Establishing Partnerships

Establishing Partnerships Between Managed Care and Aging Service Organizations

A replication manual based on the *Alzheimer's | Greater Los Angeles–*
Kaiser Permanente Metropolitan Los Angeles Dementia Care Project

Administration on Aging

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***Formerly known as the Alzheimer's Association, Los Angeles**

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Authors:

Debra Cherry, Ph.D.
Alzheimer's Association, Los Angeles

Elizabeth Heck, M.S.W.
Alzheimer's Association, National Office, Chicago

Katie Maslow, M.S.W.
Alzheimer's Association, National Public Policy Office, Washington, D.C.

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Alzheimer's Association Los Angeles, Riverside & San Bernardino Chapter
Associate Executive Director & Project Co-Director

Debra Cherry, Ph.D.
Clinical and Administrative Staff
Elizabeth Heck, M.S.W., L.C.S.W., Project Manager
Michelle De Los Santos, M.S.W., L.C.S.W.
Daniel Plotkin, M.D.
Michelle Barclay, M.A.

Kaiser Permanente
Continuing Care Physician-In-Charge & Project Co-Director
Ralph Yep, M.D.
Physician Coordinator for Elder Care
Richard DellaPenna, M.D.
Neurology
Jay Rosenberg, M.D.
Family Practice
Felicio Lorenzo, M.D.
Geriatrics
Milton Sakamoto, M.D.
Geriatrics Department
Vara Himathongkham, RNP
Clinical Services
Mona Rosenthal, M.P.H.
Social Work Management
Edith Eddlemann-Robinson, L.C.S.W., D.A.
Roy Jaffee, L.C.S.W., D.A.
Dementia Specialists
Annette Berry, L.C.S.W. Annette Silva, L.C.S.W.
Heidi Rechtegar, L.C.S.W. John Raphael, L.C.S.W.
Clerical
Lavelle Clemmons-Scot Jeffrey Govan
Educational and Training
Mary Davin, R.N., M.S.N., C.N.S.
Susan Shieff, R.N., M.S.N., Department Administrator

U.C.L.A. Alzheimer's Disease Research Center
Barbara Vickrey, M.D.

Executive Summary

In 1995, Kaiser Permanente's Metropolitan Los Angeles Service area entered into a partnership with the Alzheimer's Association of Los Angeles to assess and improve the quality of care provided to people with dementia. The Kaiser Permanente collaboration grew from both organizations' concerns about quality health care for people with dementia. There was also consensus that education was necessary but insufficient to bring about desired performance improvement.

Using evidence- and consensus-based practice guidelines, the Association worked with Kaiser Permanente staff to select quality indicators for the diagnosis and management of people with dementia. The quality indicators selected for this study were:

Educational sessions for primary care providers focused on the diagnosis and care of people with dementia per guideline recommendations. Tool kits were developed to support these practice recommendations. The Association also trained the social worker care managers to assist both physicians and family caregivers in the provision of quality care.

The Project's goals were to improve quality of care for dementia patients and to improve Kaiser Permanente member and provider satisfaction by:

- Developing an explicit care path for the diagnosis and care of people with dementia.
- Coordinating Kaiser Permanente's resources for the diagnosis and management of dementia.
- Improving primary care physicians', social workers' and family caregivers' knowledge about dementia, its diagnosis, treatment and care.
- Linking Kaiser Permanente's members with dementia to supportive, community-based services.

A detailed program evaluation was conducted. Physicians and caregivers were surveyed about care practices and satisfaction. Chart audits were conducted to examine documented care practices. The evaluation demonstrated that the interventions enhanced the quality of care significantly and improved both provider and consumer satisfaction. At the completion of the pilot, the program was expanded and disseminated within the Southern California region and nationally throughout Kaiser Permanente.

The replication manual that follows highlights some important issues that should be considered before establishing one of these partnerships. They include:

- Selecting a partner managed care organization
- Selecting goals for the project
- Considering options for the model of care
- Matching the strengths of the two partner organizations
- Determining resources for training health care providers
- Examining the role of care management and of the community aging service provider

Evaluating the project and sustaining the change.

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Introduction

Healthcare organizations are being challenged to care for the growing number of older adults with chronic health conditions. Dementing diseases, such as Alzheimer's disease, vascular dementia, and other associated disorders, present particular challenges because there are strong social and behavioral components to disease management. In the health care organization, physicians play a central role in assessment, diagnosis and treatment. Primary care physicians faced with short visit times manage a broad range of disorders and may be unaware that some of their older adult patients are compensating for cognitive losses with retained social skills. Much of the management of the psychosocial aspects of dementia including caregiver stress, patient depression, challenging behaviors and need for community services is done by families with the support of care managers and community aging service providers.

Research suggests that Alzheimer's disease is neither well recognized nor systematically diagnosed (Boise, et al, 1999, 2004; Callahan, et al, 1995; Fortinsky & Wasson, 1997). According to Callahan and colleagues (1995), physicians diagnose as few as 24% of dementia cases. In a 2004 study, Boise and colleagues screened 553 patients aged 75 years and older in three managed health care systems and reviewed the medical charts of those determined to be cognitively impaired. Of the 43% of patients who were screened to have a cognitive impairment, only 14.5% of those with moderate to severe cognitive impairment had a dementia diagnosis in their medical chart and 13.3% of those with a mild cognitive impairment had a dementia diagnosis in their medical chart.

The last ten years has seen approval of two classes of medications effective in delaying progression of Alzheimer's disease in some patients (Doody et al, 2001; Reisberg, B. et al, 2003). Delay in diagnosis also means delay in treatment. Furthermore, people with undiagnosed dementia and their families are less likely to gain access to supportive services that can ameliorate caregiver burden and perhaps delay institutionalization (Mittelman et al, 1996; Zarit et al, 1998).

Clinical practice guidelines have been developed and promoted as tools for improving dementia care (AHCPR, 1996; APA, 1997; Guttman, 1999**;** Cummings et al, 1999; Maslow et al, 2003). However, often practitioners are unfamiliar with these tools and, even when disseminated broadly, they are not implemented uniformly (Fortinski & Wasson, l997; Rosen et al, 2002, 2003). Managed care organizations offer some unique possibilities for quality improvement in dementia care. They provide the communication lines for dissemination of guidelines. Their accreditation can be dependent on adoption and implementation of guidelines-based quality improvement projects (O'Kane, 2003). Capitated payments can be used to creatively organize care and to bring in the services of less expensive professionals from the community-based aging services network that may reduce costs or hold them steady while improving quality.

Recognizing the opportunity to improve care for people with dementia in managed care settings, a number of pilot projects have been initiated (Cherry, 1999), one of which was initiated as a partnership between Alzheimer's Association and Kaiser Permanente in the Metropolitan Los Angeles area. The Los Angeles-based project is described here with suggestions on how it can be replicated by organizations in the aging services network. For the purposes of this manual, a community aging service provider (CASP) can be a local area agency on aging or another provider of social services to older adults.

Kaiser Permanente

Kaiser Permanente is a group model health maintenance organization. It is one of the oldest managed care organizations in the United States, and it entered the Southern California Medicare managed care market in 1987. Approximately 3,600 physicians of the Southern California Permanente Medical Group provide medical care to over three million members in Kaiser Permanente's Southern California Region's six service areas. Of the 3,600 physicians, 95% are board certified and 2,000 are tenured medical staff. Generally 40% are primary care physicians including those in family practice and internal medicine. An estimated 11% of Kaiser's membership is over 65 years old, of which 95% are enrolled in Senior Advantage, the Medicare managed care product.

The Metropolitan Los Angeles Service Area of Kaiser Permanente is a densely urban and ethnically diverse region. The enrollees in this service area are primarily middle and lower "working class" and represent a range of ethnic groups including Latino, African American, Asian American, Eastern European and Middle Eastern. Nearly 54,000 of the 422,000 enrollees served in this area are over 65 years of age. The Metropolitan Los Angeles Service Area consists of two major medical centers and seven satellite clinics. Based on extrapolated demographic estimates (Evans et al., 1989), there may be up to 5,000 people with dementia served by Kaiser Permanente's Metropolitan Los Angeles Service Area.

Most of Kaiser Permanente Southern California's medical services fall within the traditional medical model of service delivery (i.e., physicians providing care to patients in medical offices or hospital settings). Kaiser Permanente is focusing nationally and regionally on population approaches to care delivery including care to older adult members.

Alzheimer's Association

The Alzheimer's Association is the voluntary health agency dedicated to providing support and assistance to afflicted patients and their families, and to researching the prevention, cure and treatment of Alzheimer's disease and related disorders. It was founded by concerned family caregivers in 1980 and incorporated as a non-profit in 1984. The Alzheimer's Association in Los Angeles seeks to meet the needs of an ethnically and culturally diverse population by offering patient and family services and by educating both the public and health care professionals.

The Alzheimer's Association hosts a number of key programs to support people with dementia and their family caregivers. Many of these programs can bring added value to a managed care organization (MCO). For example, the Contact Center / Helpline is a 24/7 national call center that has capacity to respond to questions on dementia, caregiving issues, and community services in a broad range of languages. The service is enriched by trained social work professionals who provide care consultation and by local follow- up through a nationwide network of chapters. Care consultants assist families by educating them about the disease and its management as well as by connecting families to needed community services such as adult day services, support groups, diagnostic centers, long-term care facilities and more.

The Association's national website, www.alz.org, offers both a depth and breadth of information on Alzheimer's disease and associated disorders as well as educational opportunities and more. The Alzheimer's Association provides caregiver and community health education programs, which can benefit managed care plan members. Professional training programs, some with continuing education units, are offered for physicians, care managers, residential care providers, and other professionals. These programs can be adapted for use in managed care settings.

The Association also hosts a nationwide network of support groups for caregivers and a growing number of groups for people with early stage disease. Enrollees of the MCO can access these groups. The Alzheimer's Association Safe Return™ wanderer's registry is an identification program that helps to find lost people with dementia and return them safely home. Working with MCO social workers and other staff, registration in this program can be encouraged and potential adverse health consequences may be averted.

The Partnership

In 1995, Kaiser Permanente's Metropolitan Los Angeles Service area entered into a partnership with the Alzheimer's Association of Los Angeles to assess and improve the quality of care provided to people with dementia. The Kaiser Permanente collaboration grew from both organizations' concerns about quality health care for people with dementia. There was also consensus that education was necessary but insufficient to bring about desired performance improvement. Physician surveys and focus groups were conducted. Together with caregiver focus group feedback, these measures indicated that there were opportunities for performance improvement both at the practitioner and the system levels in the care of people with dementia and their families. The two organizations sought to collaborate to improve care quality as well as physician and consumer satisfaction with the care provided by Kaiser to people with dementia and their families.

Using evidence- and consensus-based practice guidelines, the Association worked with Kaiser Permanente staff to select quality indicators for the diagnosis and management of people with dementia. The quality indicators selected for this study were:

Diagnosis:

- Administration of the Folstein Mini Mental Status Exam
- Referral for select laboratory tests

Management:

- Referral to the Alzheimer's Association and its Safe Return™ Program
- Assessment for depression, performance of activities of daily living, wandering risk
- Development of an advance directive

Educational sessions for primary care providers focused on the diagnosis and care of people with dementia per guideline recommendations. Tool kits were developed to support these practice recommendations. The Association also trained the social worker care managers to assist both physicians and family caregivers in the provision of quality care.

The project's goals were to improve quality of care for dementia patients and to improve Kaiser Permanente member and provider satisfaction by:

- Developing an explicit care path for the diagnosis and care of people with dementia.
- Coordinating Kaiser Permanente's resources for the diagnosis and management of dementia.
- Improving primary care physicians', social workers' and family caregivers' knowledge about dementia, its diagnosis, treatment and care.

- Linking Kaiser Permanente's members with dementia to supportive, community-based services.

The project's deliverables included:

- Clinical guidelines for the diagnosis of dementia
- Training programs and materials for primary care physicians and social workers
- Educational materials for caregivers
- A model care coordination program integrated with primary care utilizing trained social work care managers
- A detailed evaluation of the multifaceted intervention

Results

A detailed program evaluation was conducted. Physicians and caregivers were surveyed about care practices and satisfaction. Chart audits were conducted to examine documented care practices. The evaluation demonstrated that the interventions enhanced the quality of care significantly and improved both provider and consumer satisfaction. At the completion of the pilot, the program was expanded and disseminated within the Southern California region and nationally throughout Kaiser Permanente.

The replication manual that follows highlights some important issues that should be considered before establishing one of these partnerships. They include:

- Selecting a partner managed care organization
- Selecting goals for the project
- Considering options for the model of care
- Matching the strengths of the two partner organizations
- Determining resources for training health care providers
- Examining the role of care management and of the community aging service provider
- Evaluating the project and sustaining the change

Selecting a Partner Managed Care Organization

What characteristics of managed care organizations should the community aging service provider consider when selecting a partner organization for a project?

Kaiser Permanente, the partner for this project, is a group model health maintenance organization. Kaiser Permanente in California owns its own hospitals, home health agencies, hospices, and medical offices. Physicians in the Southern California Permanente Medical Group provide all professional medical care. The group model makes it easier to engage physicians and others in clinical and system performance improvement activities compared to network managed care organizations. In the diffuse or network model, physicians work in independent offices serving patients from multiple insurance plans. This organizational model will present greater challenges to implementing this project's approach to improving the care of people with dementia. On the other hand, Kaiser is a large, self-contained organization and progress can be slow and challenging for these reasons.

Each geographic region will differ in the mix and cultures of managed care organization models. This impacts the potential for partnership. Group or staff model health maintenance organizations have features that should make them more willing collaborators than an Individual Provider Organization (IPO) model. Group model MCO's typically have greater uniformity in their clinical delivery systems, greater IT support, internalized complementary medical resources such as care managers, and existing mechanisms for staff training. Working with IPO's may present more obstacles to intervention in that they are geographically dispersed, share fewer resources or activities and function with greater autonomy. That said one can chose either model for a successful intervention. Examples of this appear in the chapter entitled, "Variations on a Theme". A critical step in establishing a partnership, however, is to make contact with a willing and influential individual at the MCO — a Medical Director, a key Geriatrician, or another leader.

The initial approach to a managed care organization must be made thoughtfully and with preparation. Some organizations are wary of external groups and fear bad publicity or pressure to make un-funded changes to care. Things outside the understanding of traditional medical care may not be understood and are particularly vulnerable to resistance. A community aging service provider (CASP) may be viewed as a lobbying or patient's advocacy group. To avoid misperceptions, the approach needs to be collaborative and include information about the CASP's strengths, capacity and the value- added to be gleaned from the collaboration. For a project to move forward, it is critical that the CASP pay attention to what the MCO views as the benefit for participation; it may be the potential for

improvement in services but it may also be physician satisfaction or a cost benefit. The MCO may acknowledge the need for collaboration because of a past experience of a poor outcome in the care of patients with dementia. The project should be tailored so that the needs of both organizations are met. The Alzheimer's Association made its initial approach to Kaiser Permanente in Los Angeles through the intervention of a physician who had a history of involvement with both the Association and with Kaiser. This person served as both "matchmaker" and "culture interpreter"; he helped representatives of each organization understand the motivations of the other group. He also identified the key decision-makers who were asked to attend the initial meeting.
In the case of this Dementia Care Project, this was the Medical Director of the Southern California Region of Kaiser Permanente who met with the Executive Director and the Program Director of the local Alzheimer's Association chapter.

This meeting was, in part, a "show and tell" presentation by the Alzheimer's Association. Using a slide presentation, the Association's expertise and services were clearly explained. An offer was made to jointly explore collaboration. No specific objectives were identified but a second meeting was arranged to which Kaiser leadership invited specific individuals who would have a role in the collaboration. It was critical to have at least the short-term commitment of Kaiser leadership to setting up the team that would work on the project. The Medical Director brought in a regional physician leader and a local physician leader, both of whom were geriatricians. Their leadership, content knowledge and familiarity with Kaiser's internal structure and the roles of people in key positions within their system were critical to the project's success.

There subsequently were a series of meetings held that focused on the quality of dementia care within the Southern California Kaiser Permanente Region. A core group formed consisting of the regional physician leader, the local geriatrician, a geriatric psychiatrist, lead personnel from the Social Work Departments, and representatives from departments concerned with member education and provider training. The group called itself the Dementia Care Workgroup. Meeting monthly for a period of time, the group became more collegial and trust and consensus began to build. The assistant to the regional physician leader was assigned to serve as a liaison to the Association and she took on the role of teacher and "culture interpreter". Indeed, learning about a managed care organization bears many parallels with learning about a different cultural group. Each has its own social structure and hierarchy, its values, communication patterns and so on. Misperceptions are easily derived and difficult to dispel. Participation by a trusted leader from each organization can help overcome these potential barriers.

Selecting a Partner: Knowledge Gained

- A group model health maintenance organization may be an easier collaborator than an Individual Provider Organization (IPO)
- The initial approach to a managed care organization must be made thoughtfully
- The project must be tailored to meet needs of both organizations
- Invite key decision makers to an initial meeting
- Allow each party to present areas of expertise and services
- Make at least a short-term commitment of assigning key staff to the work group
- Conduct a series of meetings to learn about each organization, dispel any misperceptions and built trust.
- Find a “culture interpreter”

Selecting Goals for the Project

How should the partnering organizations (managed care organization and community aging service provider/chapter/AAA) identify the challenges they are trying to address and/or the goals for the project?

In the Los Angeles project, after building a trusting relationship, the next step was to conduct an assessment of the managed care organization's baseline level of performance. The partners want to determine current performance and existing strengths and weaknesses in the system of care. This can serve two purposes. It can set a baseline against which future performance is measured. It can also be descriptive and help the workgroup see opportunities for targeting its intervention. The Dementia Care Workgroup sought to better understand how physicians cared for people with dementia in Kaiser Permanente's Metropolitan Los Angeles Service Area and to assess their satisfaction with the managed care organization's system of care for people with dementia. It also wanted to use this data to design an intervention to improve quality of care.

The evaluation used for this quality improvement project looked at three kinds of goals:

- *Performance goals*
  Was the project successful in serving the targeted number of people?
  How many physicians attended the training programs?
- *Satisfaction goals*
  How satisfied were users of services?
  How satisfied were physicians with the project?
- *Quality improvement goals*
  How many patients in the project were assessed with a mental status exam?
  How many families were referred to the Alzheimer's Association for follow-up services?

While it is not necessary to use all three levels of evaluation, each was useful in monitoring the intervention's progress and, later, in demonstrating why the intervention should be sustained. Some partnering organizations may have additional goals, such as a cost/benefit analysis, that were not addressed by this project but that would be beneficial.

The evaluation conducted for the Dementia Care Project described here may be more detailed than you will find necessary. It made use of research tools, surveys, focus groups and, later, medical chart audits. Depending on your local goals and outcome choices for evaluation, a caregiver or provider survey or chart audit approach alone may be sufficient. It may be desirable to involve a local researcher in your partnership's planning and outcome measurement. Researchers bring expertise that can improve the value, quality, precision, and sustainability of your intervention. For this study, two health systems researchers, one an employee of Kaiser Permanente and one an independent UCLA professor affiliated with the Alzheimer's Disease Research Center, were brought in to assist with the evaluation.

Physician Surveys

Members of the Dementia Care Workgroup developed a survey tool. A graduate student's services were engaged to analyze and summarize the data. The survey asked physicians about current:

- Diagnostic practices
- Referral practices
- Perceptions of the system of care for dementia patients

A total of 307 surveys were mailed to primary care physicians in the Metro Los Angeles Service Area before the Dementia Care Program was initiated. To encourage completion, each survey was sent out with a cover letter from a physician leader at Kaiser. A total of 112 surveys were returned resulting in a 36% return rate. A copy of the survey instrument appears as Appendix 1.

Through the physician surveys, the Workgroup was able to learn a range of interesting information that helped to guide program development.

- The majority of those providing dementia care were either in the departments of Internal Medicine or Family Practice.
- Many of the respondents (43%) reported that they "frequently" to "somewhat frequently" performed a diagnostic work-up on patients with suspected dementia.
- The physicians believed they had a good understanding of dementia.
- A substantial minority (34%) reported dissatisfaction with the treatment and support that Kaiser Permanente provided dementia patients and their caregivers/families.
- Only 28% of respondents believed that patients were informed about available treatments. (Note: This project was initiated prior to the advent of cholinesterase inhibitors.)
- 61% of the physicians reported that they <u>did not</u> provide patients and caregivers/families with educational information about dementia.

Focus Groups

At about the same time that the surveys were mailed, the Dementia Care Workgroup designed and conducted focus groups with Kaiser Permanente physicians, social workers and caregivers to enrollees with dementia. Kaiser Permanente and Alzheimer's Association staff jointly developed focus group questions. The structured interviews used for the focus groups can be found in Appendix 3. The reason that focus groups were used is that the implementers of the project were unsure about where best to intervene to improve quality of care. The open-ended questions allowed participants to freely discuss their concerns.

Caregiver Focus Groups

Two focus groups were conducted with caregivers. Sixteen caregivers attended the first group and six attended the second. Small stipends were offered to the caregivers for participation in these groups. Caregivers were recruited through the practices of Kaiser physicians who served people with a dementia diagnosis. Although the number of participants was small, the findings from the focus groups helped to inform the development of the service model and the development of educational materials for caregivers. The caregiver focus groups provided new feedback to Kaiser personnel about areas in the system that needed improvement. Key insights included:

- Caregivers reported that they had difficulty getting physicians to take their family members' problems seriously.
- Many participants did not feel the physicians treated them with sensitivity and respect.
- The consensus was that caregivers have to be very assertive in order to get appropriate information and referrals. In fact, the desire to obtain information and referrals was one of the main reasons why many of the caregivers agreed to participate in the focus group.
- Participants wanted information about the disease, treatments, resources and eligibility for benefits.

Overall, caregivers felt that:

- Physicians needed to more readily identify the disorder.
- Caregivers' concerns about symptoms should be attended to by physicians.
- More information should be offered to families about diagnosis and treatment.
- Caregivers must be strong advocates for the patient.

Physician Focus Group

The goal of this group was to obtain information about dementia diagnosis and treatment practices. It was more difficult to obtain physician participation in a focus group. Only four physicians attended the group, one each from Internal Medicine, Family Practice, Psychiatry and Geriatric Psychiatry. Three of the physicians had significant numbers of people with dementia in their practices. The content of the discussion focused on dementia diagnosis and treatment practices.

Overall findings from this small group of physicians mostly reinforced the findings of the broader physician survey and suggested that:

- Diagnostic practices varied and participants were unsure about their understanding of dementia.
- Physicians valued the role of a social worker as a care manager and valued linkages with community organizations such as the Alzheimer's Association.
- These physicians believed they provided caregiving families with educational information and referrals to community organizations.

Physician focus group participants recommended that Kaiser Permanente could:

- Provide more support to patients with dementia and their caregiver/families.
- Increase access to home care and in-home social worker assessments.
- Improve services to dementia patients through an organized system for evaluation and diagnosis.
- Improve services to patients with dementia through the provision of care management.

Social Worker Focus Group

With support of the directors of the Social Medicine Departments of the two participating Kaiser facilities, nine social workers took part in a focus group. They included a wide variety of specialties and the percentage of patients with dementia in the social workers' caseloads ranged from 5% to 50%. The purpose of this focus group was to get an additional perspective on how Kaiser Permanente's system of care supported people with dementia and their families. This group was also a source of information from social workers on their then current role and the role they could play in dementia care.

