Developing the Model

In 1996, the Alzheimer's Association and the National Chronic Care Consortium partnered to develop a national model of integrated primary and acute health care and supportive services for people with Alzheimer's disease and dementia in a managed care environment. In 1997, the partners selected eight sites to participate in development and demonstration of the model and engaged the Benjamin Rose Institute, Professional Evaluation Services, and Professional Data Systems to conduct an evaluation of the project. The Benjamin Rose Institute is a nonprofit health and social services agency located in Cleveland that conducts research on services for older people and their caregivers.

Each site was comprised of local partnerships of managed care organizations, health care systems, Alzheimer's Association chapters, and other community agencies. The eight sites were: Denver, Minneapolis/St. Paul, Minn., Philadelphia, Portland, Ore., Sacramento, Calif., San Francisco, Troy/Albany, N.Y., and Upstate New York through the Veterans Integrated Services Network 2 (VISN 2).[3]

An advisory group comprised of representatives from each site (physicians, other health care professionals, and staff from Alzheimer's Association chapters) worked with the Alzheimer's Association and the National Chronic Care Consortium to develop the model, which addressed the total needs of the person with Alzheimer's disease or other dementia and provided personal and family support at all stages of the illness.

The model, called Chronic Care Networks for Alzheimer's Disease, had four components:

- Early identification of people with possible dementia
- Initial dementia assessment

[3] The Veterans Health Administration organizes its hospitals and outpatient and community-based clinics into 22 regional VISNs nationwide.

- Ongoing medical and nonmedical care management
- Family caregiver information and support

See Appendix 1 for a description of these components.

By March 1999, of the eight sites:

- Four sites were ready or nearly ready to implement the model and had funding:
  - Denver and Troy/Albany sites ($600,000 from the Helen Bader Foundation)
  - Sacramento and San Francisco sites ($990,000 from the California Healthcare Foundation)
- Three sites—Minneapolis/St. Paul, Minn., Philadelphia, and Upstate New York—needed funding to prepare for implementation.
- Two sites—Portland, Ore., and Sacramento, Calif.—dropped out before implementation.

The Alzheimer's Association provided $870,000 for project planning.

RWJF's Interest in This Area

Previous RWJF programs worked explicitly to improve care for those suffering from dementia. *Partners in Caregiving: The Dementia Services Program* (PIC), created in 1992 by RWJF and the Wake Forest University School of Medicine, built on the lessons of a prior program called the *Dementia Care and Respite Services Program* (DCRSP). From 1988 to 1992, DCRSP had demonstrated that adult day centers for dementia sufferers could provide needed services to individuals across a wide range of disease severity, and could become financially viable, especially by focusing on the private-pay market. For more information on these two programs, see Program Results Report.

When RWJF issued the initial grant in this project in September 1999, it was committed to improving care and support for people with chronic conditions. Several 2001 grants worked toward giving the frail elderly or the disabled more control over needed services; this project fits within that framework.

THE PROJECT

RWJF funded project sites in Minneapolis/St. Paul, Minn., Philadelphia, and Upstate New York to plan for and then implement Chronic Care Networks for Alzheimer's Disease, as well as part of an evaluation of the model and development of a proposal to test the model in matched health centers that did and did not use it. The Alzheimer's Association served as the lead organization for the planning and implementation grants (grant ID#s 037013 and 037013, respectively), and the Benjamin Rose Institute served as

the lead organization for the evaluation and proposal preparation grants (grant ID#s 040335 and 046763, respectively).