The consensus of the participants was that before seeking help, spouses of dementia patients often waited until the situation was very advanced or a crisis. Social workers said that family members need more information about the disease and about available resources within the Kaiser system and in the community.

Social workers were asked to define the ideal role of the social worker in reference to the dementia patients and their caregivers/families. Responses included lending support to the family, assisting if they need to hire someone in the home, offering support groups to families, helping caregivers find the appropriate physicians and to be assertive with physicians, and acting as a liaison with the doctor for the patient.

The Social Workers suggested that the system of care would be improved if:

- Physicians learned about and detected dementia earlier and made referrals before crises develop.
- It acknowledged the difficulty families have with transportation.
- Home visits and referrals to other needed services like home health care were made.
- There was a multidisciplinary team to evaluate the patient in the home.

Case Examples

In addition to surveys and focus groups, a well-developed case example can also motivate a managed care organization to implement a partnership with an aging services organization to improve quality. When this project was in development, the Alzheimer's Association received a three-page document that described one family's negative experiences at the MCO including photographs taken before and after a negative reaction to anti-psychotic medications. This document was disturbing and fostered discussion within the Dementia Care Workgroup of how the system of care could be improved. It had the effect of making the issue real and accelerated the project's implementation.

Selecting Goals for the Project: Lessons Learned

- Conduct an assessment of MCO's baseline level of performance
- Use data obtained to design an intervention to improve quality of care
- Define goals of project in three areas: process, satisfaction, and quality improvement. Consider also including cost/benefit analysis.
- Utilize goals to monitor progress of intervention
- Determine evaluation methods for measuring progress and improvement (i.e. surveys, focus groups, medical chart audit) and ability to do them
- Consider involvement of local researcher

Considering Options for the Model of Care

What are the important steps in creating or establishing a model of care? Should you rely on practice guidelines?

The Los Angeles project used the baseline information collected via surveys, focus groups and case study to develop quality improvement interventions. The Workgroup was particularly struck by the divergence of caregiver perceptions about care and the perceptions of physicians. In addition, the case study propelled the intervention forward. Several key components of the intervention were derived from this initial evaluation of the system of care, which highlighted the following needs:

- Clinicians needed more education and better knowledge and skills for caring for people with dementia.
- The need to develop a more uniform clinical approach to diagnosis and management of this disease.
- The need for a system to educate and support caregivers and to connect them with supportive services.
- The need for the delivery system to acknowledge caregivers' transportation challenges.

Each of these needs fed into the development of the Dementia Care Project intervention.

Creation of the model of care

The developed model had two components:

- Implementation of provider practice guidelines with education programs and practice support tools, and
- Creation of a system of care, including a trained dementia care specialist who was a social work care manager and served as the system lynch pin.

The groundwork to establish the Dementia Care project partnership began in 1995. The focus groups and initial surveys were conducted in 1996 and 1997. During 1997, the workgroup identified a plan for implementation of the model. At this point the Workgroup divided into subcommittees, each with representatives of the two organizations, to address areas of concern, which included:

- Recognition and diagnosis of dementia (Guideline Development Subcommittee)
- Post-diagnostic management and care coordination (System of Care Subcommittee)
- Caregiver and provider education (Education Subcommittee)
- Evaluation (Evaluation Subcommittee)
- Project support (Funding Subcommittee)

Practice Guidelines

Based on focus group and survey data, the Workgroup concluded that diagnostic protocols for people with dementia within the Kaiser Permanente Metropolitan Los Angeles Area were uneven. Some enrollees had received full work-ups while others were not formally assessed. Provider knowledge about diagnostic procedures for dementia was limited. To address these problems, a consensus-based diagnostic practice guideline was developed by a multidisciplinary panel of Kaiser Permanente practitioners and representatives of the Alzheimer's Association's Medical and Scientific Advisory Board. This guideline sought to improve consistency in the diagnostic assessments done at Kaiser Permanente in this region. It presented a decision tree to provide primary care providers, those physicians who saw most of Kaiser's demented enrollees, with practice recommendations for completing a dementia evaluation. (See Appendix 5).

Later, the Dementia Care Workgroup adopted the California Alzheimer's Disease Management Guideline, an evidence- and consensus-based management guideline, for implementation by project staff (Cummings et al, 2002 a&b). It provides primary care physicians with recommendations for the treatment, on-going assessment and management of people with dementia. It includes suggestions about caregiver support and education and it underscores legally mandated reporting requirements in California for people with dementia who drive and reporting of suspected elder abuse. A one-page version of this guideline appears in Appendix 6. With additional training, the project's care managers were able to implement many of the recommendations in the management guideline.

Multiple strategies were employed to "translate" the clinical practice guidelines into actual clinical practice by providers at Kaiser Permanente. They included the following:

- Promotion by clinical leadership through letters to providers and presentations at department and continuing education meetings.
- Annual in-service training for primary care providers, presented by physician leaders and caregivers, as well as with the participation of an educational theater troupe that was used to change attitudes and increase physician empathy for presenting families and to encourage implementation of new practice behaviors.
- Broad dissemination of a laminated pocket version of the diagnostic guidelines to all primary care physicians in the service area.
- Broad dissemination of a provider "tool kit" that contained the two guidelines, a provider checklist, tests of mental status and depression and a variety of materials from the Alzheimer's

Association to support physicians as they followed guideline recommendations.

- Reliance on social work care managers to support this evidence-based quality initiative through their work with family caregivers and practitioners/physicians.

Creating or adopting an evidence-based model of care (or guidelines for care) can enhance a project's credibility with a managed care organization. It makes the project more explicitly justifiable to the organization's leadership and thus it can contribute to the sustainability of the project.

Over the course of the Dementia Care Project, a variety of interventions were used to promote implementation of the diagnostic and later the management guidelines. Some of these efforts were guided by a report written by the UCLA/Rand/VAMC Center for the Study of Healthcare Provider Behavior, which evaluated strategies for influencing physician practice behaviors in dementia care. This manuscript can be accessed on the website of Alzheimer's Greater Los Angeles (www.alzgla.org).

Guideline Implementation: Lessons Learned

Guideline Characteristics. If possible, start with guidelines that the clinicians view as important and useable and that will provide benefits to most stakeholders, so that early efforts can be visibly valuable.

Medical Group Characteristics. While (or before) implementing guidelines, pay attention to building a strong foundation for improvement by encouraging group cohesion, systems thinking, and a general priority for quality.

Organizational Change Capability. Don't expect to succeed at implementing guidelines with only passive leadership support or an organization that is not structured for managing change or does not do it well.

Implementation Infrastructure. Adopt an organizational approach to change management and quality improvement, and ensure that adequate resources have been committed to its use of guidelines.

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Training

How can/should training be done? Who should be trained?

The on-going structure and usual training practices of the managed care organization have a strong impact on what training can be done, whether it will be attended, and whether it will be effective. In the Los Angeles Dementia Care Project, the Education Subcommittee determined that there needed to be meaningful educational strategies for both health professionals and members. Member and caregiver education was accomplished through the project's support groups, patient education materials from the Alzheimer's Association, a telephone support line and 1:1 counseling with the care manager. The Alzheimer's Association provided on-going expertise and assistance to the care managers on member and caregiver education.

The Education Subcommittee decided to primarily focus its efforts primarily on strategies and opportunities to effectively educate Kaiser's professional physicians and staff about dementia care and improve their practice behaviors. The group proposed utilizing existing continuing education time slots for scheduling newly developed professional education programs for the Dementia Care Project. The use of regularly scheduled training slots enhanced attendance.

Physician Training Programs

While the Dementia Care Project's professional education activities targeted an array of Kaiser Permanente professionals as an intermediate step, the primary charge of the committee was to develop effective strategies to improve medical care (per the practice guidelines) for Kaiser enrollees with dementia and to link their families to the Project. A greater emphasis was placed on educating internal medicine and family practice physicians because they are the primary care providers to the Kaiser members. These physicians were surveyed to assess their training interests and preferred formats. The training programs took place during Kaiser Permanente's regularly scheduled medical education sessions. Department Chairpersons encouraged attendance though letters to physicians.

The educational programs reinforced the contents of the practice guidelines and sought innovative strategies to help assure content would be remembered. Some of the strategies included the use of physician leaders and care- givers as motivational speakers and the participation of a theater troupe that enacted both a physician visit and the administration of a mental status examination. The theater troupe was used to increase physician empathy for presenting families. It was also assumed that the novelty of this form of teaching would enhance learning. Indeed, observation of the physicians during the theatrical presentation suggests that this method of teaching captured their attention even more so than the traditional lecture format.

During the first year of project implementation four educational sessions entitled “Diagnosis and Management of Persons with Dementia” were held, two at each of the targeted Kaiser sites, one each for Internal Medicine and for Family Practice physicians. The sessions were 3.5 hours in length and featured a well-known geriatrician. Other speakers included one of Kaiser’s physician leaders who addressed Kaiser’s then new diagnostic guideline and a Kaiser member who spoke from a caregiver’s perspective. Topics covered included: An overview of dementia, the newly developed diagnostic guideline, use of a mental status exam, caregiver insights, management of persons with dementia, and the role of the project’s new care managers. Over 80 % of the primary care physicians attended this seminal training, which was videotaped and used for future physician training at Kaiser and elsewhere.

In year two, the focus for training shifted from diagnosis to management. California’s new Alzheimer’s Disease Management Guideline was distributed and referenced in the presentations. Sessions were 2.5 hours long. Featured speakers included an attorney, a geriatric psychiatrist and the project’s care managers. Again, the target audience was primary care physicians. Topics covered included: legal and ethical issues, administration of a mental status questionnaire, management of behavioral problems, and use of community resources.

Social Worker Training Programs

The Dementia Care Project’s Education Subcommittee surveyed topics of interest, developed the content, recruited internal and external expert presenters, and defined a marketing plan for the in-service training sessions for social workers at both medical centers. The directors of both social work departments participated in the Education Subcommittee, which ensured that the topics related to dementia care received priority in scheduling. Attendance at these social work in-service sessions was mandatory and the care manager/dementia specialists were present, identified themselves to their peers and introduced the sessions. In both these sessions and with each social worker individually, the recognition of dementia and referral to the care manager was reinforced.

Throughout the course of the project a variety of in-service trainings were offered to the social workers in all departments including those in the emergency room, mental health clinic, HIV-AIDS, surgery and general medicine. Although there were obvious departments to target such as the geriatrics clinics, it is possible that any social worker in the medical center would encounter a member with dementia either directly or indirectly and therefore it was decided that all social work staff would participate in the trainings. The topics covered a broad range, including an overview of dementia encompassing warning signs, recognition, the Kaiser Permanente diagnostic guideline and the California management guideline; ethical and legal issues such as decision making capacity, driving and elder abuse; and a session that explored issues of autonomy vs. safety through a case study.

A full list of training programs for physicians, social workers and other professional staff appears in Appendix 7.

Training: Lessons Learned

- Create meaningful educational strategies for both health professionals and enrollees
- Identify key professional groups within the managed care organization to receive educational programming
- Engage identified professional groups in selecting topics of interest/ relevance to their clinical practice and experience
- Use practice guidelines or model of care as basis for educational programming
- Invite internal and external experts to be presenters

Tools and Materials

What kinds of tools and materials are useful or worth the time it takes to develop them?

Physician Tool Kit

A physician tool kit was developed to reinforce the practices outlined in the two guidelines and it is entitled "L.A. Metro Guide to Diagnosis and Management of Dementia" (See Appendix 8). The user first encounters a provider checklist for treating a confused elder. Developed by lead geriatricians on the project and the project manager, the checklist provides a step-by-step comprehensive overview of the diagnostic and care planning process. It gives the details needed to obtain an appropriate history and physical assessment such as history of memory loss, evaluation of depression, a functional assessment and assessment for recent physical trauma. The checklist clearly lists the necessary lab tests required to screen for causes of dementia and also provides guidance on when to use MRI or CT scans. The physician is also given various social and safety issues to assess for and discuss with family such as driving assessment, elder abuse assessment and discussion of advance directives. Finally, the checklist suggests referral to a social worker and to the Alzheimer's Association for supportive services such as the Safe Return™ program, support groups and adult day care.

The tool kit contains the diagnostic guideline developed by the Dementia Care Project printed on a laminated card with a mental status questionnaire on the opposite side. The California Alzheimer's Disease Management Guideline was also presented in a portable, easy-to-use format on 8 ½ x 11 double-sided semi-glossy card stock. The Geriatric Depression Scale (Yesavage, 1983) was included as the primary tool for assessing depression. Detailed information on the California legal reporting requirements for elder abuse and the forms for reporting driving risk to the County Public Health Department and Department of Motor Vehicles were included. Alzheimer's Association specific materials included a registration brochure for the Safe Return™ program and an Alzheimer's Association Prescription Pad on which physicians could write a "prescription" for each caregiver referring him or her to the Alzheimer's Association.

The project's care managers visited each medical office to explain the program, and their role, and to review the Kaiser recommended guidelines for dementia care. Before leaving, the care manager provided a tool kit for use in the medical practice. This approach to physician education is often referred to in the literature as "academic detailing" and has been found to be an effective strategy for influencing physician practice behaviors (Soumerai

& Avorn, 1990). Academic detailing can be defined as the process by which a health educator visits a physician in his/her office to provide a brief educational intervention on a specific topic. The purpose of academic detailing is to provide complete and objective information based on best available evidence. Physicians who missed these visits with the care manager were mailed their tool kits with a letter explaining the contents signed by their chief of service.

Care Manager Tools

The psychosocial assessment is the foundation of the care manager treatment plan and approach to working with the individual and their caregiver. A comprehensive psychosocial assessment should include the following components:

- Current medical problems/diagnoses
- Ability to manage ADL's and IADL's
- Transportation needs
- Communication ability
- Cognitive ability
- Living situation/Home environment
- Support system
- Personal and family history
- Patient/Caregiver coping style and problem solving ability
- Capacity for insight
- Elder abuse risk assessment
- Substance abuse and medication misuse risk assessment
- Safety issues
- Legal and financial issues
- Involvement with other community aging service providers or other social service agencies

The model of care developed by the Dementia Care Project included a home visit and assessment by the care manager. During a home visit, the care manager would assess the safety of the neighborhood and home; adequacy of food preparation and storage facilities; adequacy of heating/cooling/ ventilation; assistive devices or technology; medication regime; driver safety; wander risk; gun and fire safety; and access to community-based services such as a grocery store and bank.

The State of California has a mandated reporting requirement for elder abuse and an assessment for elder abuse was part of the care manager's role. The National Center for Elder Abuse provides clear guidance on the major types of abuse an elder can experience and how to assess for it on their website under the section titled "Basics". The major types detailed on the website include physical, sexual, emotional or psychological abuse, neglect, abandonment, material or financial exploitation and self-neglect. (See website for more details at http://www.elderabusecenter.org/default.cfm?p=basics.cfm)

Consumer Education

Consumer education materials addressed issues identified during the assessment process. The Alzheimer's Association recommends that the following materials be part of a basic information packet:

- *Safe Return*™ brochure
- *Partnering with Your Doctor*™ booklet based on a workshop developed and implemented nationwide through Alzheimer's Association chapters to assist persons with dementia and their caregivers to communicate more effectively with their doctor
- Fact sheets on key topics including caregiver stress, behavioral symptoms, communication strategies, home safety, Alzheimer's disease and related dementias
- *10 Warning Signs*™ brochure
- Prescription pad listing chapter programs and services with Alzheimer's Association contact information and web address

Tools and Materials: Lessons Learned

- Create a provider checklist or other reminder system to increase likelihood of provider compliance with practice guidelines or model of care
- Include assessment tools that address medical, functional, and psychosocial aspects of dementia care
- Consider tools already accepted and used by the providers in the managed care organization
- Determine discipline responsible for administration and documentation of information obtained

Building a System of Care and the Role of the Care Manager

Given the strengths of the partnering organizations, what system of care can best serve the consumers of service? How does care management fit into that system? Who should offer the care management?

In the Los Angeles project, the Dementia Care Workgroup was concerned about the care people with dementia and their families would get after a diagnosis of dementia was made. The System of Care Subcommittee focused on how the project might improve Kaiser's care for those diagnosed with dementia. It developed the recommendation that care managers specially trained in dementia care be in place to help families by providing them with educational materials, dementia care workshops, emotional support, and connection to services within Kaiser and the broader community. The care managers would also support physicians by providing important information about their patients. The decision was made to provide this care management service within Kaiser rather than to out-source it to the Alzheimer's Association. The goal was to build Kaiser Permanente's internal capacity so that after the project's formal end, the managed care organization would have in place trained professionals to help families.

With oversight from the System of Care Subcommittee, two full-time professionals were recruited onto Kaiser's staff, one for each of the two participating medical facilities. These professionals were trained by the Alzheimer's Association through a 24-hour intensive course offered once a week for eight weeks, followed by seven months of mentoring through weekly case conferences to which their Kaiser supervisors also came. Participation of the supervisors was essential to assure both buy-in to the project by the Social Medicine staff and institutionalization of knowledge. It was important to assure that more than one person at each site had knowledge of the unique characteristics of these patients and their caregivers.

According to the diagnostic algorithm implemented for this project, primary care physicians referred patients to the care managers. All referred patients were required to have an informal (unpaid) caregiver and a diagnosis of a dementing disease. The care managers provided a range of services in support of the referring physicians including administration of mental status exams, follow-up with families on the psychosocial aspects of care, home visits, intervention with families on behavior management issues, and facilitation of connection to physicians for co-morbid conditions. They also pro- vided guideline-recommended services for family caregivers including: functional assessment of patients, linkage to services within Kaiser

Permanente and in the community, caregiver support groups, family education, and on-going care management.

While this project increased Kaiser's internal capacity to deliver dementia-capable care management, other projects, like the Cleveland project that is described in the chapter "Variations of the Theme" in this manual, have experimented with a system of care in which the family is referred to the community aging service provider for this service. There are advantages and disadvantages to either strategy and they are not mutually exclusive. The MCO supporting the care managers has greater quality control over the service. However, the host also carries more financial responsibility for the staff. In the Los Angeles Dementia Care Project, we believed that placing the care manager within the managed care organization and using this staff person as a consultant to other staff would increase the sustainability of the project's accomplishments. The project care managers not only saw their own clients, but were also a resource to other social work staff and physicians as they served this population. Both the care managers and their supervisors were required to come to supervision sessions. The hope for both of these strategies was that the knowledge invested in the care managers would be diffused into the managed care organization; thereby improving its ability to manage people with dementia even if the care manager position were not sustainable in the future.

Characteristics of the Care Manager

Although the value of care management is recognized by professionals in the field of geriatrics, the definition or the description of that role can vary. There are, however, consistent skills and qualities that this role requires including an ability to conduct a comprehensive assessment and to work with the client to mutually develop and carry out a plan of care. A care manager has to be knowledgeable of the systems the client will encounter and have the skills to navigate them to ensure the client gets what she needs. Because family members and other persons close to the client play a significant role in daily care activities, it is critical that the care managers recognize the value of their involvement in all aspects of care planning and delivery. A care manager must be skilled in coordination of services and be an excellent communicator when working with other health care providers and family members to ensure a successful outcome. When there is a cognitive impairment, a family member or other person close to the client is often in the role of proxy, which can add a level of complexity and confusion. Taking care of someone with dementia and navigating the health care systems on behalf of that person is an additional and large burden.

For this project, the Workgroup decided to recruit social workers into the role of care manager/dementia care specialist. Medical social work is the oldest clinical social work specialty in the United States (Carlton, 1988). It began at the turn of the last century by Richard C. Cabot, M.D. at Massachusetts General Hospital who recognized that a diagnosis was incomplete until the psychosocial factors were included. The social worker in health care is educated to work closely with both the patient and the multi-disciplinary team that is caring for the patient and family.

Role of the Care Manager within a Managed Health Care System

The care manager in the Dementia Care Project served various functions in the promotion of good dementia care. The care manager would act as monitor and intervene on issues of system delivery and responsiveness to bring about good care management. This role often required internal communications with providers and departments along the continuum of care. These functions included collaboration with physicians in implementation of diagnostic and treatment guidelines, linkage with primary and specialty care and community services, consultation with families on care issues and management of difficult situations, comprehensive in-home assessment including safety checks, and facilitation of caregiver support groups. In simple terms, the care manager became a “friend in the system” for the patient and assisted physicians in the challenges of providing agreed upon care.

Recruitment and Hiring of Care Managers

The Dementia Care Workgroup collectively outlined the expectations of the care managers and developed a job description and announcement. The care managers were required to have a Master’s degree in social work and a license to practice in California. The expectation was that each had experience in care management with older adults.

The recruitment process was handled entirely by Kaiser Permanente’s Human Resources Department. The Social Work Department head, also a member of the Dementia Care Workgroup, reviewed resumes provided by the Human Resources staff and selected likely candidates for interview by staff from both organizations, using agreed upon criteria and a standardized assessment tool. When all of the interviews had been conducted there was discussion and negotiation to determine the candidate for hire. The final hiring decision and the hire itself was made by the employer of record, Kaiser Permanente.

Training of the Care Managers

Once hired, each care manager received an 8-week long, 24-hour training with the Alzheimer's Association that included:

- Dementia defined (causes, stages, prevalence, progression of the disease, prognostication)
- Early recognition, detection, diagnosis, management approaches
- Medical co-morbidities and management
- Assessment of self-management ability, and home and safety issues
- Caregiver assessment (warning signs, level of involvement,

abuse issues, support and education, cultural differences, beliefs and values, grief and bereavement, different needs of adult child vs. spouse)
- Support group participants defined, start-up activities, facilitation of support group, importance of follow up, transitional issues, termination of group
- Communication
- Behavioral symptoms
- Legal and ethical issues
- Continuum of care
- Services/programs available internally and in the community

Different Settings and Providers within the Kaiser Permanente System

One of the greatest challenges to consistent implementation of the research methodology in this project was the existence of two unique facilities within the same organization. Medical social work services provided at the Los Angeles Medical Center (LAMC), a tertiary medical complex, are structured differently from the medical social work services provided at the West Los Angeles Medical Center (WLAMC), a community medical center. At LAMC, services are decentralized with the social workers located within specific medical areas, i.e., outpatient satellite offices and specialty acute care settings. At WLAMC the service is centralized with the social workers practicing only in the acute inpatient setting. Communication and service delivery are impacted by these differences. In the decentralized model the social worker is physically present and communication is more likely to occur directly between the social worker and the primary care provider. Each care manager was acutely aware of the differences in their respective settings and strived to compensate for challenges in communication. This issue was very apparent to the Alzheimer's Association consultant on the project as she met with each care manager and supervisor in joint supervision.

Case Finding and Case Assignment

Recognizing the differences in how the two facilities organized their health care staff, departments and patient referral processes within Kaiser, the social work department lead, the case manager and Alzheimer's Association consultant at each site worked on identifying programs and services within the health care setting that would likely be seeing patients with a cognitive impairment. The care manager worked on getting the word out to the referring physicians, other social workers and allied health professionals within that facility. Each social work department had a process for managing "walk-ins" and a triage system that included referral to the care manager if the primary issue was dementia. There was also a process of referral developed for patients who came through the emergency department and urgent care.