Planning and Pilot Test

Under grant ID# 037013 to the Alzheimer's Association, each site hired a project coordinator and conducted a pilot test, which included:

- Training health care providers, using site-developed training plans and materials:
  - The Minneapolis/St. Paul, Minn., site trained 84 health care providers (16 physicians, five nurse practitioners, and 63 other clinic staff).
  - The Philadelphia site trained 109 physicians and their office staffs.
  - The Upstate New York site, called Partners in Dementia Care, trained 112 physicians, physicians' assistants, and nurse practitioners in Syracuse (the main pilot site), as well as in Albany, Bath, Buffalo, and Canandaigua (the five medical centers of VISN 2).
- Enrolling people with dementia and their caregivers:
  - The Minneapolis/St. Paul, Minn., site enrolled four people with dementia and three caregivers.
  - The Philadelphia site enrolled 35 people with dementia and 35 caregivers.
  - Partners in Dementia Care enrolled 84 people with dementia and, in Syracuse, 43 caregivers (figures for the number of caregivers enrolled in Albany, Buffalo, and Canandaigua are not available).
- Establishing data collection capability using software provided by the Alzheimer's Association and beginning to collect demographic and other data about enrollees, their family caregivers, and their use of Alzheimer's Association chapter health care services.

Implementation

Under grant ID# 037913 to the Alzheimer's Association, project staff at each site implemented Chronic Care Networks for Alzheimer's Disease. They:

- Established relationships among the partner organizations (managed care organizations, health care systems, Alzheimer's Association chapters, and other community agencies)
- Trained health care providers and Alzheimer's Association chapter staff
- Identified and assessed people with dementia, using a list of patient behavior triggers for clinic staff, a family questionnaire, and other screening tools

- Enrolled people with dementia and their family caregivers in the project
- Provided information, support, care consultation, and community referrals for enrollees and family caregivers
- Coordinated the care provided to enrollees by the health care organizations, the Alzheimer's Association chapters, and other agencies
- Collected data, including patient and family caregiver assessments, demographic data, and data on use of health care and Alzheimer's Association chapter services by the enrollees and their families

Evaluation

Under grant ID# 040335, researchers at the Benjamin Rose Institute, in collaboration with the Alzheimer's Association, conducted an outcome survey of patients with dementia and their family caregivers at all six sites as one part of a four-part national evaluation of Chronic Care Networks for Alzheimer's Disease. Researchers interviewed patients and their family caregivers separately by telephone three times, at six-month intervals, with the first interview taking place approximately nine months after enrollment, on average.

The survey covered:

- Understanding of and satisfaction with the network
- Knowledge and understanding of dementia
- Emotional and physical well-being and care-related strain
- Use and knowledge of community and network support services

The patient survey covered four key types of assistance: daily living tasks, legal and financial issues, family concerns, and treatment options. The caregiver survey covered these plus patient services and support services. Researchers surveyed from 746 caregivers and 226 patients at the first interview to 496 caregivers and 141 patients at the third (12-month) interview. See Appendix 2 for more information on survey methodology. See Findings for survey findings.

The four-year evaluation also included an assessment of the model's impact on the organizations involved, a provider survey, and a uniform database comprised of data from all sites on diagnostic assessment, movement in and out of the program, and use of services. The Retirement Research Foundation funded this part of the evaluation ($776,304). The Alzheimer's Association also provided $100,000 in evaluation funding.

Proposal Development

Under grant ID# 046763, project staff from the Benjamin Rose Institute, in collaboration with the Alzheimer's Association and the Veterans Administration (VA), developed a proposal to the VA to conduct a controlled clinical trial of Chronic Care Networks for Alzheimer's Disease at VA medical centers to compare patient and caregiver outcomes at matched centers that did and did not use the model. They also developed an operations manual of best practices for dementia care to guide participating centers that used the model. This work was based primarily on reanalysis of data from Partners in Dementia Care and the national evaluation of Chronic Care Networks for Alzheimer's Disease. Project staff also conducted focus groups with key staff from Partners in Dementia Care.

The Alzheimer's Association also supported the development of the proposal ($198,250); the VISN 2 Educational Council ($27,400) and Eisai, Inc. ($5,000) supported staff training. RWJF accepted and funded the proposal (ID# 57816). See Program Results Report for the findings from the evaluation.