Academic detailing, mentioned earlier in this manual, proved to be a vehicle for increasing referral sources. The care manager would meet with physicians in a medical group to discuss the guidelines and other contents of the tool kit in addition to describing their role. There was increased awareness of this program and referrals from those physicians greatly increased.

Mentoring of Care Managers and Supervisors

The Dementia Care Project's Care Managers and their clinical supervisors at Kaiser had on-going bi-weekly supervision with a licensed clinical social worker from the Alzheimer's Association throughout the term of the project. In addition, there was on-going availability of supervision on an as-needed basis and a plan to routinely check in with the care manager in between supervision sessions for follow-up and to answer any questions.

Case presentation was a valuable part of the supervision process and cases were selected for presentation based on those that were most complex or at risk (warning signs, functional decline, change in caregiver, change in income, abuse situation, recent hospitalization or emergency room visit, change in living environment) or there could be a brief update on all cases. Both approaches have merit and the choice needs to be determined by the individuals involved. A blended approach may be desired. On occasion, a single case was used to illustrate a consistent systemic problem and the supervision session would be spent evaluating carefully any contributing factors and problem solving internal communication gaps and approaches to enhancement.

Continuing Education for All Social Work Staff

Continuing education on management of persons with dementia was offered to all of the social work staff at each facility in an effort to educate the staff about quality dementia care and to reinforce the role of the care manager. The most popular continuing education session was on decision making capacity, medical compliance, bioethics and appropriate interventions.

Performance Review Process

Although Kaiser was the employer of record, the Alzheimer's Association as a stakeholder provided input in the performance review process and in all personnel issues.

Care Managers: Lessons Learned

- Determine whether the care manager is to reside within managed care organization or community aging service provider organization
- Provide intensive training within first two weeks of hire and then ongoing mentoring on a regular, formal basis
- Define appropriate criteria and system of referral to care manager
- Develop case finding protocol and identify programs within the managed care organization that would likely be seeing patients with cognitive impairment
- To avoid role overlap, clarify how care manager will interface with other services provided by the managed care organization and those provided by the CASP
- Plan for follow-up with referring provider and determine preferred method for ongoing communication, e.g., phone call, secure e-mail, written reports

The Role of the Community Aging Service Provider, AAA or Alzheimer's Association Chapter

What role can the community agency play in the collaboration? What strengths do community groups bring to these partnerships?

Alzheimer's Association chapters, Area Agencies on Aging and other community aging service providers (CASPs) bring a wide variety of skills and services that can enhance the quality of care delivered to older adults in managed care organizations (MCOs). Most managed care organizations are designed to deliver health care services to people with acute health problems. However, older adults frequently have multiple, chronic health problems like elevated blood pressure, diabetes or dementia. CASPs and MCOs are both needed for the provision of high quality dementia care. To more effectively work with people with chronic health conditions, some managed care organizations offer supplementary services such as health education and care management services. Others have complex disease management programs in place for particular conditions such as diabetes or chronic obstructive pulmonary disease. Managed care organizations are increasingly cognizant of the benefits these adjunct services offer. Practice and disease management guidelines frequently recommend that providers connect their patients with community supports. Evidence of the effectiveness of care management or other services can make this an attractive partnership for the managed care organization, especially if the intervention is not too costly.

Many CASPs are proficient in the provision of care management, health education, family caregiver support, information and referral, and other services that complement a health care system and, potentially, improve quality. Expertise in the education of physicians and other health care providers can also meet a managed care organization's needs. Regardless of the range of services the CASP provides, time must be spent in consultation with the potential managed care partner organization to determine the best fit. For example, in this Dementia Care Project, it was determined that care management would be a central intervention. This service could have been provided in several different ways. It could have been out-sourced to the Alzheimer's Association as was the case in the Cleveland project as described in the chapter entitled "Variations on the Theme". In that case, the Chapter offered the care consultation service for which it has specialized knowledge in dementia care. In the Los Angeles model, the Alzheimer's Association shared its expertise in a different way. It offered its dementia care expertise in the form of technical assistance, training and mentoring care managers within the Kaiser system. Both approaches have their strengths and weaknesses but both utilize the CASP's strengths to augment the managed care organization's services. Both CASPs and MCOs have capacity constraints that may limit and define the nature of collaboration and intervention.

There are also examples of programs that can only be offered by a CASP. Services such as Meals-on-Wheels or Safe Return™ are clearly needed by many managed care enrollees. The challenge is to “sell” the managed care organization on their value and to encourage them to promote the program systematically within the organization. It is even more challenging to convince MCOs to pay for such services on behalf of their enrollees as this is not a traditional medical benefit. Again, to succeed in this, the CASP would need to demonstrate convincingly that there are significant positive outcomes in the quality of health care, its cost, or both. Another alternative is for the MCO to ask members to pay privately for these service enhancements.

Role of Community Aging Service Provider: Lessons Learned

- Recognize each organization's strengths. CASPs and MCOs are interdependent in the provision of high quality chronic health care
- Focus on the services that each organization already offered when developing your intervention. Many CASPs are proficient in the provision of care management, health education, family caregiver support, and other services that complement the MCO's medical care
- Understand early on that it may be difficult to convince an MCO to pay for non-medical benefits provided by a CASP

Evaluating the Project and Sustaining the Change

How do we demonstrate that the project has had positive outcomes? Who defines the outcomes to be evaluated? What can be done to make the project sustainable?

Evaluation data is important to the sustainability of your project. If you can generate evidence that the intervention you provide has caused outcomes that are of interest to the managed care organization and to your agency, then there is greater likelihood that the resources will be found to continue the project. Evaluation does require resources beyond the cost of doing everyday business. However, this investment is worthwhile. Unless the project demonstrates positive outcomes such as improvements in quality of care or cost-effectiveness, there will be little incentive to maintain it beyond the pilot phase. Evaluation must be considered at the outset and during the evolution of the project. The measurement burden must be seen as realistic.

In the Los Angeles Dementia Care Project, an evaluation of the intervention was planned from the outset. A joint committee of the Alzheimer's Association and Kaiser Permanente (the Evaluation Subcommittee) chose the evaluation outcomes with input from decision-makers at both organizations. As part of the planning for the project, the question was posed: *What kind of data would be needed to demonstrate that this is a successful intervention and one worth keeping?* Many options were suggested. The chosen outcomes were expected to be most effective for the sustainability of the project.

This evaluation was designed to examine whether this intervention that included development of practice guidelines, physician training, development of caregiver education materials and the implementation of a dementia-specific care management program led to:

- Improved provider and caregiver satisfaction with Kaiser Permanente's system of care in this region, and
- Improvements in the quality of care as measured by key quality indicators derived from the practice guidelines.

Given available resources, the Evaluation Subcommittee decided not to address the issue of cost-effectiveness of these interventions. However, other collaborations between Kaiser Permanente and the CASPs have found significant cost savings for the MCO (see Chapter entitled "Variations on the Theme").

Because the project had a research design, participation was limited to people who met Project criteria. In order to participate in the *Dementia Care Project*, the person with dementia needed to have a primary care physician in the designated Kaiser Permanente service area, have a guideline-based dementia diagnosis, dwell in the community (not in an institution) and have an involved, non-paid caregiver.

As stated earlier in the "Selecting Goals for the Project" chapter, two health services researchers provided guidance in the implementation of this project. Without their participation, a much simpler evaluation strategy would have been adopted. This would still have included:

- Establishment of a baseline for the outcome variable
- An intervention
- Completion of a post-intervention measure to assess change in quality within the system of care or change in consumer satisfaction care

An article describing the evaluation study's design, methodology and findings has been published in ***The American Journal of Managed Care***. A copy appears in Appendix 16 of this manual and can be read for more detailed information.

The evaluation was primarily focused on improving the quality of care for people with dementia in this targeted region. Indicators of improved quality were drawn from the practice guidelines. The indicators based on documentation were:

- Cognitive assessment using a validated mental status exam, the Folstein Mini Mental State Exam, administered to patients as part of the diagnostic work-up for dementia
- Consensus directed diagnostic laboratory tests (B12, VDRL/RPR, TSH, CBC) were part of the work-up
- Referral of the patient or caregiver to the Alzheimer's Association and to the Safe Return™ Program for wandering risk
- Assessment of patient functional capacity which may include activities of daily living, decision-making capacity, depression, and/or risk for wandering

These care processes were selected as study outcomes in part because they were guidelines targeted by the intervention. In addition, they have been identified and used with some frequency in studies of dementia care quality (Chow & MacLean, 2001). It was predicted that adherence to these practices would increase as a result of project participation.

Three different sources of data were used to assess the impact of the project on provider practices and satisfaction with care:

- Interviews were conducted with caregivers at baseline and again between three to six months after the program was implemented, to assess change in satisfaction with dementia care.

- Surveys of primary care physicians, administered before the program was implemented and again three years later, were used to assess self-reported practice behaviors and provider satisfaction with Kaiser Permanente's system of care for people with dementia.
- Medical records, including primary care provider and social work files, were abstracted to assess practice of quality indicators derived from the guidelines. Pre- and post-intervention adherence to these guidelines were measured and compared.

Findings

Consumer Satisfaction

A comparison of structured interviews administered to 83 participating caregivers before and after participation in the Dementia Care Project demonstrated improvements in their satisfaction with services. At baseline, 17 % and 51% of caregivers reported being very satisfied or satisfied with dementia care, respectively. In contrast, at follow-up, 40% and 39% of caregivers reported being very satisfied and satisfied with dementia care, respectively ($p< .05$). Sensitivity and respect shown by Kaiser Permanente staff was rated more satisfactory after participation in the intervention, with 38% very satisfied at baseline as compared to 70% very satisfied three to six months after enrollment ($p< .001$). Caregivers also indicated that they were more likely to have been given educational material about dementia after the Dementia Care Project was initiated: 36% at baseline compared to 94% post- intervention ($p< .001$). Post-intervention, a higher proportion of caregivers reported receiving referrals to community services such as home health (2% pre- vs. 13% post-intervention, $p< .01$); support groups (4% pre- vs. 17% post-intervention, $p< .01$); and Meals-on-Wheels (1% pre- vs. 12% post- intervention, $p< .01$).

Physician Satisfaction and Changes in Practice Behaviors

A comparison of physician responses before and after the intervention commenced showed a trend toward increased satisfaction with the treatment and support Kaiser Permanente provides to people with dementia (t-test, $p= .067$). Looking specifically at the quality indicators: 49% of physicians in the post-intervention sample reported using a mental status test more frequently than they had prior to the intervention period. Similarly, physicians were more likely to obtain recommended laboratory tests as part of a diagnostic assessment of dementia. Prior to project implementation, 46% of physicians reported that they never obtained laboratory tests but after the intervention this percentage fell to 14% (chi-square, $p< .001$). Frequency of physician referrals to the Alzheimer's Association did not change.

In an effort to assess the specific impact of provider workshops on guideline adherence, responses of physicians who reported attending the initial Dementia Care Workshop used to launch this project in 1997 were compared to those physicians who did not attend the workshop. One hundred and fifty-two physicians, primarily in the Family Practice and Internal Medicine fields, attended the workshop; of these, 47 completed and returned the post-intervention physician survey. As compared to the 77 physicians who responded to the survey and who did not attend the workshop, workshop attendees were more likely to report that they: (1) recall the diagnostic guide- line for dementia ($p< .015$), (2) administer the mental status exam ($p< .005$),
(3) provide educational material to families ($p< .001$), and (4) refer to the Alzheimer's Association ($p< .016$).

Quality Improvement

Medical record abstractions were performed for a subset of 42 participating patients. Their care before and after implementation of the project was compared. The results showed improvement in each of the quality indicators selected for this project, administration of mental status exams and diagnostic laboratory tests, referral to the Alzheimer's Association and assessment of daily function. These results are summarized on Table 1.

Table 1: System Changes Reflected in Chart Audit Quality Indicators

Quality Indicator	% Documented Prior to Project N = 42	% Documented After-Project N = 42	Chi-Square p-value
Diagnostic Guideline			
Mini-Mental Status Exam	16%	93%	<. 001
Management Guidelines			
Referral to Alzheimer's Association	3%	76%	<. 001
Referral to Safe Return™ Program	0%	29%	<. 001
Functional Assessments			
Activities of Daily Living	13%	93%	<. 001
Decision-making Capacity	3%	19%	<. 001
Depression	11%	57%	<. 001
Wandering	8%	74%	<. 001

There was an increase in the reporting of Mini Mental Status Examination scores from 16% prior to the project to 93% after the project (Chi-square p<. 001). Documentation of referrals to the Alzheimer's Association increased from 3% prior to the project to 76% afterwards (Chi-square p< .001), and referrals to the Alzheimer's Association's Safe Return™ Program increased from 0 to 29% (Chi-square p< .001). There was increased documentation of assessments of activities of daily living (13% pre, 93% post; p< .001), decision-making capacity (3% pre, 19% post; p< .001), depression (11% pre, 57% post; p<. 001), and wandering potential (8% pre, 74% post; p< .001). These assessments were most likely to have been conducted by the dementia project care managers (32%), followed by neurologists (26%). Care managers also documented 68% of all assessments for wandering risk. However, depression was noted most frequently by primary care physicians (39%), followed by dementia project social workers (20%) and neurologists (17%). Physicians more frequently documented an assessment of decision-making capacity, (31% by neurologists, 19% by primary care physicians).

Evaluating the Project and Sustaining the Change: Lessons Learned

- Demonstrate the benefit of the intervention to the MCO by providing meaningful data.
- Invest in evaluation. It is important to project sustainability.
- Consider evaluation at the outset of the project.
- Determine what those involved in the intervention can realistically measure.
- Find experienced evaluators. They are strong assets to your project.

Variations on the Theme

Introduction

Previous chapters of this manual have described the dementia managed care project conducted by the Alzheimer's Association chapter and Kaiser Permanente in Los Angeles. For various reasons, some aspects of the Los Angeles project may not fit for other chapters and community aging service providers (CASPs).

From 1996-2003, Alzheimer's Association chapters in other parts of the country also conducted dementia managed care projects. All these projects had the same general objective, to improve care for managed care enrollees with dementia, but their specific goals and approaches differed. This chapter describes these projects briefly, and based on their experiences and findings, it identifies alternate approaches that other chapters and CASPs may want to consider in designing their own managed care projects. The chapter discusses approaches with respect to four aspects of project development and implementation: 1) selecting a partner managed care organization, 2) selecting goals, 3) creating a model of care, and 4) the role of care managers.

The Cleveland Alzheimer's Managed Care Demonstration

From 1998-2000, the Cleveland Area Alzheimer's Association Chapter and Kaiser Permanente of Ohio conducted a dementia managed care project. The project was intended to test the effect of care consultation provided by the chapter on Kaiser enrollees' use of health care services and psychosocial outcomes for enrollees and their family caregivers.

For the Cleveland project, Kaiser identified enrollees with a diagnosis of dementia or a symptom code for memory loss in their medical record. Each enrollee was randomly assigned to the treatment or control group. Those in the control group received no special services from either the chapter or Kaiser. Those in the treatment group received an initial call from the chapter care consultant, a telephone assessment, a care plan, the offer of any information, referral, training, and support services provided by the chapter, and additional calls and services, as needed and desired. A total of 210 Kaiser enrollees and their family caregivers participated in the project.

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

From 1997-2003, Alzheimer's Association chapters, managed care organizations, and other agencies participated in CCN/AD, a dementia managed care project that was conducted in six communities across the country. CCN/AD was a joint project of the national Alzheimer's Association and the National Chronic Care Consortium (NCCC). It was intended to design, implement, and evaluate a model of coordinated health care and supportive services for managed care enrollees with dementia.

After the CCN/AD sites were chosen in 1997, a project model was developed to address problems in identification and assessment of dementia, medical and nonmedical care management, and information and support for family caregivers. Each CCN/AD site used the model to create site-level protocols for care. More than 1,500 people with dementia and 1,450 family caregivers were served in the six CCN/AD sites**.**

Appendices 14 and 15 provide more detailed information about the CCN/AD and Cleveland projects and references for published papers about these projects.

I. Selecting a Partner Managed Care Organization

Selecting the right managed care organization to work with is an important first step in creating a successful project. At the time the Los Angeles, Cleveland, and CCN/AD projects were being planned, little was known about characteristics of different types of managed care organizations that might affect the success of a project. With hindsight, however, observations from these projects can provide useful guidance for other chapters and CASPs that are trying to select a partner managed care organization.

<u>In the CCN/AD project</u>, the initial request for proposals was sent in late 1996, to all 28 NCCC member organizations and the Alzheimer's Association chapters in the same geographic areas, inviting them to submit a joint proposal to participate in the project. In response, the NCCC member organizations (mainly managed care organizations) usually initiated contact with the chapter, rather than vice versa. In effect, therefore, the managed care organizations selected a chapter partner.

In evaluating the 15 submitted proposals, reviewers looked for a strong working relationship between the managed care organization and the chapter and tried to select sites that together had characteristics important for replication, e.g., different types of managed care organizations and diverse geographic locations. Some reviewers undoubtedly knew a lot about differences between various types of managed care organizations, but they probably could not have known at that time how those differences would affect the likelihood of success for the project.

<u>In the Cleveland project</u>, staff of the Alzheimer's Association chapter first considered Kaiser Permanente of Ohio as a partner in 1996, when the chapter began thinking about the project. The chapter had a fairly clear idea about the project goals and design and wanted a managed care partner that could identify enrollees with dementia to participate in the project and later provide data on the enrollees' use of health care services.

At that time, Kaiser already had a protocol for diagnosis of dementia, the first such protocol in the United States. Kaiser also had an electronic medical record system that would be useful in generating the desired data. More- over, the chapter had a relationship with two Kaiser case managers who could help chapter staff understand the Kaiser system and identify other Kaiser staff and administrators to approach about the project.

The chapter had a strong commitment to working on a non-exclusive basis with all organizations in Cleveland that provided services for people with dementia. Even though there were good reasons for selecting Kaiser as a partner, chapter staff were concerned that other managed care organizations in Cleveland might be offended by this exclusive partnership. Despite this concern, the chapter decided to establish the partnership. Initial announcements about the project were carefully worded to emphasize Kaiser's diagnostic protocol and electronic medical record system and the chapter's intention to create similar partnerships with other managed care organizations in the future.

Types of Managed Care Organizations

In considering possible managed care organizations as partners, it is helpful to distinguish between two types: 1) staff or group model health maintenance organizations (HMOs), and 2) network model or independent practice organizations (IPOs). Staff and group model HMOs are generally large, self-contained organizations that own their own hospitals and other health care facilities; have physicians and other health care professionals on staff; and provide all kinds of health care services for their enrollees.

Network model and IPO managed care organizations generally have a smaller, central organization that contracts with independent hospitals, physicians, medical clinics, and other health care providers (e.g., home health agencies) for health care services for its enrollees. The central organization may have physicians and other health care professionals on staff to perform administrative functions, e.g., development and delivery of training pro- grams, but these employees usually do not provide direct health care services for the enrollees.

Challenges and Benefits of Partnering with a Staff or Group Model HMO

The Cleveland project and two CCN/AD sites (San Francisco, CA and Albany, NY) involved partnerships between an Alzheimer's Association chapter and a Kaiser Permanente staff model HMO. In contrast, the Kaiser organization in Los Angeles was a group model HMO with one component that owned the organization's hospitals and other health care facilities, and a separate component, Kaiser Permanente Medical Group, that provided medical care for the organization's enrollees.

Observations from all four sites indicate that initiating a partnership with a staff or group model HMO like Kaiser is likely to be time-consuming. These large, self-contained organizations have many levels of leadership and administration, and numerous individuals and departments must agree before the project can start. On the other hand, once agreement is reached, the project is likely to benefit from the organization's capacity and resources for creating and delivering training programs, care guidelines, and protocols, and its ability to require, or strongly encourage, its staff to attend the training programs and adopt the care guidelines and protocols.

Another benefit one might expect from partnering with a large staff or group model HMO like Kaiser is the likelihood that, once committed, these organizations will be able to follow through with the project. This benefit is not guaranteed, however. The CCN/AD site in Albany almost failed when its Kaiser partner withdrew completely from the Northeast region of the country, leaving the Alzheimer's Association chapter with the challenge of finding another managed care partner halfway through the project.

Challenges and Benefits of Partnering with a Network Model or IPO Managed Care Organization

Four CCN/AD sites involved partnerships between Alzheimer's Association chapters and network model or IPOs. Observations from these sites indicate that it is generally less time-consuming to initiate a partnership with a network model or IPO, primarily because there are fewer people and fewer levels of administration that have to agree to the project. On the other hand, it is often more difficult to implement project-related training because the physicians and other health care professionals work in independent, geographically separate offices, and the central organization usually has less ability to convince these professionals to attend training programs. For the same reasons, it is likely to be more difficult to get care protocols and guidelines adopted in a network model or IPO.

One benefit of partnering with a network model or IPO is that this type of managed care organization is more common than staff or group model HMOs. This is an important consideration if replication is a central objective of the managed care project.

A challenge in partnering with a network model or IPO is that the affiliated physician offices and clinics usually have patients with many different kinds of health insurance. The CCN/AD sites where this was the case were generally not able to convince the physicians and clinics to adopt the project model when it was only for their patients who were enrolled in the partnering managed care organization at that site. Eventually, project leaders decided that the model and related services, including chapter services, would be made available to all the physicians' patients with dementia, regardless of a patient's health insurance. That decision resulted in more widespread adoption of the project model, but it also meant that the project was serving many people for whom data on use of health care services could not be obtained for project evaluation. With prior awareness of this problem, future managed care projects can be designed to avoid it. The problem does not arise in projects with a staff or group model HMO because all patients of the staff physicians in these organizations are enrolled in the same HMO.

In considering a partnership with a network model or IPO managed care organization, chapters and other CASPS should be aware of two characteristics of particular organizations that could affect the success of the project. One of these characteristics pertains to capitation practices, and in particular, which parts of the network or IPO are capitated for which health care services. All the dementia managed care projects discussed in this manual were built on the concept that capitated payment can be used creatively to provide and organize care in ways that are not possible in fee-for-service health care. The Cleveland and CCN/AD projects were intended to test whether better dementia care management and additional services that are not covered in fee-for-service health care could reduce the use of high-cost hospital and emergency room care and thereby save funds that could be used to maintain the care management and extra services. In a network model or IPO managed care organization, this outcome is only achievable if the same part of the network is capitated for hospital, emergency room, physician, and other services, so that savings from reduced use of hospital and emergency room care accrue to the same part of the network that pays for the care management and additional services. (This issue is rare but can arise in a staff or network model HMO if the HMO does not include hospital and emergency room care in its capitated services.)

A second important characteristic of particular network model and IPO managed care organizations is the presence or absence of case managers in the central organization. Such case managers can be extremely helpful in delivering project-related training and facilitating the adoption of care protocols in independent and geographically separate physician offices. Observations from CCN/AD sites that involved partnerships with network model and IPOs point to the value of having case managers in the central organization and the difficulty of implementing physician office-based training and care protocols without them.

Implications

Chapters and CASPs would be wise to invest time and effort upfront to learn as much as they can about the characteristics of potential managed care partners and to consider how well those characteristics fit with the goals for their project. Given the number and complexity of potentially relevant characteristics, it may be tempting to select a managed care partner because the chapter or CASP has a personal contact in the organization to facilitate the partnership. The authors are aware, however, of several dementia managed care projects that failed even though the chapter had a personal contact in the managed care organization. In most of these situations, the characteristics of the managed care organization did not fit with the goals of the project, but considerable time and effort were spent in meetings to create a model of care before these projects were terminated.