RESULTS

Implementation of Chronic Care Networks for Alzheimer's Disease at the Three Sites:

The Alzheimer's Association reported the following results in a report to RWJF:

- **Together, Minneapolis/St. Paul, Minn., Philadelphia, and Partners in Dementia Care in upstate New York enrolled 835 people with dementia and 773 caregivers.** Each site used Alzheimer's Association tools within Chronic Care Networks for Alzheimer's Disease to:

  — Identify and assess people with dementia

  — Provide information, support, care consultation, and community referrals to the enrollees and their caregivers

  — Coordinate care provided for enrollees and their families by the partnering organizations within each site

  Each site participated in the national evaluation through site visits, structured telephone interviews, and a mailed provider survey.

  "The Alzheimer's Association now has a model of care that addresses basic problems of care for people with dementia on the health care side and the community side," said Katie Maslow, project director at the Alzheimer's Association, about implementation of Chronic Care Networks for Alzheimer's Disease.

- **In Minneapolis/St. Paul, Minn., 76 people with dementia enrolled in the project, and all but one had a family caregiver who also enrolled.** UCare Minnesota,

HealthEast, Fairview Health Services, the Amherst Wilder Foundation, and the Minnesota-Dakotas Alzheimer's Association chapter participated. Each health system had a dementia care coordinator who worked with, and trained, staff to implement the project.

- **In Philadelphia, 185 people with dementia and 185 family caregivers enrolled in the project.** Temple University Health System and the Philadelphia Geriatric Center participated, along with the Southeastern Pennsylvania Alzheimer's Association chapter. A nurse manager trained participating physicians and their staffs and referred enrollees and their families to information, support, care consultation, and community services.

- **Partners in Dementia Care enrolled 574 veterans with dementia and 513 family caregivers.** The project included the five medical centers of VISN 2 (in Albany, Bath, Buffalo, Canandaigua, and Syracuse) and four Alzheimer's Association chapters serving the same areas. A dementia care manager in each medical center handled staff training, completed the dementia assessment, referred enrollees to the local Alzheimer's Association chapter, and provided care coordination. Implementation spread beyond the five centers to VA outpatient clinics in other areas of VISN 2.

Project staff from the Benjamin Rose Institute reported the following results:

- **The proposal to the VA suggested a controlled clinical trial of the effectiveness of Partners in Dementia Care for veterans with dementia and their caregivers.** The trial would cover psychological and social well-being, health care service use, health care costs, and the role and intrapsychic strains (e.g., emotional strain, relationship strain, and social isolation) for patients and caregivers.

  It called for a match of two sites that would use the model (intervention sites) and two sites that would not use the model (control sites) on organizational, provider, and patient characteristics. Each site would include a VA medical center and a partner Alzheimer's Association chapter. Project staff from the Benjamin Rose Institute, in collaboration with the Alzheimer's Association and the VA, prepared the proposal and submitted it to the VA.

- ***A Best Practice Care Model for Dementia: Operations Manual* details for providers and support staff on how to implement Partners in Dementia Care.** Project staff from the Benjamin Rose Institute developed the manual in collaboration with the Alzheimer's Association and the VA. See the Bibliography.

- **Project staff updated *Tools for Early Identification, Assessment, and Treatment of People with Alzheimer's Disease and Other Dementias*, which describes the protocols and instruments used to implement Chronic Care Networks for Alzheimer's Disease (originally written before the RWJF grant period).** The document is available on the website of the National Chronic Care Consortium. See the Bibliography.

Communications Results

Project staff from the Benjamin Rose Institute and the Alzheimer's Association published six articles, including in the *Journal of Gerontology: Medical Sciences*, and *Disease Management & Health Outcomes*, and made 64 presentations about the project.