Selecting a Partner Managed Care Organization: Lessons Learned

- Pre-existing contracts and relationships were important in the development of the chapter/managed care partnerships in most of the projects discussed in this chapter. In some projects, the chapter selected the managed care organization. In other projects, the managed care organization selected the chapter.
- Chapters and other CASPs should, to the extent possible, select a partner managed care organization with characteristics that fit the goals and design of their project. Doing so may be difficult, however, because selection of a partner organization must occur before the extensive joint discussions needed to select the project's specific goals and model of care.
- There are benefits and challenges in selecting a staff or group model HMO vs. a network model or IPO partner organization. It is generally less time-consuming to initiate a project with a network model or IPO, and a successful project conducted with a network model or IPO may be more widely replicable than a project conducted with a staff or group model HMO. On the other hand, it is generally easier than implementing training and new care protocols in a staff or group model HMO.
- In considering a network model or IPO as a partner organization, chapters and CASPs should find out what parts of the networks are capitated for what services and select a partner organization in which the financial incentives created by the organization's capitation practices are aligned with the project goals.
- In considering a network model or IPO as a partner organization, chapters and CASPs should find out whether the central organization has case managers who can help with project-related training and adoption of care protocols in independent and geographically dispersed physician offices.
- In selecting a partner managed care organization, chapters and CASPs should consider the impact of creating this exclusive partnership on their relationships with other health care organizations in their communities.

II. Selecting Goals for the Project

Although all the dementia managed care projects described in this manual had the same general objective of improving care for managed care enrollees with dementia, each project had specific goals that reflect the problems the partnering organizations hoped to address in the project. The projects differed in the amount of time spent and research conducted at the start of the project to identify these problems.

In the Cleveland project, a specific goal was established by the chapter before the project began. This was possible because there was no expectation of changes in the managed care organization's usual care practices. The goal established by the chapter reflected its awareness that, regardless of the particular health care setting, people with dementia and their families often do not receive adequate information about dementia diagnosis, treatment, support services, and strategies for coping with symptoms and care. Chapter staff believed that a chapter-provided care consultation intervention could reduce this problem and thereby decrease Kaiser enrollees' use of unnecessary, crisis-driven health care services and improve satisfaction and psycho- social outcomes. Chapter staff hoped these results would convince Kaiser and other managed care organizations to pay for on-going chapter care consultation for their enrollees with dementia. Thus, the specific goal of the project was to test the impact of chapter care consultation on Kaiser enrollees' use of health care services and enrollees' and family caregivers' satisfaction with Kaiser, depression, and other psychosocial outcomes.

Unlike the Los Angeles project, no new research was conducted at the beginning of the Cleveland project to identify problems in care and select the project's specific goal. Baseline interviews were conducted with Kaiser enrollees with dementia and their family caregivers, however, and findings from these baseline interviews were useful in later evaluation of the project outcomes.

Kaiser provides case management for its high-risk and high-cost enrollees. Data obtained before the project began showed that one-third of Kaiser enrollees who were receiving Kaiser case management had dementia. As in the Los Angeles project, these data findings were useful in convincing Kaiser leaders of the importance of the project.

In the CCN/AD project, a specific goal was established in the first six months of the project through numerous teleconferences and three in-person meetings of the project's Leadership Committee, a group of about 35 representatives from all the partnering organizations at each CCN/AD site. This intensive, in-person process was time-consuming and costly but probably essential because of the number and diversity of project sites and the need for agreement on a common goal for the multi-site demonstration.

(See Appendix 14)

No new research was conducted to select the CCN/AD project goal. Rather it emerged from meetings during which committee members presented and discussed existing research and case examples illustrating problems in dementia care. Published studies on dementia care, managed care, and systems change were circulated among committee members. The decision about the project goal was based, however, on members' perceptions of problems in care, their knowledge of existing research, and their clinical experience rather than on new research conducted for the project.

Selecting Goals: Lessons Learned

- Although project initiators may have general and intuitive ideas about project goals, specific goals are necessary to guide the next step, creating a model of care.
- Specific goals should reflect the problems the partnering organizations want to address in the project.
- In projects where there is an expectation of change in the managed care organization's usual care practices, representatives of that organization must be involved in selecting the project's specific goal(s).
- Research conducted in the managed care organization at the beginning of a project can help define problems and select goals. Such research takes time, but the findings provide valuable baseline data for later project evaluations and for convincing the managed care organization that the project is important.
- Anecdotes and case examples illustrating problems in care are also useful for defining problems, selecting goals, and convincing leaders of the managed care organization that the project is important.
- Selecting specific goals is more difficult when the project involves multiple sites and partnering organizations and various types of managed care.

III. Creating a Model of Care

A project's model of care describes the intervention that will be implemented and that is intended to achieve the project goal(s). The models of care created for the Los Angeles, Cleveland, and CCN/AD projects differ substantially. One important difference among them was the locus of expected change in usual care practices; that is, whether the change was expected to occur primarily in the managed care organization, primarily in the Alzheimer's Association chapter, or both.

In the Los Angeles project, the model of care and practice guidelines placed the intervention in the managed care organization, where Kaiser physicians, nurses, social workers, and others were trained and then implemented the diagnostic and post-diagnostic guidelines. The chapter was extensively involved in project planning and training and provided usual chapter services for Kaiser enrollees and families who contacted the chapter, but the locus of expected change in usual care practices was the managed care organization. As described below, this was not the case in the Cleveland and CCN/AD projects.

<u>In the Cleveland project</u>, the model of care focused on comprehensive care consultation. The model was based on the chapter's usual care consultation service, except that project care consultants made proactive initial calls to the people with dementia and their families, rather than waiting for these individuals to contact the chapter. The proactive calls were possible because the individuals had formally consented to be called.

The care consultation intervention reflected the chapter's extensive experience and long-standing commitment to identifying the strengths of people with dementia and their families and providing information and support to empower them to make their own decisions about care and services to the extent possible. The intervention also reflected findings from research con- ducted previously by the chapter and others about help-seeking behaviors, families' decisions about service use, and related issues. For the project, the chapter care consultants needed an in-depth understanding of the Kaiser sys- tem, but Kaiser was not involved in creating the project model.

The Cleveland model of care was described less explicitly at the start than the Los Angeles and CCN/AD models. Since there was no expectation of change in the managed care organization's usual care practices in the Cleveland project, it was not necessary to communicate the model to Kaiser staff. Likewise, it was not necessary to document the model's research base to gain acceptance for it from Kaiser administrators or staff. During the project, adjustments were made to the model in response to the experiences and insights of chapter staff, but it was not necessary to involve Kaiser administrators or staff in decisions about the adjustments or even to communicate these decisions to them.

The model of care for the Cleveland project placed the intervention entirely in the chapter. The managed care organization identified enrollees for the project and provided data for evaluation, but the locus of change in usual care practices was the chapter.

In the CCN/AD project, the model of care focused on identification of people with possible dementia, diagnostic assessment, on-going medical and non-medical care management, and information and support for family caregivers. As in the Los Angeles project, the CCN/AD Leadership Committee appointed two advisory groups to create the model. The Care Management Advisory Group consisted of physicians, other health care and social service professionals, and administrators from the managed care organizations, chapters, and other partnering organizations at each site. This advisory group created the first three components of the model (identification, diagnostic assessment, and care management). A second advisory group, the Education and Support Advisory Group, created the fourth component, family caregiver information and support. This advisory group consisted primarily of chapter staff members from each CCN/AD site.

Unlike the Los Angeles and Cleveland projects, CCN/AD was implemented in many different health care systems and communities. The project's Leadership Committee recognized that the same care protocols could not be successfully implemented in these different settings. The committee agreed that there would be a national model of care, and the partnering organizations at each site would use the model to develop their own care protocols. The model would identify essential functions, but the sites would decide which functions would be accomplished by the managed care organization, the chapter, and other partnering agencies at the site.

The CCN/AD model of care was based on research findings to the extent possible, and the research base for the model was carefully documented. The advisory groups that created the model also relied on their own clinical expertise and practice experience. Initial acceptance of the model was assured because it was created by representatives of all the organizations that would implement it.

At the start of the CCN/AD project, the Leadership Committee committed to on-going reevaluation of the model of care and adjustments based on sites' experiences in implementing it. Making such adjustments was problematic because each site had somewhat different care protocols based on the national model. One substantial adjustment to the model was made, however, to delete one recommended assessment instrument that was being used incorrectly in most sites and was determined to be unnecessary in achieving the project goal.

Since the CCN/AD model only identified essential functions, and the sites decided which of these functions would be accomplished by each of the partnering organizations at their site, the main locus of expected change in usual care practices differed across sites. Identification and diagnostic assessment generally occurred in the health care system, but chapter staff completed some parts of the assessment in some sites. Chapters took the lead in family information and support in all sites, but care management was provided primarily by the managed care organization or health care system in some sites and the chapter or other partnering agencies in other sites.

Since coordination of medical care and supportive services was a major objective for CCN/AD, it could be said that the ideal locus of change in usual care practices would have been the intersection between the managed care organization and/or health care systems, on the one hand, and the chapter and/or other community agencies, on the other hand. Preliminary evaluation findings indicate that the best outcomes were achieved in CCN/AD sites that were most effective in making change happen at this intersection.

Creating a Model of Care: Lessons Learned

- The model of care is important because it describes what will be done to achieve the project goal(s) and solve the identified problem(s).
- The model of care identifies the main locus of expected change in usual care practices, whether in the managed care organization, the chapter or CASP, or both.
- In projects where there is an expectation of change in the managed care organization's usual care practices, representatives of that organization should be involved in creating the model of care.
- In projects where there is an expectation of change in the managed care organization's usual care practices, the model should be simply stated and specific so that it can be effectively communicated to the health care and social service professionals who will be asked to implement it. This is probably less important when the change in usual care practices will occur only in the chapter or CASP.
- Use of available research to create the model of care and careful documentation of that research will increase the credibility and acceptance of the model among health care and social service professionals who will be asked to implement it.
- Unless a model of care is created specifically for one chapter, managed care organization, health care setting, and community, it will re- quire adjustments to accommodate differences in each of these factors. Chapters and CASPs should anticipate such adjustments in planning a managed care project and creating or selecting a model of care.
- Agreeing on a model of care is more difficult when the project involves multiple sites and partnering organizations and various types of managed care.

IV. The Role of Care Managers

All the dementia managed care projects discussed in this manual employed care managers. These individuals had many different titles, for example, social work care manager, dementia specialist, care consultant, and dementia care manager. More importantly, they performed many different kinds of tasks, only some of which were clearly defined or even recognized at the start of the project.

For comparison purposes, it is useful to identify the following interrelated but different kinds of tasks that were performed by care managers in one or more of the dementia managed care projects:

- Usual care management tasks, including assessment, care planning, referrals, and assistance in arranging needed services;
- Counseling for people with dementia and their family caregivers;
- Support groups for people with dementia and their family caregivers;
- Educational programs for people with dementia and their family caregivers;
- Introduction and on-going representation of the project to other staff in the care manager's organization;
- Project management;
- Scheduling and delivery of formal staff training;
- Provision of informal, one-on-one and case-based training;
- Supervision of other project staff;
- Advocacy for people with dementia and better dementia care inside and outside the care manager's organization;
- Advocacy for family caregivers inside and outside the care manager's organization;
- Creation and maintenance of working connections between the partnering organizations in the project; and
- Collection of data for project evaluation.

In the Cleveland project, the chapter care consultants performed the usual case management tasks (first bullet above) and extensive telephone counseling. They also provided one-on-one, case-based training and supervision for chapter volunteers who made follow-up calls to people with dementia and family caregivers that had been stable at the time of their most recent contact with the care consultant.

In the CCN/AD project, care managers in different sites performed various combinations of the tasks listed above. Some sites had one or more care managers in the managed care organization or health care system. Some had one extra care manager in the chapter, and some had care managers in both settings.

In some CCN/AD sites, care managers' tasks were not explicitly or clearly defined when the intervention began. Moreover, caregiver managers' tasks changed somewhat over time in all the sites. Individuals in these positions responded differently to the lack of clear definition and change. Some found the uncertainty exciting and appreciated the opportunity to help define their own tasks; others found the uncertainty frustrating. In hindsight, some care managers suggested that usual case management tasks and counseling should be performed by one person, and tasks such as introducing and representing the project to other staff members, scheduling and delivering formal training, and providing educational programs, should be performed by a different person. This suggestion leaves many tasks unassigned, and it is likely that the most effective distribution of tasks will vary for different organizations and partnerships.

As in the Los Angeles project, care managers in some CCN/AD sites were said to be the system lynch pin. At the same time, some project managers and evaluators pointed out that CCN/AD was intended to change the system of care and expressed skepticism about the value of adding one or more care managers to fragmented care settings. While overstated, this dichotomy highlights an important question about the role of care managers in these and other projects where systems change is a stated objective.

The Role of Care Managers: Lessons Learned

- Care managers, with whatever title, are likely to play important roles in managed care projects intended to improve and coordinate care for people with dementia and other elderly people with physical, emotional, and cognitive impairments.
- Chapters and CASPs should define as clearly as possible the tasks to be performed by care managers in their managed care projects. This will be helpful in hiring, training, establishing expectations, and supervising the care managers.
- Chapters and CASPs should also define the project-related tasks that will *not* be performed by care managers and decide who will perform these tasks. This will support effective project implementation. It will also support planning to sustain change after the project ends since administrators and others will have a clearer understanding of the likely effects of maintaining or eliminating the project care managers and/or altering their tasks.

Building and Maintaining a Working Partnership

What problems arise in building and maintaining a working partnership between a community aging service provider and a managed care organization, and what can be done to avoid or resolve those problems?

Implementing change in a managed care organization is challenging and takes much patience. There are periods in these partnerships when frustrations seem overwhelming and partners may consider quitting. The authors observe that this occurred not only in the collaboration being described in Los Angeles but in many other joint MCO-CASP projects as well. It appears to be part of the normal course of project implementation. Frustration should be expected and can be planned for. The collaborations are turning over new ground in territory that is increasingly focused on the highly technical and medication oriented and that is short on time for needed assessments, communications and planning.

Revisiting mutually defined goals

In the course of the Metropolitan Los Angeles Dementia Care Project, the workgroup periodically found it necessary to revisit and re-sanction its goals. Such a process can include a review of what has been accomplished to date. These collaborative projects may take years. Over the course of time there can be personnel turnover, differences in commitment to the project, bureaucratic obstacles to implementation, financial shortages and many other causes for concern. A refresher session that reinforces the project's goals and accomplishments can be helpful.

Mutual recognition activities

Another strategy to prevent project burnout is to plan events at which partners can be recognized for their contributions to the project. Kaiser personnel attended meetings of the Alzheimer's Association's Board of Directors and co-presented project findings at conferences. Alzheimer's Association personnel were invited to make presentations to Kaiser professional staff and to consult on related projects. An application was submitted and this project won an award from the American Society on Aging. These activities gave participants support, enabling them to manage project frustrations.

The role of external cheerleaders

In the course of this project's implementation, key leaders from the MCO and the CASP who were not day-to-day participants in the project were able to play a role in re-motivating project staff. Their periodic visits highlighted the importance of the work. They made participants feel that their efforts were worthwhile and valued; that the Dementia Care Project would improve people's lives and was an important undertaking. Their contribution was immeasurable.

Partnerships between managed care organizations and community aging service providers can produce sustainable results. In this project, while the Dementia Care Workgroup has been disbanded and data collection for the partnership has ceased, the impact of the collaboration between Kaiser Permanente and the Alzheimer's Association in Los Angeles has continued and evolved over time. This service area of Kaiser Permanente now has in place a panel of geriatric care managers serving frail and vulnerable older adults. Dementia is the dominant diagnosis among their clients. This expansion of the original program was made possible by the data collected from the original collaboration and through the advocacy of the local physician leader involved in the project. In addition, Kaiser Permanente has developed a national guideline for the diagnosis and management of dementia in primary care. This practice guideline drew, in part, from the work done in the original project. Similarly, this project's emphasis on collaboration led to a six site, multi-state collaboration in which Kaiser Permanente regions increased their partnerships with community providers.

The partnerships discussed in this manual were challenging to initiate, implement and sustain. However, the results were valuable and led to improved quality of care for people with dementing diseases.

Building and Maintaining a Working Partnership: Lessons Learned

- Bringing about change in a managed care organization takes time and a lot of patience
- Review accomplishments periodically and revisit project goals
- Seek opportunities for recognition of the project and the individuals involved in making it happen
- Invite positive feedback and reinforcement from organizational leadership and others not involved in the day-to-day operations of the project to re-charge enthusiasm

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Appendices

Appendix: 1

Physician Dementia Survey

Pre-Interview

1. How often do you perform a diagnostic work-up on patients with suspected dementia?

O Frequently
O Somewhat frequently
O Somewhat infrequently
O Infrequently

Please indicate the extent to which you agree or disagree with each of the statements below.

	Strongly Agree	Agree	Disagree	Strongly Disagree
2. I believe I have a good understanding of dementia………………………………………..	O	O	O	O
3. I believe that I understand dementia's effects on patients and their caregivers/families……….	O	O	O	O
4. I feel comfortable with the diagnostic work-ups patients with dementia receive……….	O	O	O	O
5. I feel comfortable explaining a diagnosis of dementia to patients and their families………...	O	O	O	O
6. I believe that patients and their caregivers/ families are appropriately informed about available drug therapies………………………..	O	O	O	O
7. I feel that the physicians and other providers give patients and their caregivers/families consistent information about dementia throughout the course of the illness……………	O	O	O	O
8. When I refer patients to another physician or provider, I get adequate feedback……………..	O	O	O	O
9. I feel that patients with dementia and their caregivers/families are regularly treated with sensitivity and respect at Kaiser Permanente.. ..	O	O	O	O
10. I believe I understand the role of the social worker……..……..………………………	O	O	O	O
11. I feel comfortable with the present system of care around ethical issues affecting treatments of co-morbidity (e.g., cataracts, pacemakers)…	O	O	O	O
12. I have someone I can talk with who can help me resolve ethical issues/problems……………	O	O	O	O

13. Do you provide patients and caregivers/families with educational information about dementia?

○ Yes ○ No

13a. *If yes,* what information?

- ○ Printed material (Please specify) ____________________________
- ○ Video
- ○ Healthphone
- ○ Other (Please specify) ____________________________________

14. Do you ever refer patients <u>outside</u> of Kaiser Permanente?

○ Yes ○ No

14a. *If yes,* where do you refer them?

- ○ Alzheimer's Association
- ○ Home Health Aide
- ○ Support Groups
- ○ Adult Day Care
- ○ Second Opinion / Diagnosis
- ○ Medications / Treatment
- ○ Nursing homes / board-and-care homes
- ○ Other (please specify) ______________________________

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
15. How satisfied are you with how crises involving patients with dementia and their caregivers/families are handled?...	○	○	○	○
16. Overall, how satisfied are you with the treatment and support that KP provides to patients with dementia and their caregivers/families?……….	○	○	○	○
17. Overall, how satisfied are you with the treatment and support that KP provides to patients with dementia *who lack (or have inadequate)* caregivers/families?………………….	○	○	○	○

About You

18. In which medical center do you work? *(Check only one)*

- ○ Los Angeles Medical Center
- ○ West Los Angeles Medical Center
- ○ Baldwin Park Medical Center
- ○ Bellflower Medical Center
- ○ Harbor City Medical Center

19. In what department do you primarily work? *(Check only one)*

- ○ Emergency Department
- ○ Inpatient Medicine and Surgery
- ○ Internal Medicine (outpatient)
- ○ Family Practice (outpatient)
- ○ Other (please specify) ______________________

20. How long have you been in your present position? *(Check only one)*

- ○ Less than a year
- ○ 1-2 years
- ○ 3-5 years
- ○ More than 5 years

Thank you.

Please return this survey in the enclosed envelope by_____________to:
Shelia Maradiaga
Organizational Research, 6th Floor
Los Robles, Pasadena

Appendix: 1

Physician Dementia Survey

Post-Interview

1. In the last <u>3 months</u> of practice, approximately how many patients with dementia have you seen?

Number of new patients diagnosed with dementia = ________
Number of follow-up patients diagnosed with dementia = ________

2. What percent of all patients in your practice would you estimate have a diagnosis of dementia?

○ 0%–5% ○ >5%

3. In the last year, how often have you used the following consultations or referral resources to assist in diagnosing dementia in your patients with symptoms of dementia or with possible dementia? (Please mark one box in each row)

	<u>Always</u>	<u>Sometimes</u>	<u>Never</u>
a. Neurology……………………….	○	○	○
b. Psychiatry……………………….	○	○	○
c. Neuropsychology……………….	○	○	○
d. Radiology……………………….	○	○	○
e. Geriatric Screening…………….	○	○	○
f. Laboratory……………………...	○	○	○

4. In the last year, how frequently have you used the following Kaiser Permanente referrals for your dementia patient populations and/or their families?

	<u>Always</u>	<u>Sometimes</u>	<u>Never</u>
a. Social Medicine…………………	○	○	○
b. Outpatient Mental Health……….	○	○	○
c. In-patient Mental Health………..	○	○	○
d. Geriatric Assessment Clinic…….	○	○	○
e. Member Services….…………….	○	○	○
f. Member Health Education………	○	○	○
g. Pharmacy……………………….	○	○	○
h. CDRP/Addiction Medicine…….	○	○	○
i. Home Health……………………	○	○	○
j. Hospice…………………………	○	○	○

5. In the last year, how frequently have you or your staff referred your dementia patients and their families to the following non-Kaiser community-based resources?

	Always	Sometimes	Never
a. Alzheimer's Association…..…….	○	○	○
b. Residential Care………...……….	○	○	○
c. Meals on Wheels………………..	○	○	○
d. Adult Day Care……………..……	○	○	○
e. Support Groups..…..……………..	○	○	○
f. Case Management…………..……...	○	○	○
g. Legal/Financial Help..…………..	○	○	○
h. In-home Services……………….	○	○	○

Please indicate the extent to which you agree or disagree with each of the statements below.

	Strongly Agree	Agree	Disagree	Strongly Disagree
6. I feel comfortable with the diagnostic work-ups patients with dementia receive……...	○	○	○	○
7. I feel comfortable explaining a diagnosis of dementia to patients and their families………	○	○	○	○
8. I believe that patients and their caregivers/ families are appropriately informed about available drug therapies………………………	○	○	○	○
9. I feel that patients with dementia and their caregivers/families are regularly treated with sensitivity and respect at Kaiser Permanente...	○	○	○	○
10. I believe I understand the role of the Dementia Care Social Worker at Kaiser Permanente….	○	○	○	○

11. Thinking back over the past year, how often have you directly provided patients and caregivers/families with educational information about dementia?

○ Always ○ Often ○ Sometimes ○ Never

11a. *If always, often, or sometimes,* what educational information have you directly provided in the past year? (Check all that apply)

○ Printed Material (Please specify) ______________________________
○ Alzheimer's Association Rx Pad
○ Healthphone
○ Other ____

12. In early 1998, Kaiser Permanente physicians organized a workshop on dementia diagnosis and care. Did you attend the dementia workshops in 1998 where the dementia diagnostic guidelines were presented by physician leaders at Kaiser Permanente and which included a demonstration by actors?