Project staff from the Alzheimer's Association testified before Congress about Chronic Care Networks for Alzheimer's Disease upon written invitation; staff testified before the U.S. Senate Committee on Veterans' Affairs (April 25, 2002) and the House Committee on Veterans' Affairs (January 28, 2004), and submitted a written statement, upon the request of the House Committee on Veterans' Affairs, on VA long-term care programs (May 22, 2003).

FINDINGS

Researchers from the Benjamin Rose Institute reported the following findings from the patient and caregiver survey at all six sites in a report to RWJF:

- **At the initial interview, caregivers most frequently reported receiving help with support services (87.3%) and treatment options (86.0%).** Assistance with legal and financial services (67.2%) and with daily living tasks (65.6%) were next, followed by patient services (53.0%) and family concerns (29.8%).
- **At the initial interview, patients most frequently reported receiving assistance with treatment options (61.9%), followed by legal issues (38.4%) and daily living tasks (32.7%), with family issues receiving the least attention (20.7%).**
- **The amount of assistance both caregivers and patients reported receiving decreased over the study period, with most of the decrease occurring during the six months between the first and second interviews.** For example, between the two interviews:
  - The percentage of caregivers who reported receiving assistance decreased from 87.3 to 77.1 percent for support services and from 86 to 73.9 percent for treatment options.
  - The percentage of patients who reported receiving assistance decreased from 61.9 to 45.6 percent for treatment options and from 38.4 to 25.2 percent for legal issues.
- **Caregivers' perceptions of the adequacy of assistance increased over time, particularly between the first and second interviews.** For example, between the two interviews, the percentage of caregivers who reported completely adequate assistance increased from 66.1 to 75.0 percent for patient services and from 63.9 to 76.3 percent for daily living tasks.

- **Patients' perceptions of the adequacy of assistance increased over time.** More than half the patients reported having enough assistance with legal concerns (55.3%) and daily living tasks (53.1%) at the initial interview. This increased to almost three-quarters 12 months later at the third interview (73.2% for legal issues and 70.8% for daily living tasks). Adequacy of assistance also increased from 40.9 to 47.0 percent for treatment options and from 32.9 percent to 67.3 percent for family concerns.
- **Caregivers and patients reported receiving more assistance when they had used Alzheimer's Association services and when patients had larger networks of family and friend helpers.**
- **Caregivers and patients reported care from the project as less adequate for meeting their needs when patients had more coexisting medical conditions and when they had fewer family and friend helpers.**
- **Caregivers, on average, "agreed" (on a four-point scale from "strongly disagree" to "strongly agree") that they were satisfied with project care from physicians, other providers, and the overall health plan.** Higher caregiver satisfaction was consistently associated with more assistance with daily living tasks and with caregivers reporting adequate assistance with information on treatment options.

  Patients' satisfaction with care from physicians and other providers was high on a scale of 0=lowest to 12=highest satisfaction. It ranged from an average of 10.10 at the first interview to 10.17 at the second and third interviews. (Patients were not asked about satisfaction with the health plan.)
- **For caregivers, more adequate assistance with family concerns was consistently related to less emotional and relationship strain and fewer symptoms of depression.** Adequacy of assistance with daily living tasks had a somewhat consistent association with less strain and depression. However, there was little relationship between the amount of assistance provided by the project and care-related strain or depression.
- **Use of Alzheimer's Association services in the project was much higher than would have normally occurred.** Of enrolled families, 57 percent used information and referral services, 44 percent used care consultation or care planning services, and 12 percent used support groups or counseling services. Use of care consultation or care planning was related to a decreased likelihood of patients having a specialty physician visit. For less cognitively impaired patients, these services were also associated with a decreased likelihood of a hospital admission and nursing home placement.

Researchers from the Benjamin Rose Institute, the Alzheimer's Association, and the VA reported patient and caregiver survey findings for Partners in Dementia Care in a report entitled *Final Report on an Innovative Partnership Between Veterans Integrated Service Network 2 (VISN 2) & Four Upstate New York Alzheimer's Association Chapters*.

- **The majority of surveyed veterans reported that they received enough information or help with important areas of care, including daily living tasks (93%), family concerns (85%), legal and financial issues (82%), and treatment options (60%).** Caregivers reported similar ratings for adequacy of assistance, ranging from 85 percent for daily living tasks to 67 percent for support services.

  Veterans and caregivers who used Alzheimer's Association 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 with Partners in Dementia Care and less likely to have symptoms of depression and other negative psychosocial outcomes.

- **Use of VA health care services changed little in the six months after enrollment in Partners in Dementia Care.** Use of Alzheimer's Association 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, more 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.

- **Partners in Dementia Care worked less well for some subgroups of veterans and families.** These included veterans who lived alone, veterans who had more coexisting 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.

Limitations

Researchers noted the following limitations to the findings.

- The lack of control groups not using Chronic Care Networks for Alzheimer's Disease limited the researchers' ability to evaluate fully the project's effectiveness. (See Appendix 2 for information on lack of control groups.)

- Many patients, due to their dementia, were unable to complete one or more of the interviews and, thus, the findings do not include their views.

LESSONS LEARNED

1. **Allow sites that are using a model the time and effort needed to adapt the model to their sites.** Staff designed Chronic Care Networks for Alzheimer's Disease to be flexible, but the adaptation needed was greater than anticipated. However, lasting change is more likely to occur when the people who provide care take ownership of a new model by adapting it to their own situation. (Project Director/Maslow)

2. **Pilot test the model to identify and address problems early.** Some problems only became obvious as the model was put into place. The pilot period allowed staff to make revisions needed to rectify problems not envisioned by model designers,

resulting in a model that is feasible for real-world health care settings. (Project Director/Maslow)

3. **Reiterate project objectives frequently.** Site-level staff members, who deal with many day-to-day issues unrelated to the project, need reminders about project objectives. New staff members need training that includes a full explanation of the project's objectives and background. (Project Directors/Maslow and Bass)

4. **Use multiple approaches to change provider behavior.** This project used both training by site medical directors and one-on-one encouragement and persuasion by other project staff. (Project Director/Maslow)

5. **Use tools to identify people with dementia that work best in each health care setting.** For example, the family questionnaire seemed to fit better in a clinic setting than in a private physician's office. (Project Director/Maslow)

6. **Identify a staff member at each participating organization to coordinate the multiple aspects of care included in the model.** The absence of such a "care manager" at one site meant that someone else in the office had to take on care coordination tasks or they did not happen. (Project Director/Maslow)

7. **Establish a fax consent process to allow community agencies to contact patients with chronic conditions and their family caregivers.** In this project, the fax consent process significantly reduced the average two-year delay between referral to an Alzheimer's Association chapter and actual contact by the patient or caregivers. (Project Director/Maslow)

8. **Pay attention to capitated financing when selecting health care organization partners for programs to expand and coordinate health care and community services for people with dementia or other chronic diseases.** This project's ability to use the incentives created by capitated financing depended upon the extent to which a physician's patients were in the same capitated health plan and what health services (especially hospital care) were included in the capitation payment. (Project Director/Maslow)

9. **Enlist an organizational "champion" with enough clout to move the organization to implement a project.** In this project, sites that worked best were those that had high-level champions in both the health plan and the Alzheimer's Association chapter. (Project Director/Bass)

AFTERWARD

As of October 2005, project staff reported the following developments after completion of this project:

- The VA Office of Geriatric Research and Evaluation for Dementia Care Initiatives was disseminating *Final Report on an Innovative Partnership Between Veterans*

Integrated Service Network 2 (VISN 2) & Four Upstate New York Alzheimer's Association Chapters and the operations manual, *A Best Practice Care Model for Dementia: Operations Manual*, throughout the VA system.

- In Minneapolis/St. Paul, Minn., the Metropolitan Area Agency on Aging received an 18-month state grant to use Chronic Care Networks for Alzheimer's Disease to improve the way care is provided to people with dementia. This project involved coordinating care between a hospital and the Alzheimer's Association's Minnesota-Dakotas chapter.