○ Yes ○ No

13. In 1998, Kaiser Permanente physicians developed a guideline for the evaluation of people with possible dementia. A laminated pocket card version was distributed. Do you recall this guideline?

○ Yes ○ No (If no, please skip Q14 & 15 and
proceed to Q16 below)

14. Thinking back over your clinical experiences in the last year, how useful have you found this guideline to be in your evaluation of patients with memory problems or at risk for cognitive impairment or dementia?

○ Extremely useful	○ Very useful
○ Somewhat useful	○ Not at all useful

15. How many times have you referred to or used this dementia guide in the last 3 months? ____________ (Please write in your best estimate)

16. Please indicate how much you agree or disagree with the following statements regarding your evaluation and management of dementia patients now compared to how you felt before January 1998.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
a. I make more appropriate neurology consults now than prior to January 1998…………………..	○	○	○	○	○
b. I make more appropriate use of psychiatry consults now than prior to January 1998…………………..	○	○	○	○	○
c. I am more confident about the appropriate tests to include in a dementia work-up now than prior to January 1998……………..	○	○	○	○	○
d. I receive fewer crisis calls from patients with dementia and their families now than prior to January 1998……………………..	○	○	○	○	○

17. Compared to the time period before January 1998, would you say that the frequency with which you personally administered and recorded the results of Mini Mental Status Exams on patients over the last year is:

○ Much more frequently now
○ Somewhat more frequently now
○ About the same now as before January 1998
○ Somewhat less frequently now
○ Much less frequently now

18. If you use the Mini Mental Status Exam in screening patients for dementia, how useful is it to you?

Not useful at all	Somewhat useful	Quite useful	Very useful	Do not use it
○	○	○	○	○

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
19. Based on your experience since January 1998, how satisfied are you with how crises involving patients with dementia and their caregivers/families are handled? …………………………….	○	○	○	○
20. Since January 1998, overall, how satisfied are you with the treatment and support that KP provides to patients with dementia and their caregivers/families? ...	○	○	○	○

21. Have you had a clinical interaction with the Dementia Care Social Worker?

○ Yes ○ No

21a. *If yes*, overall, how satisfied were you with the help the Dementia Care Social Worker provided to the patient?

○ Very satisfied ○ Satisfied ○ Dissatisfied
○ Very dissatisfied ○ Did not refer to SW

21b. If dissatisfied or very dissatisfied, please explain____________

____

22. How long have you been in your present position at SCPMG? (Check only one)

○ Less than a year ○ 1-2 years ○ 3-5 years ○ Over 5 years

Thank you.
Please return this survey in the enclosed envelope to:
Shelia Maradiaga
Organizational Research, 6th Floor, Los Robles, Pasadena

Appendix: 2

Dementia Caregiver Survey

Pre-Interview

Interviewer to fill out:

Patient's Gender: O Male O Female
Patients Age: __________

Hello, my name is_______________and I am calling from Kaiser Permanente. May I speak to_______? We are conducting a research study about the care of dementia patients at KP. According to my records, [patient's name] was diagnosed as having memory problems. Is this correct?

O Yes O No (Thank respondent and terminate interview)

We are interviewing family members and other caregivers of patients with memory problems regarding the care they are receiving at a Kaiser facility. According to my records, you are the patient's primary caregiver. Is this correct?

O Yes O No (Thank respondent and terminate interview)

Recently, we sent you a letter describing our research study and asked you to participate. We just received your consent letter and would like to ask you some questions. This interview will take about 20-30 minutes. Is this a convenient time for you?

O Yes O No (When would be a convenient time for you?)

Participating in this research may involve some loss of privacy, though all research records will be handled as confidentially as possible. All records will be coded and kept in locked files so that only the study investigators have access to them. Your name and other personal information will not be used in any reports resulting from this study and results will be presented only in a summary form with answers from many caregivers.

It is hoped that the information gained from the study will help in the treatment and management of future patients and their caregivers. You don't have to participate in this study. If you decided not to participate, it will not affect the patient's medical care in any way.

Appendix: 2

1. Was the patient diagnosed by a Kaiser Permanente physician?
O Yes O No

1a. ***If no*****,** who told you about the diagnosis? ___________________

2. Was the diagnosis explained to you? O Yes O No

2a. ***If yes,*** how satisfied were you with the explanation you were given about the diagnosis of dementia?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

3. Do you feel that Kaiser Permanente physicians and staff have given you consistent information about the illness? O Yes O No

3a. ***If no,*** please explain: ____________________________________
____

	Yes	No
4. Do you think that the patient's Kaiser Permanente physician and other staff appropriately share information about the patient's condition?…………………………………..	O	O
5. Have Kaiser Permanente physicians or other staff given you educational materials about the illness?……………..	O	O

6. How satisfied have you been with the sensitivity and respect shown to you and the patient at Kaiser Permanente?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

7. Have you seen a Kaiser Permanente social worker?
O Yes O No **(Skip to Q8)**

7a. Please rate how knowledgeable you think your social worker is about dementia

.

Very	Somewhat	Only a little	Not at all
O	O	O	O

Referrals

8. Has a Kaiser Permanente physician or other staff referred you to any services within Kaiser Permanente? O Yes O No

8a. ***If yes***, list up to three KP services:
1) ____________________
2) ____________________
3) ____________________

1st KP Service Referred

9. Did you ask for this referral? O Yes O No

10. Did the KP doctor or other staff give you this referral without you asking? O Yes O No

11. How satisfied were you with this Kaiser Permanente referral?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

12. Have you had any problems with this referral within Kaiser Permanente? O Yes O No

12a. ***If yes***, please explain: ____________________

2nd KP Service Referred

13. Did you ask for this referral? O Yes O No

14. Did the KP doctor or other staff give you this referral without you asking? O Yes O No

15. How satisfied were you with this Kaiser Permanente referral?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

16. Have you had any problems with this referral within Kaiser Permanente? O Yes O No

16a. ***If yes***, please explain: ____________________

3rd KP Service Referred

17. Did you ask for this referral? O Yes O No

18. Did the KP doctor or other staff give you this referral without you asking? O Yes O No

19. How satisfied were you with this Kaiser Permanente referral?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

20. Have you had any problems with this referral within Kaiser Permanente? O Yes O No

20a. ***If yes***, please explain: ________________________________

____

21. Has a Kaiser Permanente physician or other staff referred you to dementia-related services outside of Kaiser Permanente?

O Yes O No **(Skip to Q22)**

21a. ***If yes***, what are these services? (Check all that apply)

O Alzheimer's Association
O Home Health Aide
O Support Groups
O Adult Day Care
O Meals on Wheels
O Other (please specify) ________________________

22. Have you sought any dementia-related services outside of Kaiser Permanente on your own?

O Yes O No **(Skip to Q23)**

22a. ***If yes,*** what are these services? (Check all that apply)

O Alzheimer's Association
O Home Health Aide
O Support Groups
O Adult Day Care
O Second Opinion / Diagnosis
O Medications / Treatment
O Nursing homes / board-and-care homes
O Other (please specify) ________________________

23. Have you ever had a crisis with the patient requiring emergency services at Kaiser Permanente?

O Yes O No **(Skip to Q24)**

23a. ***If yes,*** how satisfied were you with the way this emergency situation was handled?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

23b. ***If not satisfied*****,** why not? ______________________________

____

23c. Was this Kaiser Permanente emergency service provided between the hours of 9 a.m. and 5 p.m.? O Yes O No

Now I want to ask you about overall dementia-related care received at Kaiser Permanente.

24. Overall, how satisfied have you been with the dementia-related services you and the patient have received at Kaiser Permanente?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

25. What other services could Kaiser Permanente provide for you and the patient that you are not now receiving?__________________________

____

____

About the Patient

26. Where does the patient live?

O With spouse
O With daughter
O With son
O Nursing home / board-and-care home
O Alone
O Other (please specify) ________________________

27. In which medical center is the patient receiving dementia services?

O Los Angeles Medical Center
O West Los Angeles Medical Center
O Baldwin Park Medical Center
O Bellflower Medical Center
O Harbor City Medical Center
O Other (please specify) _______________________

Appendix: 2

28. Patient's Ethnicity:

○ Anglo
○ African-American
○ Asian/Pacific Islander
Please specify ______________

○ Latino/Hispanic
○ Native American
○ Other
Please specify _____________

29. What is the patient's primary language?

○ English
○ Spanish
○ Other (please specify) ________________

About the Caregiver

30. What is your relationship to the patient with dementia?

○ Spouse
○ Daughter
○ Son
○ Other (please specify) __________________________

31. Are you: ○ Male ○ Female

32. Your age: __________

33. Your ethnicity**:**

○ Anglo
○ African-American
○ Asian/Pacific Islander
Please specify ______________

○ Latino/Hispanic
○ Native American
○ Other
Please specify _____________

Thank you.

Appendix: 2

Dementia Caregiver Survey

Post-Interview

<u>This script is to be used if the caregiver who was interviewed on the pre-interview is no longer the primary caregiver at the time of the post-interview.</u>**

<u>Interviewer to fill out:</u>

Patient's Gender: ○ Male ○ Female
Patient's Age: ______________

Hello, my name is________________and I am calling from Kaiser Permanente. May I speak to____________? Are you currently the primary caregiver of Mr./Mrs.____________?
○ Yes ○ No (Thank respondent and terminate interview)

About______months ago, we interviewed________________(previous caregiver's name) for our research study about the care that Mr./Mrs. ___________ (patient's name) receives at Kaiser Permanente. We stated at that time that we would be calling again in several months to follow-up. We would like to interview you now, as the current primary caregiver, about the services Mr./Mrs.__________is receiving from Kaiser Permanente. This interview will take about 20-30 minutes. Is this a convenient time for you?
○ Yes ○ No (When would be a convenient time for you?)

All research records will be handled as confidentially as possible. They will be coded and kept in locked files so that only the study investigators have access to them. It is hoped that the information gained from the study will help in the treatment and management of future patients and their caregivers.

Interactions with Kaiser Permanente Physicians and Other Staff

1. Was the patient diagnosed by a Kaiser Permanente physician?
○ Yes ○ No

1a. ***If no***, who told you about the diagnosis? ___________________

2. Was the diagnosis explained to you? ○ Yes ○ No

2a. ***If yes,*** how satisfied were you with the explanation you were given about the diagnosis of dementia?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

3. Do you feel that Kaiser Permanente physicians and staff have given you consistent information about the illness? O Yes O No

3a. ***If no****,* please explain: ____________________________________
____

	Yes	No
4. Do you think that the patient's Kaiser Permanente physician and other staff appropriately share information about the patient's condition?……………………………………..	O	O
5. Have Kaiser Permanente physicians or other staff given you educational materials about the illness?……………	O	O

6. How satisfied have you been with the sensitivity and respect shown to you and the patient at Kaiser Permanente?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
O	O	O	O

7. Have you seen a Kaiser Permanente social worker?

O Yes O No **(Skip to Q8)**

7a. Please rate how knowledgeable you think your social worker is about dementia.

Very	Somewhat	Only a little	Not at all
O	O	O	O

8. Has a Kaiser Permanente physician or other staff referred you to dementia-related services outside of Kaiser Permanente?

O Yes O No **(Skip to Q9)**

9. Have you sought any dementia-related services <u>outside</u> of Kaiser Permanente on your own?

○ Yes ○ No **(Skip to Q10)**

9a. ***If yes,*** what are these services? (Check all that apply)

○ Alzheimer's Association
○ Home Health Aide
○ Support Groups
○ Adult Day Care
○ Second Opinion / Diagnosis
○ Medications / Treatment
○ Nursing homes / board-and-care homes
○ Other (please specify) ________________________

10. Have you ever had a crisis with the patient requiring emergency services at Kaiser Permanente? (If he/she had more than 1 emergency, ask about the most recent one, even it it's not dementia related).

○ Yes ○ No **(Skip to Q11)**

10a. ***If yes,*** how satisfied were you with the way this emergency situation was handled?

<u>Very satisfied</u>	<u>Satisfied</u>	<u>Dissatisfied</u>	<u>Very dissatisfied</u>
○	○	○	○

10b. ***If not satisfied*,** why not? ______________________________

____

10c. Was this Kaiser Permanente emergency service provided between the hours of 9 a.m. and 5 p.m.? ○ Yes ○ No

10d. Who or which department provided the emergency services?

○ Dementia Specialist / Social Worker
○ Emergency Room
○ Urgent Care
○ Primary Physician
○ Advise Nurse
○ Other (please specify)

____

Appendix: 2

Now I want to ask you about overall dementia-related care received at Kaiser Permanente.

11. Overall, how satisfied have you been with the dementia-related services you and the patient have received at Kaiser Permanente?

Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
○	○	○	○

12. Would you recommend the dementia services at Kaiser Permanente to a family member or friend? ○ Yes ○ No

12b. ***If no,*** please explain: ____________________________
____

13. What other services could Kaiser Permanente provide for you and the patient that you are not now receiving?______________________
____
____

About the Patient

14. Where does the patient live?
- ○ With spouse
- ○ With daughter
- ○ With son
- ○ Nursing home / board-and-care home
- ○ Alone
- ○ Other (please specify)

____

15. In which medical center is the patient receiving dementia services?
- ○ Los Angeles Medical Center
- ○ West Los Angeles Medical Center
- ○ Baldwin Park Medical Center
- ○ Bellflower Medical Center
- ○ Harbor City Medical Center
- ○ Other (please specify) ________________________

Thank you.

Appendix: 3

Focus Group Questions

Family/Caregiver Focus Groups

Introduction

- Ask each participant to introduce themselves by stating the following:
    - What is your relationship to the patient?
    - How long has it been since the patient you care for was diagnosed with dementia?
    - Do you live with the patient? (Current living arrangements)

Probes

Interactions with Physicians and Other Providers

- Was your relative's illness diagnosed by KP?
    - Who gave the diagnosis? (MD? Other?)
    - Were you referred to geriatric assessment?
    - What specialists were involved?

- What kind of diagnostic procedures did the patient go through?
    - Mental status exam?
    - Was the patient referred to radiology to have a "brain scan" (CT or MRI)?

- Was the diagnosis explained to you?
    - Was the explanation satisfactory?
    - Were you given brochures? Told about Healthphone?
    - Do you still have any questions?

- Do you believe you have an adequate understanding of the disease process?

- What were you told about treatments? (e.g., Cognex/Tacrine; Aricept, Haldol, antidepressants)
    - Was this helpful?
    - Were your questions answered satisfactorily?

- Do you feel providers give you consistent information?

- Do you think the providers you deal with communicate with each other?

- Do you feel you and your relative have been treated with sensitivity and respect?

Internal Referrals

- Were you referred to any services within KP? (Social services? Other?)
    - What were your experiences with these services?

- Were there any glitches with your referral within KP?
    - Did you have any problem getting an appointment?
    - Did you receive appointment cards?
    - Did you have any problems with related services because of the dementia?

- Do you think that KP is providing enough support for you and/or the patient?
    - What else would you like?
    - What would you like to see improved?

- Have you ever had an after-hours emergency with your relative? How did that go?

External Referrals

- Were you referred outside KP? Did you seek any of these services on your own?

- Where were you referred outside KP? (Alzheimer's Association? Legal? Respite?)
    - What was your experience with these services?
    - What went well? What didn't?

Conclusion

- Overall, what would you like to have that you don't now have?

Appendix: 3

Primary Care Physician Focus Group Discussion Guide

Introduction

- Review the Joint Dementia Project and confidentiality issues.

- Have each participant introduce themselves by answering the following:
  - In which medical center and specialty area do you work?
  - How long have you been in your present position?
  - What percentage of your caseload involves dementia patients and their caregivers/families?

Probes

<u>Interactions with Other Physicians and Providers</u>

- How often do you diagnose a patient as having dementia? How often do you use the CDAP code for dementia?

- Do you feel that you have a thorough understanding of dementia and its impact on patients and their caregivers/families?

- In general, do you feel dementia patients receive appropriate diagnostic work-ups?

- Do you feel that, in general, primary care physicians do an appropriate job of explaining the diagnosis to patients and their families?
  - Do you give patients and caregivers/families any educational information? (e.g., brochures, Healthphone, community agency referrals)

- Do you believe that patients and their caregivers/families are appropriately informed about available drug therapies? (e.g., Cognez/Tacrine; Aricept, Haldol, antidepressants)

- Do you feel that physicians and other providers give patients and their caregivers/families consistent information about dementia throughout the course of the illness?

- Do you feel that the other physicians and providers you deal with about these patients communicate appropriately with each other?

- Do you feel that dementia patients and their caregivers/families are regularly treated with sensitivity and respect at your medical center?

Referrals

- What kind of problems do patients and their caregivers/families typically experience with referrals within your medical center? (Do they have difficulty getting a timely appointment?)

- Do you know what are patients and their caregivers/families' overall experiences with referrals within KP?

- Do you refer patients outside of KP? Where do you refer them? (Alzheimer's Association? Legal? Respite?)
    - Do you know what caregivers/families experiences are with these services?

Emergencies

- In your experience, how does KP deal with dementia patients' and caregivers' crises (both daytime and after-hours)?

Conclusion

- Overall, do you think that KP is providing enough support to dementia patients and their caregivers/families?
    - What are the problems?
    - What would you like to see improved?

- In your experience, what are dementia patients' experiences when there is no (or inadequate) caregiver/family available?
    - What would you like to see improved?

Appendix: 3

Social Worker Focus Group Discussion Guide

Introduction

- Review the Joint Dementia Project and confidentiality issues.

- Have each participant introduce themselves by answering the following:
  - In which medical center and specialty area do you work?
  - How long have you been in your present position?
  - What percentage of your caseload involves dementia patients and their caregivers/families?

Probes

Interactions with Physicians and Other Providers

- Do physicians regularly refer dementia patients to you?
  - What kind of doctor (primary care or specialist) typically refers to you?
  - What are the barriers to patients and their caregivers/families getting referrals?
  - Does most of your contact with dementia patients come from provider referrals? *If not, how do these cases get to you?*

- Do you believe that physicians do an appropriate job of explaining the diagnosis to patients and their families?
  - Are you regularly involved in explaining the diagnosis to patients and their caregivers/families?
  - Do you give patients and caregivers/families any educational information? (e.g., brochures, Heathphone, community agency referrals)

- In your experience, do you feel dementia patients receive appropriate diagnostic work-ups?

- Do you feel that physicians and other providers give patients and their caregivers/families consistent information about dementia throughout the course of the illness?

- Do you believe that patients and their caregivers/families are appropriately informed about available drug therapies? (e.g., Cognex/Tacrine; Aricept, Haldol, antidepressants)

- Do the physicians and other providers you deal with about these patients communicate appropriately with each other?

- Do you feel that physicians and other providers deal with you appropriately in caring for dementia patients?

- What is the role of the social worker in reference to the dementia patients and their caregivers/families?

- Do you feel that the physicians and other providers understand your role and utilize your services appropriately?

- Do you feel that dementia patients and their caregivers/families are regularly treated with sensitivity and respect at your medical center?

- Do you feel that dementia patients and their caregivers/families are aware of the availability of social work services?

- Do you feel that you have a thorough understanding of dementia and its impact on patients and their caregivers/families?

Referrals

- What kind of problems do patients and their caregivers/families typically experience with referrals from within your medical center?
    - Do they have difficulty getting a timely appointment?

- What are patients and their caregivers/families' overall experiences with referrals within KP?

- Do you think that KP is providing enough support to dementia patients and their caregivers/families?
    - What are the problems?
    - What would you like to see improved?

- In your experience, how does KP deal with dementia patients' and caregivers' crises (both daytime and after-hours)?

- In your experience, what are dementia patients' experiences when there is no (or inadequate) caregiver/family available?

- Do your refer patients <u>outside</u> of KP? Where do you refer them? (Alzheimer's Association, Legal, Respite?)
    - Do you know what caregivers/families' experiences are with these services?
    - Are you satisfied with your ability to follow up on these referrals?

<u>Conclusion</u>

- Overall, how do you think the treatment and support of dementia patients and their caregivers/families can be improved within KP?

- Overall, how do you think the treatment and support of Dementia patients who lack (or have inadequate) caregivers/families can be improved within KP?

Appendix: 4

Dementia Chart Audit Form

Study ID#: ________________

Patient name: ______________________________________

MR#: ________________

Location: ________________

Date abstracted: ________/_____/________

Abstractor name: ______________________

Year of birth: _______________

Gender: (circle one)

Male - 1
Female - 2
No data - 9

Patient deceased: ________ Date: ______________

____ Outpatient chart audit completed

____ Dementia specialist data obtained

Appendix: 4

The purpose of the first four steps is identification of Index Study Outpatient Visit. The Index Visit is the first note in the medical chart that the physician indicates possible dementia.

Instructions for abstractor:

1. Go to section of medical record beginning **AFTER January 1, 1998.**

2. In chronological order, review each note (any kind of visit to physician or nurse practitioner/physician assistant or social worker) for any of the following terms, in any part of the note:

   Dementia
   Senile dementia
   Vascular dementia
   Alzheimer's disease
   Memory problems/impairment/loss
   Cognitive problems/impairment
   Confusion
   Mini-mental status exam score
   Referral to dementia specialist social worker

3. Be careful to look for any notes that may be out of chronological order.

4. When you identify the FIRST note after January 1, 1998 that includes one of these terms, record the following:

   Date of Index Study Visit:_________/________/_________

   Terms used (circle ALL that apply):

   Dementia - 1

   Senile dementia - 2

   Vascular dementia - 3

   Alzheimer's disease - 4

   Memory problems/impairment/loss, forgetfulness - 5

   Cognitive problems/impairment - 6

Confusion - 7

Mini-mental status exam score - 8

Referral to dementia specialist social worker - 9

Something else (write verbatim) - 10

____

____

____

Can't find any terms suggesting dementia - 11

Type of note: Outpatient physician visit – 1

Outpatient NP or PA visit – 2

Outpatient social worker note (not dementia specialist) – 3

Something else – 4
Specify: ____________________________

Unable to tell – 9

If this is an outpatient physician visit, indicate the type of clinic:

Primary care – 1
Write in the name of the primary care physician

____________________ ____________________
Last name First name

Neurology – 2

Psychiatry – 3

Geriatrics – 4

Something else – 4
Specify: ____________________________

Unable to tell – 9

If the index study note was **not** at an outpatient physician visit with a primary care physician, go to the first subsequent note that was an outpatient visit with a primary care physician, and record the date of that note and the name of the primary care physician:

Date of note:______/_____/_____

Name of the primary care physician

______________________________ ______________________

Last name First name

I. ASSESSMENTS

Beginning with the date of the note identified as the **INDEX STUDY VISIT,** review that note and all subsequent notes for the following:

A. MINI-MENTAL STATUS EXAM (MMSE)

Was any MMSE score found in the medical record or dementia specialist chart?

Yes – 1
No – 2

If YES, record the following for THE FIRST THREE MMSE scores found:

Date recorded	Who administered (Fill in a number)	MMSE Score (0-30) (Fill in a number)
___/___/___	_____	_____
___/___/___	_____	_____
___/___/___	_____	_____

Use the following codes for who administered:

Physician who provided care at the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4
Geriatrician – 5
Some other physician (specify:_______________________) – 6

Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:__________________________) – 10
Can't tell – 11

B. FUNCTIONAL ASSESSMENTS:

Again, beginning with the date of the note identified as the **INDEX STUDY VISIT**, review that note and all subsequent notes for the FIRST documentation or recording that the patient was assessed, for each of the following areas. (An assessment means any documentation that a query was made, not that the response to the query was 'yes'. For example, if a note in the chart states "no falls", then circle '1' = yes under assessment below for "falls".)

	Yes	Date	Who assessed	Not mentioned
Decision-making capacity	1	___/___/___	_____	2
Activities of daily living (bathing, dressing, toileting, feeding)	1	___/___/___	_____	2
Depression	1	___/___/___	_____	2
Agitation (aggressive behavior, combative, pacing, restless, hostile)	1	___/___/___	_____	2
Wandering	1	___/___/___	_____	2
Falls	1	___/___/___	_____	2
Abuse	1	___/___/___	_____	2

Use the following codes for who assessed:

Physician who provided care at the first visit after the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4

Geriatrician – 5
Some other physician (specify:________________________) – 6
Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:___________________________) – 10
Can't tell – 1

II. REFERRALS

Beginning with the INDEX STUDY VISIT, review all records from that visit forward in time. Indicate if any of the following referrals were documented in the chart as having been made or recommended, and who made each referral.

Referral	Yes	First date	Who made	Not mentioned
Dementia specialist	1	___/___/___	_____	2
KP Social Medicine	1	___/___/___	_____	2
Alzheimer's Association	1	___/___/___	_____	2
Safe Return™ Program	1	___/___/___	_____	2
Caregiver Resource Center	1	___/___/___	_____	2
Other community service (Specify:______________)	1	___/___/___	_____	2
Other community service (Specify:______________)	1	___/___/___	_____	2
Other community service (Specify:______________)	1	___/___/___	_____	2

Use the following codes for who administered:

Physician who provided care at the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4

Geriatrician – 5
Some other physician (specify:__________________________) – 6
Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:____________________________) – 10
Can't tell – 11

III. ADVANCE DIRECTIVE/DURABLE POWER OF ATTORNEY

Is there a copy of an ADVANCE DIRECTIVE or DURABLE POWER OF ATTORNEY anywhere in the chart?

Yes – 1 Write in the date:____/___/___ ___ Advance Directive____DPA

Who obtained the advance directive/durable power of attorney?
(Write in # from list below)_________then SKIP to Section IV

Physician who provided care at the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4
Geriatrician – 5
Some other physician (specify:______________________) – 6
Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:____________________________) – 10
Can't tell – 11

No – 2 CONTINUE

Beginning with the date of the note identified as the **INDEX STUDY VISIT,** review that note and all subsequent notes for any wording that suggests that there was any discussion of completion of an Advance Directive/ Durable Power of Attorney:

Note found; discussion occurred: patient declined to complete – 1
Note found; discussion occurred: note documents plan, no form found – 2
Note found; no discussion because patient deemed too impaired to complete – 3
No note found anywhere discussing the issue of Advance Directives – 4

Other (specify:____) – 5

Record date of note for 1-3 about:_____/___/___

Physician who provided care at the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4
Geriatrician – 5
Some other physician (specify:________________________) – 6
Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:___________________________) – 10
Can't tell – 11

IV. REPORTING TO DMV

Beginning with the date of the note identified as the **INDEX STUDY VISIT**, review that note and all subsequent notes for the following:

A. Is it recorded in the chart at the INDEX STUDY VISIT that the patient does <u>not</u> currently hold a driver's license?
    Yes – 1   If yes, then skip to Section V
    No – 2   CONTINUE to B

B. Is there a copy of a Confidential Morbidity Report Form (see training packet) in the chart?
    Yes – 1
        If yes, then is the DISEASE BEING REPORTED dementia, Alzheimer's disease, or some other term? (circle all that apply from the list below)

            Yes – 1   If yes, then skip to Section V
            Dementia
            Senile dementia
            Vascular dementia
            Alzheimer's disease
            Memory problems/impairment/loss/forgetfulness
            Cognitive problems/impairment
            Confusion
            Something else: _________________________

            No – 2   CONTINUE to C.

    No – 2 CONTINUE to C.

C. Is there any documentation in the chart at any time after the INDEX STUDY VISIT date that the patient's diagnosis was reported to the Department of Motor Vehicles?

Yes – 1 If yes, please specify what was recorded (write in verbatim):

____

____

Date of first mention of reporting: ___/___/___

Who reported the patient? (fill in a #): ______

Physician who provided care at the index visit – 1
Another primary care physician – 2
Neurologist – 3
Psychiatrist – 4
Geriatrician – 5
Some other physician (specify:_____________________) – 6
Nurse practitioner or physician assistant – 7
Social worker (NOT dementia specialist) – 8
Dementia specialist – 9
Someone else (specify:__________________________) – 10
Can't tell – 11

No – 2

V. DIAGNOSTIC TESTS

Now, re-record here the DATE OF THE INDEX STUDY VISIT (from page 2):

___/___/___

A. Labs

Now turn to the laboratory section of the chart. Beginning with the DATE OF THE INDEX STUDY VISIT, review forward in time from that date for whether any of the following are reported in the labs results section of the medical record:

(circle one number and fill in date, where appropriate)

	Yes	Date first mentioned after INDEX STUDY VISIT	Not mentioned
Calcium	1	___/___/___	2
TSH	1	___/___/___	2
RPR/VDRL/MHATP	1	___/___/___	2
B12/vitamin B12	1	___/___/___	2
CBC	1	___/___/___	2
Electrolytes	1	___/___/___	2
BUN	1	___/___/___	2
Creatinine	1	___/___/___	2
Glucose/random blood sugar	1	___/___/___	2

On the list below, circle the names of all tests listed above for which the response you circled was '2', 'no/not mentioned'. Then, look backwards in the lab section from the index study visit date, and record whether or not this lab was conducted during the two-year period <u>prior</u> to the index visit.

INDEX STUDY VISIT DATE: ___/___/___

INDEX STUDY VISIT DATE MINUS TWO YEARS: ___/___/___

Step 1: Circle the names of those tests having an answer of "Not mentioned" above.

Step 2: Review the lab section for any of the tests you circled below. Look for a lab result between the two dates you have listed above (INDEX STUDY VISIT DATE MINUS TWO YEARS to INDEX STUDY VISIT DATE). Fill in the date, if you find a lab was done. Circle "not mentioned" if **no** test is found during those dates.

Remember, you only need to fill in "date reported" or circle "no/not mentioned" IF you circled the test. That is, you do not need to look for any test for which there is a result in the chart AFTER the INDEX STUDY VISIT DATE.

	Date Reported		
Calcium	___/___/___	OR	No/Not mentioned
TSH or T4 or T3	___/___/___	OR	No/Not mentioned
RPR/VDRL/MHATP (Index date 5 years)	___/___/___	OR	No/Not mentioned
B12/vitamin B12	___/___/___	OR	No/Not mentioned
CBC	___/___/___	OR	No/Not mentioned
Electrolytes	___/___/___	OR	No/Not mentioned
BUN	___/___/___	OR	No/Not mentioned
Creatinine	___/___/___	OR	No/Not mentioned
Glucose/random blood sugar	___/___/___	OR	No/Not mentioned

Now, re-record here the DATE OF THE INDEX STUDY VISIT
(from page 2): ___/___/___

B. Radiology

Now turn to the radiology report section of the chart. Beginning with the DATE OF THE INDEX STUDY VISIT, review forward in item from that date for whether any of the following are reported in the radiology results section of the medical record:

(circle one number and fill in date, where appropriate)

	Yes	Date first mentioned after INDEX STUDY VISIT	Not mentioned
Brain or head CT scan	1	___/___/___	2
Brain MRI scan	1	___/___/___	2

On the list below, circle the names of all tests listed above for which the response you circled was '2', 'no/not mentioned'. Then, look backwards in the radiology section from the index study visit date, and record whether or not this test was conducted during the two-year period prior to the index visit.

INDEX STUDY VISIT DATE: ___/___/___

INDEX STUDY VISIT DATE MINUS TWO YEARS: ___/___/___

Step 1: Circle the names of those tests having an answer of "Not mentioned" above.

Step 2: Review the radiology section for any of the tests you circled below. Look for a report between the two dates you have listed above (INDEX SUTDY VISIT DATE MINUS TWO YEARS to INDEX STUDY VISIT DATE). Fill in the date, if you find a test was done. Circle "not mentioned" if **no** test is found during those dates.

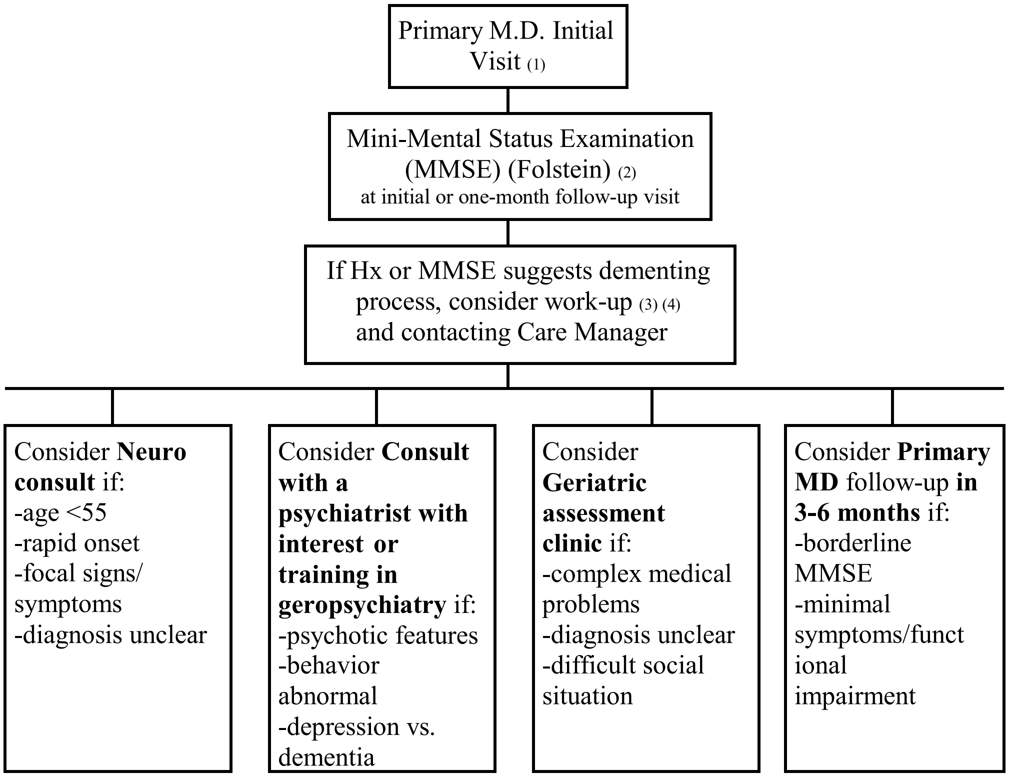
Remember, you only need to fill in "date reported" or circle "no/not mentioned" IF you circled the test. That is, you do not need to look for any test for which there is a result in the chart AFTER the INDEX STUDY VISIT DATE.

	Date Reported		
Brain or head CT scan	___/___/___	OR	No/Not mentioned
Brain MRI scan	___/___/___	OR	No/Not mentioned

Appendix: 5

Kaiser Diagnostic Algorithm

June, 1997



1. Patient seen for specific complaint of memory problems or for routine or complete physical exam and is noted to be at risk (*e.g., unkempt, behavior disturbance, delirious, impairment of ADLs, IADLs, etc.)*. Patient's family notes problems with behavior or cognition.
2. Folstein Mini-Mental Status Examination: 30 point scale; consider <25 abnormal. See copy of MMSE
3. Work-up should include the following core tests: CBC, lytes, BUN, Cr, RBS, calcium, TSH, RPR, MHATP, B12, Neuroimaging: heat CT (consider MRI)
4. Consider the following if clinical presentation suggests: LFTs, Folate, ISR, HIV, tox screen, 24-hour urine test for heavy metals, UA, serum copper, CXR. Consider DNA testing for Huntington's Disease if suspicion warrants.

References

Folstein, M.D., Folstein, S.E., McHugh, P.R.: *Mini-Mental State: A Practical Method for Grading the Cognitive State of Patients for the Clinician,* Journal of Psychiatric Research, 12:189-198, Pergamon Press, 1975

See also:

Crum, R.M., et al, *Population Based Norms for the MMSE, etc.*, JAMA 269:2389-2391, 1993

Appendix: 5

REFER TO CARE MANAGER FOR:

- Social / caregiver support groups
- Alzheimer's Association
- Area Agency on Aging
- Advance Directives
- Driving issues / DMV
- Polypharmacy
- Financial assessment
- Conservatorship

24-hour physician back-up provided by
ON-CALL CONTINUING CARE PHYSICIAN

This Guideline was developed by:

Richard Della Penna, M.D.	Continuing Care, SDMC Regional Coordinator, Elder Care
Eli Friedler, M.D.	Geropsychiatry, LAMC
Susan McPherson, Ph.D.	Alzheimer's Association Consultant
Dan Plotkin, M.D.	Geriatric Psychiatrist, Gateway Hospital Alzheimer's Association Consultant
Jay Rosenberg, M.D.	Neurology, SDMC
Milton Sakamoto, M.D.	Continuing Care, Metro MSA
Ralph Yep, M.D.	Continuing Care, Metro MSA

Appendix: 6

California Guideline for Alzheimer's Disease Management

GUIDELINES FOR ALZHEIMER'S DISEASE MANAGEMENT

ASSESSMENT

- Conduct and document an assessment of:
  - Daily function, including feeding, bathing, dressing, mobility, toileting, continence and ability to manage finances and medications
  - Cognitive status using a reliable and valid instrument (e.g. the MMSE)
  - Other medical conditions
  - Behavioral problems, psychotic symptoms, or depression
- Reassessment should occur every 6 months or more frequently with any sudden decline or behavioral change.
- Identify the primary caregiver and assess the adequacy of family and other support systems.
- Assess the patient's decision-making capacity and whether a surrogate has been identified.
- Caregiver's needs and risks should be assessed and reassessed on a regular basis.
- Assess the patient's and family's culture, values, primary language, literacy level and decision-making process.

TREATMENT

- Develop and implement an ongoing treatment plan with defined goals. Include:
  - Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
  - Appropriate treatment of medical conditions
  - Referral to adult day services for appropriate structured activities, such as exercise and recreation
- Treat behavioral problems and mood disorders using:
  - Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.
  - Referral to social service agencies or support organizations, including the Alzheimer's Association's Safe Return Program for people who may wander
  - Medications, if clinically indicated and non-pharmalogic approaches prove unsuccessful

PATIENT & CAREGIVER EDUCATION & SUPPORT

- Discuss the diagnosis, progression, treatment choices and goals of AD care with the patient and family in a manner consistent with their values, preferences and the patient's abilities.
- Refer to support organizations for educational materials on community resources, support groups, legal and financial issues, respite care, future care needs and options. Organizations include:

Alzheimer's Association	1-800-660-1993	www.caalz.org
Family Caregiver Alliance & Caregiver Resource Centers	1-800-445-8106	www.caregiver.org

or your own social service department

- Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.
- Discuss the intensity of care and end of life care decisions with the person with AD and the family.

REPORTING REQUIREMENTS

- Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment) to Adult Protective Services or your local police department, as required by law (California Welfare Institution Code, Section 15630).

- Driving: Report the diagnosis of AD to your local health officer in accordance with California law (Sections 2800 - 2812 of Title 17, California Code of Regulations).

Prepared by the California Workgroup on Guidelines for Alzheimer's Disease Management. Supported by the California Department of Health Services and the Alzheimer's Association, Los Angeles, under Contract No. 00-91317, the federal Health Resources and Services Administration's Bureau of Primary Health Care, and the Administration on Aging.

California Version-R 010102 ©2002

Alzheimer's Disease and Its Impact:

As the population ages, the incidence of Alzheimer's disease (AD) becomes greater. One in ten persons over 65 and nearly half of those over 85 have AD. Currently, 4 million persons in the U.S. have a diagnosis of Alzheimer's disease. A person with AD can live from 3-20 years or more from the onset of symptoms and at some point that person will require 24 hour care including assistance with daily activities such as eating, grooming and toileting. The yearly monetary costs of AD exceed $100 billion in the U.S. The social and emotional toll on caregivers and families is immeasurable. Fortunately, there are effective strategies for management of Alzheimer's disease and related dementias that are covered in this guideline.

About the Guideline:

This document was developed by the California Workgroup on Guidelines for Alzheimer's Disease Management through a collaborative effort of healthcare providers, consumers, academicians, professional and volunteer organizations, and purchasers of health care. A companion document is available which explains each of the areas of the Guideline in greater detail. To download a copy of the Guideline and related information, visit the California Council of the Alzheimer's Association website at www.caalz.org.

Purpose of the Guideline:

This clinical practice guideline represents core care recommendations for AD management that are clear, measurable, practical and based on scientific evidence, as available. The California Workgroup has provided its expert opinion when research evidence has been unavailable or when research results were inconsistent. The intended audience of this guideline is primary care practitioners, including physicians, nurse practitioners, physician assistants, social workers, and other professionals providing primary care to AD patients and their families.

***Note: Many of the activities mentioned in the Guideline do not require a physician and can be done by other members of the treatment team.**

Guidelines for the Diagnosis of Alzheimer's Disease:

The guideline suggests care management principles and is based on the assumption that a proper diagnosis of Alzheimer's disease has been made using reliable and valid diagnostic techniques. For organizations seeking guidance in developing or adopting a diagnostic guideline for Alzheimer's disease, a useful reference is the *Clinical Practice Guideline on Early Alzheimer's Disease: Recognition and Assessment* developed by the Agency for Health Care Research and Quality. To obtain a copy, contact the AHRQ Publications Clearinghouse at 1-800-358-9295 or visit them on the web at www.ahrq.gov. Additional guidelines and references are available from the National Guideline Clearinghouse at www.guidelines.gov.

Appendix: 7

Professional Training Programs: Dementia Care Project

Professional Education

Internal Medicine and Family Practice

- Diagnosis and Management of Persons with Dementia
  - Overview of dementia
  - Use of mental status examination in diagnostic process
  - KP Diagnostic Guideline
  - Introduction to the management of persons with dementia
  - Caregiver insights
  - Role of project's new care managers
- Behavior Management and Legal Issues
  - Behavior Management
    - Types of behavioral symptoms
    - Review of pharmacological and non-pharmacological interventions
    - Determining the most appropriate intervention
    - Case study
  - Legal Issues
    - Elder abuse
    - Driving
      - Advance Directives
    - Long-term planning and Medi-Cal
- Competency, Capacity and Co-Morbidity (3 part workshop)
  - Panel discussion about assessing competency and capacity in cognitively impaired persons with Kaiser Permanente geropsychiatrist, elder law attorney, Kaiser Permanente attorney
  - Discussion with Ralph Yep, MD about medical conditions that can cause or exacerbate dementia and the benefit of overall medical management of co-morbid conditions
  - Administering the Mini Mental State Exam – hands on teaching by Mark Pippenger, MD

Emergency Department Physicians

- Recognizing and Managing Cognitive Impairment in the Emergency Department
  - Warning signs
  - Safe Return™

    - Managing catastrophic reactions
    - Hospitalization – when to hospitalize

Nursing Staff (All Departments -1 hour segment of a larger 2 day training to renew nursing competencies)

- Dementia Care
    - Overview of dementia
    - Warning signs and recognition
    - KP Diagnostic Guideline
    - Role of project's new care managers

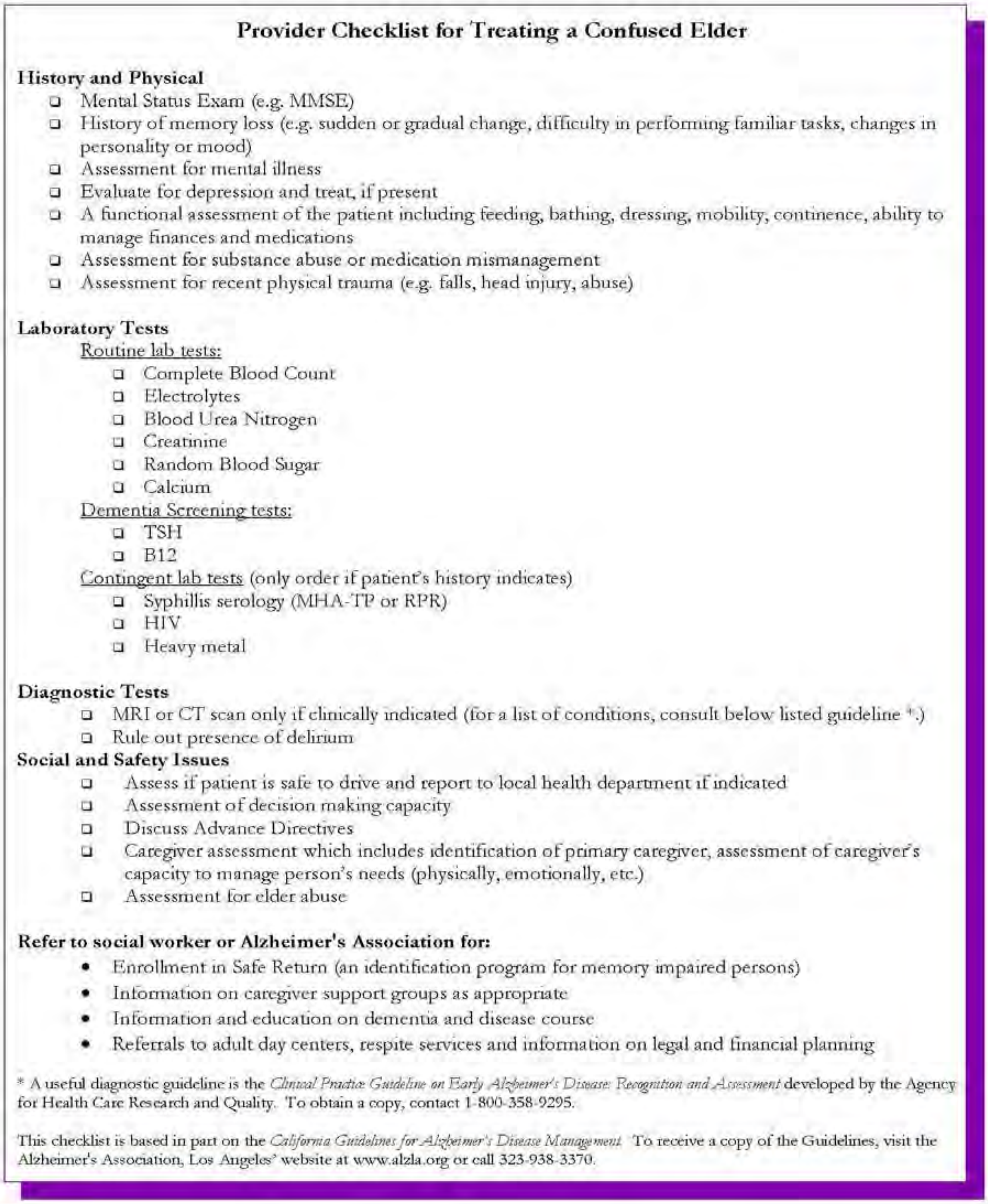
Social Work (3 different in-service trainings for social workers in all departments)

- Dementia Care
    - Overview of dementia
    - Warning signs and recognition
    - KP Diagnostic Guidelines
    - Role of project's new care manager
- Ethical and Legal Issues
    - Capacity
    - Elder abuse
    - Driving
    - End of life
- It Takes More than a Mini Mental
    - Definitions
    - Assessing capacity and competency
    - Preserving autonomy while managing issues of safety
    - Case study

Note: All of the above trainings occurred at both Kaiser Permanente medical centers.