  Also in Minnesota, the *Working Together* program, which was supported by a federal Administration on Aging Alzheimer's Disease Demonstration grant, was using the model's framework in its efforts to improve care for people with dementia at four rural sites and one urban site that focuses on Hispanic and Hmong people in St. Paul.

- Project directors from the Alzheimer's Association and the Benjamin Rose Institute planned to write a book to provide an overview of Chronic Care Networks for Alzheimer's Disease and results from the VA planning project. The Alzheimer's Association planned to publish the book.

In October 2005, the VA accepted the proposal developed under this project to conduct a five-year controlled trial of Partners in Dementia Care at four VA sites (two intervention sites and two control sites). The project began in October 2006, directed by David M. Bass, PhD, director of research at the Benjamin Rose Institute, and included intervention sites in VA medical centers in Boston (with a control site in Providence, R.I.) and Houston (with two control sites—in Oklahoma City and Beaumont, Texas—to provide enough participants). The study was supported by RWJF with grant ID# 57816. It concluded in 2011. See the Program Results Report for results and findings from the study.

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APPENDIX 1

Chronic Care Networks for Alzheimer's Disease—Model Components

Early Identification of Persons with Possible Dementia

The identification process includes:

- Triggers to identify people who may have dementia (10 triggers based on the Alzheimer's Association's 10 warning signs of Alzheimer's disease and seven triggers based on symptoms that physicians, nurses, and their office staffs are likely to notice).
- A brief family questionnaire to identify people who may have dementia. (This part of the identification process was abandoned early in the project because it was found to be unnecessary.)

Initial Dementia Assessment

The assessment includes medical and psychosocial histories, physical and neurological examinations, mental status tests, functional assessments, laboratory tests, and other procedures, divided into three levels:

- Those that should be done for every person
- Those that should be done unless there is a good reason for not doing them
- Those that should not be done unless there is a good reason for doing them

Ongoing Medical and Nonmedical Care Management

This component includes "blueprints" for six domains of care: patient functioning, caregiver support, medical treatment, psychosocial, patient nutrition, and advance directives planning (i.e., specifying an individual's end-of-life wishes through living wills and medical powers of attorney).

For each domain, the blueprints identify desired outcomes, assessment areas, goals, interventions, and responses at each of three phases of care: (1) initial identification, (2) longitudinal monitoring and treatment, and (3) end of life.

Family Caregiver Information and Support

To assist providers in identifying and organizing programs and materials to offer caregivers, six charts list objectives to achieve for families in six phases of caregiving: (1) pre-diagnostic, (2) diagnostic, (3) role change, (4) chronic caregiving, (5) transition to alternative care, and (6) end of life.

Providers use the charts to identify programs and materials and to decide which organization (e.g., the Alzheimer's Association chapter or the health care system) will be responsible to provide each.

APPENDIX 2

Patient and Caregiver Survey Methodology

Timing and Sample Sizes

- T1=Initial survey interview
- T2=Second survey interview at six months
- T3=Last survey interview at 12 months
- Caregiver sample sizes: T1=746, T2=581, T3=496
- Patient sample sizes: T1=225, T2=168, T3=141

Sample sizes decreased due to death, leaving the program or, in the case of patients, decrease in the cognitive ability needed to participate.

Lack of Control Groups

The evaluation did not include control groups that did not participate in Chronic Care Networks for Alzheimer's Disease. This was for three reasons:

- It was difficult to identify comparable managed care organizations and Alzheimer's Association chapters to serve as controls.
- Researchers were concerned about the inappropriateness of creating controls within participating organizations by restricting access to the model services to segments of the population of providers, patients, and caregivers.
- Researchers expected that the use of the model would vary among enrolled patients and caregivers. In a true controlled study, all subjects in the experimental group have the same exposure to an intervention.

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