Appendix: 8

Provider Checklist



Provider Checklist for Treating a Confused Elder

History and Physical

- ☐ Mental Status Exam (e.g. MMSE)
- ☐ History of memory loss (e.g. sudden or gradual change, difficulty in performing familiar tasks, changes in personality or mood)
- ☐ Assessment for mental illness
- ☐ Evaluate for depression and treat, if present
- ☐ A functional assessment of the patient including feeding, bathing, dressing, mobility, continence, ability to manage finances and medications
- ☐ Assessment for substance abuse or medication mismanagement
- ☐ Assessment for recent physical trauma (e.g. falls, head injury, abuse)

Laboratory Tests

<u>Routine lab tests:</u>
- ☐ Complete Blood Count
- ☐ Electrolytes
- ☐ Blood Urea Nitrogen
- ☐ Creatinine
- ☐ Random Blood Sugar
- ☐ Calcium

<u>Dementia Screening tests:</u>
- ☐ TSH
- ☐ B12

<u>Contingent lab tests</u> (only order if patient's history indicates)
- ☐ Syphillis serology (MHA-TP or RPR)
- ☐ HIV
- ☐ Heavy metal

Diagnostic Tests

- ☐ MRI or CT scan only if clinically indicated (for a list of conditions, consult below listed guideline *.)
- ☐ Rule out presence of delirium

Social and Safety Issues

- ☐ Assess if patient is safe to drive and report to local health department if indicated
- ☐ Assessment of decision making capacity
- ☐ Discuss Advance Directives
- ☐ Caregiver assessment which includes identification of primary caregiver, assessment of caregiver's capacity to manage person's needs (physically, emotionally, etc.)
- ☐ Assessment for elder abuse

Refer to social worker or Alzheimer's Association for:

- Enrollment in Safe Return (an identification program for memory impaired persons)
- Information on caregiver support groups as appropriate
- Information and education on dementia and disease course
- Referrals to adult day centers, respite services and information on legal and financial planning

* A useful diagnostic guideline is the *Clinical Practice Guideline on Early Alzheimer's Disease: Recognition and Assessment* developed by the Agency for Health Care Research and Quality. To obtain a copy, contact 1-800-358-9295.

This checklist is based in part on the *California Guidelines for Alzheimer's Disease Management*. To receive a copy of the Guidelines, visit the Alzheimer's Association, Los Angeles' website at www.alzla.org or call 323-938-3370.

Appendix: 9

Sample Job Description

Care Manager/Dementia Specialist

The care manager in this position is a professional who is specially trained in dementia care and understands the unique needs of persons with dementia and their families. The care manager has to be knowledgeable of the systems the patient will encounter and have the skills to navigate them. Because family members and other persons close to the client play a significant role in daily care activities, it is critical that the care manager recognizes the value of their involvement in all aspects of care planning and delivery. The care manager must be skilled in coordination of services and be an excellent communicator when working with other health care providers to ensure successful outcome.

Major Duties:

- Provide education and support to persons with dementia and family members by sharing educational materials, hosting dementia care workshops and facilitating support groups
- Monitor and intervene on issues of system delivery and responsiveness to bring about good care management
- Facilitate care by connecting the patient with services within [enter name of managed care organization] and in the broader community
- Collaborate with physicians in implementation of diagnostic and treatment guidelines
- Provide both formal and informal education about dementia to providers and other staff
- Consult with families on care issues and management of difficult situations
- Conduct comprehensive in-home assessment, develop and implement treatment plans
- Function as integral part of interdisciplinary team
- Effectively counsel patients and/or family members on issues related to chronic and/or deteriorating illnesses and death

Minimum Qualifications:

- R.N., M.S.N., M.S.W. Valid and current license in the state
- A minimum of 3 years in a public or private agency providing direct service
- Experience in case management with older adults
- Knowledge of assessment, treatment, discharge and aftercare planning process and guidelines as defined by JCAHO standards and other state and professional requirements
- Ability to work effectively and cooperatively as a member of the interdisciplinary team
- Excellent written and oral communication skills
- Ability to work across organizational boundaries
- Demonstrated experience and commitment to culturally competent practice
- Must be self-starter with ability to work independently and prioritize multiple tasks

Interested Applicants Apply to:
[Provide address and phone of contact person in personnel/H.R.]

Application Deadline: [date of deadline]

Salary: [Include salary range or specific amount and information on benefits if available]

Suggested Websites & Other Sources of Referral

Alzheimer's Association, Los Angeles, Riverside, San Bernardino counties mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to re- duce the risk of dementia through the promotion of brain health. www.alzla.org

Kaiser Permanente mission is to provide quality care for members and their families, and to contribute to the well-being of the community. www.kaiserpermanente.org

Kaiser Permanente's Care Management Institute (CMI) Created in 1997, CMI draws on the extensive clinical experience, research, and data of an integrated health care system with more than 8 million members — as well as from research centers internationally. CMI synthesizes knowledge about the best clinical approaches in order to create, implement, and evaluate effective and efficient care management programs. www.kpcmi.org

California Guidelines for Alzheimer's Disease Management were developed by the California Workgroup on Alzheimer's Disease Management through a collaborative effort of healthcare providers, consumers, academicians, professional and volunteer organizations and purchasers of health care. The Guidelines present a practical management approach encompassing medical, pharmacological, and psychosocial interventions based on evidence from the literature and expert consensus. www.alzgla.org/

Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia - A publication of the Chronic Care Networks for Alzheimer's Disease initiative. Unless otherwise noted, the tools and information in this publication were developed by the Care Management Advisory Group and the Education and Support Advisory Group of the Chronic Care Networks for Alzheimer's Disease (CCN/AD) initiative. Duplication for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer's Association as the source. www.alz.org/Health/coordinatedcare.asp

Appendix: 10

National Center on Elder Abuse (NCEA) mission is to promote understanding, knowledge sharing, and action on elder abuse, neglect, and exploitation. The NCEA is the result of a partnership with the American Bar Association (ABA) Commission on Law and Aging, Clearinghouse on Abuse and Neglect of the Elderly at the University of Delaware, National Adult Protective Services Association, and the National Committee for the Prevention of Elder Abuse. It is a resource for health and legal professionals, pol- icy makers and researchers and is administered under the auspices of the National Association of State Units on Aging. http://www.elderabusecenter.org/default.cfm?p=basics.cfm

Appendix: 11

Home Assessment Tool

Circle: Home/Apartment/Senior Residence/Assisted Living/Nursing Home/ Other

Lives alone? Y/N

Who does patient live with? ____

How long has patient lived there?_____years

Does patient feel safe at current place of residence? Y/N

Explain: ____

How many floors? _____ What entrance is used most often? ____________

Are there stairs? Y/N How many?________Do the stairs have railings? Y/N

On what floor is the bedroom?______Bathroom?______Kitchen?______

Is there anything in the home that may cause a fall? Check all that apply:

___loose flooring _scatter rugs ___electrical cords ___clutter

___storage space too high or low ___adequate lighting

___doors open and close easily_____bathroom safety ___kitchen safety

___other Explain: ____

Are there adequate cooking facilities? Y/N

Is there adequate food storage space? Y/N Refrigeration? Y/N

Is there adequate heating/cooling/ventilation? Y/N

Are there any assistive devices or durable medical equipment needs?

Is the home in good repair? Y/N

Explain: ____

Is there evidence of relationships/activities/interests? (such as pictures, handicrafts, calendars, awards, art work, musical instruments etc.) Y/N

Explain: ____

Safety/Security:

How are medications stored and dispensed? __________________________

____

Is wandering an issue? Y/N Are there any security devices or systems in place? Y/N

Explain: ____

Is there a car present? Y/N Is patient safe to drive? Y/N Does patient drive? Y/N

Explain: ____

Are there any guns in the home? Y/N

Explain: ____

Are there smoke detectors? Y/N

Is there a disaster preparedness plan? Y/N Explain: ____________________

Can patient use the phone? Y/N Explain: ______________________________

Services within walking distance (4-6 blocks) – check all that apply:

___Grocery Store_____Drug Store ___Post Office_____Bank

___Beauty Shop____Barber Shop_____Laundromat_____Restaurants

___Fast Food_____Senior Center

Is there access to public transportation? Y/N

Appendix: 12

The SOAPE Format for Progress Notes

Subjective data: Client's own statement about the problem, his/her feelings or moods, activities, plans and concerns. In addition, include client's expectations of treatment. Such information may also come from family members and others involved.

In the initial note, information about symptoms, complaints, onset and duration of the problem, the effect on client's lifestyle, and the client's response to the referral are relevant. In subsequent entries, information on the client's perception of progress in the resolving of problems and altered expectations of treatment should be included.

Objective data: Observable data from reliable sources including primary care physician and others on the care team. May include diagnostic findings and verified information from social worker's observations regarding mood, dress, flow of ideas, bodily reactions, symptoms and verbal behavior.

Assessment: Evaluative statement of the subjective objective data, including the worker's analysis of the problem. An assessment of the client's ability to work (expectations, motivation, ambivalence and ability to use help) should be indicated. Relevant factors might include habits, coping patterns, role conflicts, symptoms, relationships, attitudes and inner conflicts.

Plan: Care manager's plan of action that includes gathering more data, a treatment plan for managing any safety issues or crisis, interventions to improve adaptive functioning, and referrals for service.

Education of client: Information given to the client to help understand and/or manage the dementia diagnosis and other issues.

Case Presentation Outline/Guide

I. Identifying Information of patient and primary caregiver(s)
  a. Age
  b. Gender
  c. Marital status
  d. Ethnicity
  e. Economic status
  f. Employment situation if applicable

II. Presenting Problem
  a. Source of referral and reason given for referral
  b. Patient's understanding of problem including causes, duration, frequency

III. Psychosocial Assessment
  a. Current medical problems/diagnoses
  b. Ability to manage ADL's and IADL's
  c. Transportation needs
  d. Communication ability
  e. Cognitive ability
  f. Living situation/Home environment
  g. Support system
  h. Personal and family history
  i. Patient/Caregiver coping style and problem solving ability
  j. Capacity for insight
  k. Elder abuse risk assessment
  l. Substance abuse and medication misuse risk assessment
  m. Safety Issues
  n. Legal and financial issues
  o. Involvement with other community aging service providers

IV. Treatment Plan
  a. Define the short-term and long-term goals
  b. Interventions for safety issues and plan to stabilize any crisis
  c. Interventions to improve adaptive functioning
  d. Referrals for services within MCO
  e. Community referrals
  f. Explore patient/caregiver feelings and expectations regarding referrals
  g. Follow-up

V. Your Evaluation of Your Case
  a. What has been your most successful intervention and why?
  b. What has not worked or you think you would do differently?

VI. Questions or Concerns for Discussion (have these prepared ahead of time)

Appendix: 14

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

Project Description

Partnering Organizations

In the six CCN/AD sites, Alzheimer's Association chapters partnered with managed care organizations, health care systems, and other local agencies. The six sites and partnering organizations at each site were:

Denver
Pacificare of Colorado
Centura Health
Alzheimer's Association Chapter

Philadelphia
Temple University Health System
Abramson Center for Jewish Life
Alzheimer's Association Chapter

Minneapolis/St. Paul
UCare Minnesota
HealthEast
Fairview Health Services
Alzheimer's Association Chapter

Troy/Albany, NY
Capital District Physicians Health Plan
Northeast Health/The Eddy
Alzheimer's Association Chapter

San Francisco
Kaiser Permanente
Brown and Toland Medical Group
Goldman Institute on Aging
Alzheimer's Association Chapter

Upstate New York
VA Network (VISN 2)
Four Alzheimer's Association Chapters

Problems Addressed by the Project:

CCN/AD was intended to address four major problems in existing dementia care: 1) inadequate identification of possible dementia; 2) inadequate diagnostic assessments; 3) lack of coordinated medical care and supportive services; and 4) lack of information and support for family caregivers.

Project Goal:

The CCN/AD Leadership Committee developed the following project goal: "To demonstrate that networks of integrated care, support, and education can be developed to incorporate the range of services needed by people with dementia and can be sustained under managed care financing and that these networks result in better health outcomes and greater customer satisfaction."

The Leadership Committee also identified objectives under the goal, for example, to recognize dementia earlier in the disease process, and guiding principles, for example, that the project would provide a "dual track of support" for both the person with dementia and his or her family.

Model of Care:

The CCN/AD model of care was created over an 18-month period by two advisory groups. The Care Management Advisory Group, which consisted of physicians, other health care and social service professionals, administrators, and chapter staff from the partnering organizations at each site, created the first three components. The Education and Support Advisory Group, which consisted primarily of chapter staff from each CCN/AD site, created the fourth component. Thus, the model was created by the people who would eventually implement it. The four components of the model are:

1. Identification of possible dementia**:** the model includes three lists of signs and symptoms that indicate a need for a dementia assessment; the lists are to be used for staff training. It also includes a brief family questionnaire to elicit family members' perceptions of a relative's memory and other problems that may also indicate a need for a dementia assessment.
2. Initial dementia assessment: the model includes procedures and instruments for an initial assessment, including those to be used for every person, those to be used unless there is a good reason not to do them, and those to be used only if there is a good reason to do them.
3. Care management blueprints: the model lists desired outcomes of care, areas for assessment, and possible interventions in six domains: caregiver support, patient nutrition, patient functioning, psychosocial care, medical treatment, and advance directives planning. Sites used this information to develop care protocols.
4. Information and support for family caregivers**:** the model includes grids with objectives to be achieved for family caregivers in six phases of caregiving. The grids were used at each CCN/AD site to identify materials and programs to achieve the objectives.

The CCN/AD model of care can be seen and downloaded from the Alzheimer's Association website, www.alz.org/Resources/FactSheets/CCN-AD03.pdf

Training:

All CCN/AD sites provided extensive training for staff of the partnering organizations at their site. Training was provided in many locations and formats: e.g., formal group presentations, office visits, grand rounds, one-on-one case-based discussions. Training topics included the CCN/AD model, the partnership, and general information about Alzheimer's/dementia care. Over time, providers in some sites requested additional formal training on specific topics, e.g., managing difficult behaviors.

System of Care and the Role of Care Managers:

People with possible dementia were identified in the health care systems at each site. They were enrolled in CCN/AD when they had been assessed as having dementia and they and/or their family caregivers had provided consent. Each site developed procedures for coordinating health care and chapter services for enrollees, and information and support for family caregivers. All the sites had one or more care managers who were employed by the health care system, the chapter, and/or another partnering organization. On- going care coordination occurred through calls, e-mails, and joint care plans at some sites.

Evaluation:

An extensive evaluation of CCN/AD was conducted by a team of researchers from the Margaret Blenkner Research Institute in Cleveland, Professional Evaluation Services, Inc. in Minneapolis, MN, and Professional Data Systems, Inc., in Minneapolis, MN. The evaluation used four main approaches:

1. collection of data on enrollee/family characteristics and use of health care and chapter services;
2. site visits and structured telephone interviews with site-level staff and providers;
3. mailed surveys of participating health care and social service professionals and chapter staff; and
4. telephone interviews of family caregivers and people with dementia who were able to participate.

References:

Coon, DW, Williams MP, Moore RJ, Edgerly ES, Steinback CM, Roth SP, Phillips CL, Hanh N, Dowling GA, Dunning EA, and Feigenbaum LZ. "The Northern California Chronic Care Network for Dementia." *Journal* *of the American Geriatrics Society* 52(1):150-156, 2004.

Maslow K, and Selstad J. “Chronic Care Networks for Alzheimer’s Disease: Approaches for Involving and Supporting Family Caregivers in an Innovative Model of Dementia Care.” *Alzheimer’s Care Quarterly.* 2(1):33- 46, 2001.

Maslow K, Skalny MA, Looman W, McCarthy K, Bass D, and Striano J. *Partners in Dementia Care: Final Report on an Innovative Partnership between Veterans Integrated Service Network 2 (VISN 2) & Four Up-state New York Alzheimer’s Association Chapters*, April 2005, available at: www1.va.gov/geriatricsshg/docs/PartnersDementiaCareFinalRpt1.pdf

Appendix: 15

Cleveland Alzheimer's Managed Care Demonstration

Project Description

Partnering Organizations:

The Cleveland Area Alzheimer's Association Chapter partnered with Kaiser Permanente of Ohio, a large staff model HMO.

Problems Addressed by the Project:

People with dementia and their families generally do not receive enough information and support from health care professionals. Insufficient information is provided about dementia symptoms, diagnosis, available treatments, supportive services, and strategies to manage symptoms and care. Lack of this information and supportive services can result in crisis-driven emergency room visits and hospitalizations for the person with dementia and care-related strain, depression, and other negative psychosocial outcomes for the person and his or her family.

Project Goal:

The project was a research study to test the effects of chapter care consultation on use of hospital, emergency room, and other health care services and psychosocial outcomes for people with dementia and their families. The project's long-term objective was to use the study findings to convince Kai- ser and other managed care organizations and health care systems that chap- ter care consultation is a valuable service and that they should pay for this service for their enrollees and patients with dementia.

Model of Care:

For the research study, Kaiser identified enrollees with a diagnosis of dementia or a symptom code for memory loss in their medical record. These enrollees and their family caregivers were interviewed by Benjamin Rose, the project's research team, and then randomly assigned to the treatment or control group. Enrollees in the control group received no special services from either Kaiser or the chapter.

Contact information for enrollees in the treatment group was given to the chapter, and chapter care consultants initiated calls to the enrollees and/or

their family caregivers. The care consultants offered individualized assistance to identify problems and various kinds of help to address the problems. They also worked to expand and strengthen the enrollees' informal caregiving systems. They continued to work with the enrollees and family caregivers, as needed and desired, over a one-year period. The frequency and intensity of contacts between the care consultants, enrollees, and family caregivers varied, but on average, care consultants had ten direct communications with enrollees and/or their family caregivers in a year.

Care consultants taught families how to use their healthcare providers more effectively by identifying and articulating their questions. They helped families keep journals to provide more information about when a challenging behavior occurred and strategies that they tried. This coaching enabled families to have more descriptive data for physicians to consider when discussing these issues. The care consultants did not interact directly with Kaiser physicians or case managers, except very infrequently when an urgent medical problem was identified.

Training:

The chapter care consultants trained a few volunteers who contacted the treatment group enrollees and their family caregivers at regular intervals to monitor their status after it had been determined that the enrollees and family caregivers had no priority issues to address. These volunteers completed a follow-up form and would alert the care consultants if new issues developed that warranted their involvement.

System of care and the role of care managers:

Care consultation was the central intervention in this project. As provided by chapter staff for treatment group enrollees and their family caregivers, it was a flexible, telephone-based process in which a chapter care consultant conducted an assessment and then worked with the enrollee and/or family caregiver to create an individualized action plan. The assessment identified priority concerns/issues, short-term goals, and strengths of their family support system. The action plan identified specific tasks to be completed, assigned each tack to the enrollee, a family caregiver, a chapter staff member or a volunteer, and set a time frame for completion of the task. The purpose of this process was to identify strengths and resources in the person, family, chapter, and community to help the person and family manage and cope with challenging issues. Follow-up calls were scheduled to monitor progress and add new tasks, as needed. Enrollees and their family caregivers were encouraged to use available chapter services, such as education and

training programs, support groups, and a respite reimbursement program. They were also referred to other community agencies and public organizations for services, as needed.

Evaluation:

The project evaluation was conducted by a research team from the Margaret Blenkner Research Institute at Benjamin Rose in Cleveland, OH. Evaluation data came from telephone interviews with the family caregivers and enrollees who were able to participate in an interview, Kaiser medical records, and chapter administrative reports. The researchers compared treatment and control group outcomes with respect to:

1. enrollees' use of Kaiser hospital, emergency room, physician, and case management services;
2. enrollees' and family caregivers' satisfaction with Kaiser;
3. enrollees' feelings of depression, embarrassment, isolation, difficulty coping with their memory problems, and relationship strain with their family caregiver; and
4. family caregivers' feelings of depression, role captivity, and relationship strain with their relative with dementia.

References:

Bass DM, Clark PA, Looman WJ, McCarthy CA, and Eckert S. "The Cleveland Alzheimer's Managed Care Demonstration: Outcomes After 12 Months of Implementation," *Gerontologist.* 43(1):73-85, 2003.

Clark PA, Bass DM, Looman WJ, McCarthy CA, and Eckert S. "Outcomes for Patients with Dementia from the Cleveland Alzheimer's Managed Care Demonstration." *Aging and Mental Health.* 8(1):40-51, 2004.

Appendix: 16

American Journal of Managed Care Article

Interventions to Improve Quality of Care: The Kaiser Permanente-Alzheimer's Association Dementia Care Project

Authors:
Debra L.Cherry, Ph.D.
Associate Executive Director
Alzheimer's Association of
Los Angeles
Barbara G. Vickrey, M.D., M.P.H.
Associate Professor, Department
of Neurology
U.C.L.A. Alzheimer's Disease Center
Lenore Schwankovsky, Ph.D.
Researcher
Kaiser Permanente, Southern California Region
Elizabeth Heck, LCSW
Director, Quality Initiatives
Alzheimer's Association
Michelle Plauché, M.A.
Associate Director, Community
Education
Alzheimer's Association of Los
Angeles
Ralph Yep, M.D.
Continuing Care Physician-in-
Charge
Kaiser Permanente, Metropolitan
Los Angeles Region

Cherry DL, Heck E, Plauché M, Schwankovsky L, Vickrey BG, Yep R. Interventions to Improve Quality of Care: The Kaiser Permanente-Alzheimer's Association Dementia Care Project. *American Journal of Managed Care.* 2004; 10(8): 553-60

ABSTRACT

Objective: To improve quality of dementia care in a Kaiser Permanente service area through rigorous dissemination of practice guidelines and social worker support to physicians and patients.

Study Design: The study employed a pre-post design with practice behavior change assessed by medical record review, and provider and caregiver satisfaction with care assessed by surveys.

Methods: A diagnostic and later a management guideline were adopted for use by Kaiser physicians in Metropolitan Los Angeles. Physicians received training based on the guidelines and social workers provided ancillary support. Eighty-three community-dwelling dementia patients and their caregivers were referred to the project by primary care physicians, then assessed and followed by social workers. Data were abstracted from medical records to assess whether these interventions led to improved quality of care as indicated by adherence to key care processes derived from the adopted dementia guidelines. Chi-squares and t-tests were applied to compare guideline adherence and satisfaction rates before and after the interventions.

Results: Compared to baseline, higher rates of provider and caregiver satisfaction with Kaiser's system of dementia care were found at the post-intervention follow-up. There were also significantly higher rates of adherence to several practice guideline-based quality measures: assessment of cognitive status; referrals to the Alzheimer's Association; and assessments of activities of daily living, decision-making capacity, depression and wandering risk.

Conclusions: Quality of primary care for people with dementia can be improved through guideline implementation with social work care management support.

Key Phrases: dementia care in managed care, quality of dementia care

Appendix: 16

Introduction

Health care organizations are challenged by the care of the growing number of older adults with chronic health conditions. Dementing diseases, such as Alzheimer's disease, vascular dementia, and other associated disorders, present particular challenges because there are strong social and behavioral components to disease management. Physicians play a central role in assessment, diagnosis and treatment, but much of management for non-institutionalized individuals is done by families with the support of social work care managers and community resource organizations. Furthermore, primary care physicians are daily faced with a broad range of disorders and are challenged by dementia patients, who may compensate for cognitive losses with retained social skills during the brief office visit.

Research suggests that Alzheimer's disease is neither well recognized nor systematically diagnosed (Boise, et al, 1999; Callahan, et al, 1995; Fortinsky & Wasson, 1997). According to Boise and colleagues (1999), physicians diagnose as few as 50% of dementia cases. Focus groups of primary care physicians from three geographic areas found significant barriers to the recognition and formal diagnosis of dementia. Physicians reported difficulty in recognizing possible dementia. Many reported that they relied on families to bring the dis- ease to their attention. There was also a prevalent viewpoint that a formal diagnostic evaluation including a comprehensive clinical history and mental status examination, laboratory referrals to rule out treatable conditions, and other procedures, is not always necessary.

Yet, the last ten years has seen approval of several medications effective in delaying progression of Alzheimer's disease, the most common type of dementia in people with mild or moderate cognitive impairment (Doody et al, 2001). Delay in diagnosis also means delay in treatment. Furthermore, people with undiagnosed dementia and their families are less likely to gain access to supportive services that can ameliorate caregiver burden and perhaps delay institutionalization (Mittelman et al, 1996; Zarit et al, 1998).

Clinical practice guidelines have been developed and promoted as tools for improving dementia care (AHCPR, 1996; APA, 1997; Guttman, 1999; Cummings et al, 1999; Maslow et al, 2003). However, often they are not familiar to practitioners and, even when disseminated broadly, they are not implemented uniformly (Fortinski & Wasson, l997; Rosen et al, 2002).

Managed care organizations offer some unique possibilities for quality improvement in dementia care. They provide the communication lines for dissemination of guidelines. Their accreditation is dependent on adoption and implementation of guidelines-based quality improvement projects (O'Kane, 2003). Capitated payments can be used creatively to bring in the services of less expensive professionals that may reduce costs or hold them steady while improving quality. Recognizing the opportunity to improve care for people with dementia in managed care settings, a number of pilot projects have been initiated (Cherry, 1999), one of which was initiated in a large managed care plan in Los Angeles and is described here.

> Two full-time professionals were trained by the Alzheimer's Association through a 24-hour intensive course followed by seven months of mentoring through case conferences. Patients were referred to the social workers by their primary care physicians. The social work care managers provided a range of services in support of physicians including administration of mental status exams, follow-up with families on the psychosocial aspects of care, home visits, intervention with families on behavior management issues, and facilitation of connection to physicians for co-morbid conditions.

They also provided guideline-recommended services for family caregivers including: assessments of patients, linkage to services within Kaiser Permanente and in the community, caregiver support groups, family education, and on-going care management. In order to participate in the *Dementia Care Project*, the person with dementia needed to have a primary care physician in the designated Kaiser Permanente services area, have a guideline-based dementia diagnosis, dwell in the community (not in an institution) and have an involved, non-paid caregiver.

Methodology

Overview of Project and Description of Intervention

In 1995, Kaiser Permanente's Metropolitan Los Angeles Service area entered into a partnership with the Alzheimer's Association of Los Angeles to assess and improve the quality of care provided to people with dementia. The Metropolitan Los Angeles Service Area of Kaiser Permanente serves a densely urban and ethnically diverse region. It includes two major medical centers and several satellite clinics. Based on extrapolated demographic estimates (Evans et al., 1989), there may be up to 5,000 people with dementia served by Kaiser Permanente in this region.

The goal of this Dementia Care Project was to improve the quality of care for people with dementia while increasing provider and consumer satisfaction. The study employed a longitudinal pre/post-intervention design, with evaluation data collected by medical record review, caregiver interview, and provider survey. A consensus-based diagnostic practice guideline was developed by a multidisciplinary panel of Kaiser Permanente practitioners and representatives of the Alzheimer's Association's Medical and Scientific Advisory Board. Neurology, psychiatry, geriatrics, family practice, psychology and social work were all disciplines represented in the development group. This guideline sought to improve consistency in the diagnostic assessments done at Kaiser Permanente in this region. Later, a management guideline was adopted for implementation by the project (Cummings et al, 2002). The components of the Dementia Care Project intervention that were initiated to implement these guidelines were:

- Promotion by Kaiser Permanente's clinical leadership through letters to providers and presentations at meetings.
- Broad dissemination of a laminated pocket version of the diagnostic guideline to all primary care physicians in this service area.
- Annual in-service training for primary care providers that was notable for its inclusion of physician leaders and caregivers as speakers, as well as the participation of a theater troupe that enacted a physician visit and the administration of a mental status examination. The theater troupe was utilized to increase physician empathy for presenting families. It was also assumed that the novelty of this form of teaching would enhance learning.
- Broad dissemination of a provider "tool kit" that contained the two guidelines and a variety of forms and tests of mental status and depression to support physicians as they followed guideline recommendations.

Tables 1 and 2 are outlines of the diagnostic and management guidelines used for the Dementia Care Project.

The Dementia Care Project relied heavily on social work care managers to support this guidelines-based quality initiative. Two full-time professionals were trained by the

Alzheimer's Association through a 24-hour intensive course followed by seven months of mentoring through case conferences. Patients were referred to the social workers by their primary care physicians. The social work care managers provided a range of services in support of physicians including administration of mental status exams, follow-up with families on the psychosocial aspects of care, home visits, intervention with families on behavior management issues and facilitation of connection to physicians for co-morbid conditions. They also provided guideline-recommended services for family caregivers including: assessments of patients, linkage to services within Kaiser Permanente and in the community; caregiver support groups, family education, and, on-going care management.

Sample

In order to participate in the Dementia Care Project, the person with dementia needed to have a primary care physician in the designated Kaiser Permanente service area, have a guidelines-based dementia diagnosis, dwell in the community (not in an institution), and have an involved, non-paid caregiver. Participants also needed to be referred for participation by their primary care physicians. Data were collected on 83 persons with dementia and their caregivers. The dementia patients ranged in age from 63 to 93 years of age (mean=80). They were 52% male and ethnically diverse (55% African American, 21% Caucasian, 3% Latino, 1% Asian, and 19% other or not specified). This ethnic diversity is reflective of the membership of Kaiser Permanente in this geographic region. Initial Folstein Mini-Mental Status Exam scores recorded after the program intervention began (Folstein, 1985) were available for over 90% of patients and ranged from 2 - 29 with a mean of 17. The 83 participating caregivers were 63% spouses, 16% daughters, 11% sons and 10% other. Their mean age was 66. The ethnic breakdown of caregivers was 52% African American, 23% Caucasian, 4% Latino, 4% Asian, 1% Native American and 16% other or not specified.

Study Outcome Variables

The study was primarily focused on improving the quality of care for people with dementia in this targeted region. Indicators of improved quality were drawn from the practice guidelines.

The indicators were:

- Conduct a cognitive assessment with the Folstein Mini-Mental Status Examination (Folstein & Folstein, 1985).
- Obtain laboratory tests (B12, VDRL/RPR, TSH, CBC, and selected blood chemistries).
- Refer to the Alzheimer's Association and to the Safe Return™ Program (for wandering risk) of the Alzheimer's Association.
- Conduct assessments including activities of daily living, decision-making capacity, depression, and wandering risk.

These care processes were selected as study outcomes in part because they were guidelines targeted by the intervention. In addition, they have been identified and used with some frequency in studies of dementia care quality (Chow & MacLean, 2001). It was predicted that each of these practices would increase as a result of project participation.

Kaiser Permanente physicians were surveyed about their diagnostic practices, referral behaviors, perceptions of services provided to patients with dementia, use of educational materials and overall satisfaction with the care of patients with dementia and their families. Satisfaction was assessed with a single question, "How satisfied are you with the treatment and support that Kaiser Permanente provides to patients with dementia and their caregivers?" Similarly, participating caregivers were surveyed regarding their satisfaction with dementia-related services at Kaiser Permanente through a series of questions including:

- "Overall, how satisfied have you been with the dementia-related service you and the patient have received at Kaiser Permanente?"
- "How satisfied have you been with the sensitivity and respect shown to you and the patient at Kaiser Permanente?"
- "Have Kaiser Permanente physicians and staff given you educational materials about dementia?"

Caregivers were also questioned regarding referrals they were given both within the organization and to community services.

Evaluation

The study design and consent forms were reviewed and approved by the Kaiser Permanente Institutional Review Board. All study participants gave informed consent for the study. Three different sources of data were used to assess the impact of the project on provider practices and satisfaction with care:

- Medical records including primary care provider and social work files were abstracted to assess practice of quality indicators derived from the guidelines. Pre- and post-intervention adherence to these guidelines were measured and compared.
- Surveys of primary care physicians, administered before the program was implemented and again three years later, were used to assess self-reported practice behaviors and provider satisfaction with Kaiser Permanente's system of care for people with dementia.
- Interviews were conducted with caregivers at baseline and between three and six months after the program was implemented, to assess change in satisfaction with dementia care.

Medical Record Abstractions

Medical records including social work files were audited to examine the system of care before and after implementation of the Dementia Care Project. Project co-investigators designed and applied a structured chart abstraction form to review the records of the 83 program participants. First, abstractors identified the first mention of dementia or memory problems by medical staff after January 1998, the date in which the Dementia Care Project intervention was initiated. After this index visit, abstractors recorded dates of documentation of the mental status exam, assessments and results of laboratory tests. The abstractors also documented referrals to staff social workers and to outside resources such as the Alzheimer's Association.

Next, a random sample of 42 participants was selected out of the 83 patients, to compare pre- versus post-intervention care. Resource limitations dictated the need for this more restricted sample. Records for this subset of subjects were abstracted over three years prior to the onset of the intervention in January 1998 to evaluate differences in rates of adherence to the guidelines from before to after the intervention.

Pre- and Post-Intervention Physician Surveys

With cover letters from the Chiefs of Internal Medicine and Family Practice, a total of 307 surveys were mailed to primary care providers in the Metropolitan Los Angeles Service Area prior to project implementation; 112 surveys were returned, yielding a 36% response rate. Three years after the project was initiated, 345 surveys were sent to primary care providers in the same Service Area, and 126 were returned for a 37% response rate. (Because identifiers were not linked to the surveys, it was not possible to determine the percentage of follow-up surveys received from the original pre-intervention sample.) As an incentive for participation, physicians who completed the follow-up survey were entered into a lottery for a complementary dinner for two.

Caregiver Interviews

Caregivers of patients with a diagnosis of dementia who were enrolled in the project participated in two structured telephone interviews. The first interview was conducted by a trained interviewer or the social work care manager at the time of enrollment of the caregiver and patient in the Dementia Care Project. A trained interviewer also conducted the post-intervention interview three to six months after the caregiver and patient began receiving services from the social worker. All 83 participating caregivers completed the baseline and post-intervention interviews.

Analysis

Chi-square and t-tests were applied to compare guideline adherence rates prior to the intervention with those after the intervention, based on the medical record reviews and on the physician surveys. Chi-square and t-tests were used to compare caregiver satisfaction with care before and after the project intervention.

Results

Medical Record Abstractions

There was an increase in the reporting of Mini Mental Status Examination scores from 16% prior to the project to 93% after the project (Chi-square $p < .001$) among the subset of 42 pre- and post-intervention charts reviewed. The first post-intervention mental status exam documented in records was most frequently administered by a neurologist (27%), followed by a primary care physician (23%), and then by a social worker (20%). The percentages of patients who obtained each of the following guideline-supported laboratory tests during the post-intervention period were: TSH, 84.3%; RPR/VDRL, 67.5%; B12, 69.9%; CBC, 94.0%; Electrolytes, 84.3%; BUN, 81.9%; Calcium, 75.9%; Creatinine, 81.9%; and, Glucose, 89.2%.

Documentation of referrals to the Alzheimer's Association increased from 3% prior to the project to 76% afterwards (Chi-square $p < .001$), and referrals to the Alzheimer's Association's Safe Return™ Program increased from 0 to 29% (Chi-square $p < .001$). Project social workers made most of the referrals to the Alzheimer's Association (34%), followed in frequency by other staff social workers (19%).

The medical record abstraction identified increased documentation of assessments of activities of daily living (13% pre, 93% post; $p < .001$), decision-making capacity (3% pre, 19% post; $p < .001$), depression (11% pre, 57% post; $p < .001$), and wandering potential (8% pre, 74% post; $p < .001$). Post-intervention, dementia project social workers were most likely to document an assessment of daily living (32%), followed by neurologists (26%). Dementia project social workers also documented 68% of all assessments for wandering risk. However, depression was noted most frequently by primary care physicians (39%), followed by dementia project social workers (20%) and neurologists (17%); physicians more frequently documented an assessment of decision-making capacity, (31% by neurologists, 19% by primary care physicians).

Table 3 presents a summary of documented changes in the selected quality indicators pre- and post-intervention.

Physician Surveys

A comparison of physician responses before and after the intervention commenced showed a trend toward increased satisfaction with the treatment and support Kaiser Permanente provides to people with dementia (t-test, p= .067). Looking specifically at the quality indictors: 49% of physicians in the post-intervention sample reported using a mental status test more frequently than they had prior to the intervention period. Prior to project implementation, 46% of physicians reported that they never obtain laboratory tests as part of a diagnostic assessment of dementia; the percentage of those never obtaining these tests fell to 14% after the intervention (chi-square, p< .001). No significant change in referrals to the Alzheimer's Association were reported: prior to the intervention, 58% of physicians sometimes or always referred their patients to the Alzheimer's Association, while after the intervention, 63% reported making this referral at least some of the time (chi-square, p= .440).

In an effort to assess the specific impact of provider workshops on guideline adherence, responses of physicians who reported attending the initial Dementia Care Workshop used to launch this project in 1997 were compared to those physicians who did not attend the workshop. One hundred and fifty two physicians, primarily in the Family Practice and Internal Medicine fields, attended the workshop; of these, 47 completed and returned the post-intervention physician survey. Workshop attendees who completed the survey were more likely to report that they recall the diagnostic guideline for dementia (p< .015), administer the mental status exam (p< .005), provide educational material to families (p< .001), and refer to the Alzheimer's Association (p< .016), compared to the 77 physicians who responded to the survey and who did not attend the workshop.

Caregiver Interviews

A comparison of structured interviews administered to caregivers before and after participation in the Dementia Care Project indicated improvements in satisfaction and in several quality measures. At baseline, 17% and 51% of caregivers reported being very satisfied and satisfied with dementia care, respectively. In contrast, at follow-up, 40% and 39% of care- givers reported being very satisfied and satisfied with dementia care, respectively (p< .05). Sensitivity and respect shown by Kaiser Permanente staff was rated more satisfactory after participation in the intervention, with 38% very satisfied at baseline as compared to 70% very satisfied three to six months after enrollment (p< .001). Caregivers also indicated that they were more likely to have been given educational material about dementia after the Dementia Care Project was initiated: 36% at baseline compared to 94% post-intervention (p<.001). Post-intervention, a higher proportion of caregivers reported receiving referrals to community services such as home health (2% pre- vs. 13% post-intervention, p< .01); sup- port groups (4% pre- vs. 17% post-intervention, p< .01); and Meals on Wheels (1% pre- vs. 12% post-intervention, p< .01).

Discussion

The Dementia Care Project was a collaborative effort of the Alzheimer's Association and Kaiser Permanente in Los Angeles to improve the quality of care given to people with dementia and their caregivers. Practice guidelines were the framework used to establish quality goals for the system of care. They were reinforced by educational programs and materials for primary care providers and by social workers, who provided care management, sup- port and other services to patients and their families.

Over the course of this project's implementation from 1997-2000, the medical record review and survey data both revealed greater use of mental status exams to screen patients for dementia. The finding that physicians who attended the initial educational workshop reported that they were more likely to administer this exam further supported this outcome. How much this reported increase in use of this test is due to the workshops versus differences in characteristics of physicians who do and do not attend such workshops (in terms of their receptivity to change and their interest in dementia care) cannot be determined from this study. Significantly, however, despite an increase in physician administration of the mental status examination, 20% of project participants were given their initial mental status exam by the dementia project social worker, rather than a physician.

The specially trained social workers were clearly an asset to quality dementia care when quality indicators of *post*-diagnostic management are examined. The chart audits revealed that these professionals were important to guideline implementation. Most frequently they were the professionals who evaluated patients for ability to perform activities of daily living and risk for wandering. Less frequently, they provided assessments of patient depression and decision-making capacity. As was similarly noted by the American Association of Health Plans Foundation (1999), the care managers were the professionals most likely to refer families to the Alzheimer's Association and its Safe Return™ Program as well as to other community organizations for supplementary support services.

The number of study subjects was low (83) relative to the estimated number of people with dementia in the targeted service area (5,000). Limited research funding and a relatively short period of data collection (under 2 years) were contributing factors. In addition, referrals to the study were initially low and grew over time as the primary care providers became more familiar and comfortable with the intervention. Changing physician referral patterns takes time. Following the management guideline promoted through this project, physicians were not expected to make community referrals themselves but rather they were encouraged to refer to a social work care manager. The physicians needed to have confidence in the social workers. Over time, this confidence developed. Using preliminary outcome data from this project as evidence of value, Kaiser Permanente has since established a broad care management system for memory-impaired and frail elders in this service area. Since 2001, there have been over 3,000 inquiries or requests for service from the care management pro- gram and the number of care managers was expanded to the current six to meet this demand. The Senior Care Management Program currently averages 140 inquiries a month, and the care managers carry an active caseload of 210 patients, of whom 75%-80% have dementia.

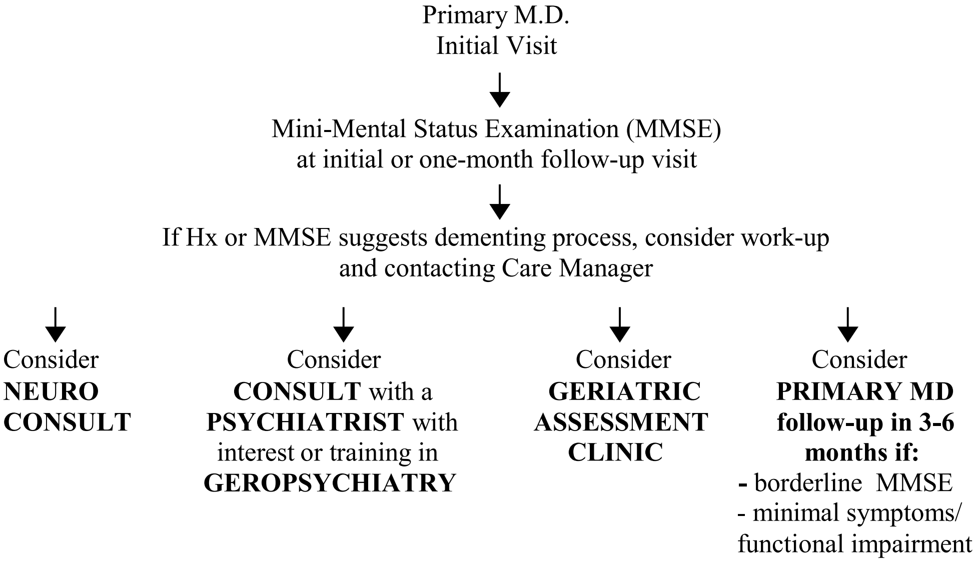
In terms of potential limitations in generalizability, because Kaiser Permanente is a staff model-type managed care organization, some components of this intervention might be more feasible to implement in this type of health care system than in solo or small practices, or in loosely organized practice models. Another limitation to be taken into consideration in interpreting evaluation findings is that our pre-post study design did not include a comparison group that did not receive the intervention. Thus, while this study’s findings suggest that there was an improvement in the quality of dementia care for intervention participants, there are concurrent events that may also have been a factor in study outcomes. For example, cholinesterase inhibitors became more common during the period of the intervention. Both pharmaceutical company interventions and the availability of a treatment may have increased provider attention to these disorders. In addition, dementia is a progressive condition, and changes in the severity of dementia over time certainly occurred in the study sample. Without a control group, it is impossible to assign improvements in care solely to the intervention, as the worsening course of the disease itself could have prompted clinicians to conduct additional assessments and management changes over time. Future studies of refinements to this dementia care intervention applied in other health care settings should include a control group.

Appendix: 16

Based on the experience of developing and implementing the Dementia Care Project, the following recommendations are made to other providers of dementia services:

1. Chronic diseases such as Alzheimer's disease and the other dementias demand a multidisciplinary, bio-psycho-social approach to care. The addition of social workers specially trained in dementia care and partnership with community based organizations like the Alzheimer's Association can help assure that the multi-faceted needs of these patients and their family supporters are met. Primary care providers alone cannot provide the range of care needed by people with dementia.
2. Evidence and consensus-based practice guidelines are useful tools for targeting and improving quality of care in a managed care setting, especially when they are reinforced through opinion leader endorsement, provider-training programs, and provider practice support tools (e.g., tool kits or computer generated prompts), and by bringing in allied medical staff as part of a disease management program.

Table 1: Diagnostic Guidelines for Alzheimer's Association – Kaiser Permanente Metro L.A. Dementia Care Project



Primary M.D.
Initial Visit

Mini-Mental Status Examination (MMSE)
at initial or one-month follow-up visit

If Hx or MMSE suggests dementing process, consider work-up and contacting Care Manager

Consider **NEURO CONSULT**

Consider **CONSULT** with a **PSYCHIATRIST** with interest or training in **GEROPSYCHIATRY**

Consider **GERIATRIC ASSESSMENT CLINIC**

Consider **PRIMARY MD follow-up in 3-6 months if:**
- borderline MMSE
- minimal symptoms/ functional impairment

Table 2: California Alzheimer's Disease Management Guideline
ASSESSMENT

- Conduct and document an assessment of:
  - Daily function, including feeding, bathing, dressing, mobility, toileting, continence and ability to manage finances and medications
  - Cognitive status using a reliable and valid instrument (e.g., the MMSE)
  - Other medical conditions
  - Behavioral problems, psychotic symptoms, or depression
- Reassessment should occur every six months or more frequently with any sudden decline or behavioral change.
- Identify the primary caregiver and assess the adequacy of family and other support systems.
- Assess the patient's decision-making capacity and whether a surrogate has been identified.
- Caregiver's needs and risks should be assessed and reassessed on a regular basis.
- Assess the patient's and family's culture, values, primary language, literacy level and decision-making process.

TREATMENT

- Develop and implement an on-going treatment plan with defined goals. Include:
  - Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
  - Appropriate treatment of medical conditions
  - Referral to adult day services for appropriate structured activities, such as exercise and recreation
- Treat behavioral problems and mood disorders using:
  - Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.
  - Referral to social service agencies or support organizations, including the Alzheimer's Association's Safe Return™ Program for people who may wander
  - Medications, if clinically indicated and non-pharmacologic approaches prove unsuccessful

PATIENT & CAREGIVER EDUCATION & SUPPORT

- Discuss the diagnosis, progression, treatment choices and goals of Alzheimer's disease care with the patient and family in a manner consistent with their values, preferences and the patient's abilities.
- Refer to support organizations for educational materials on community resources, support groups, legal and financial issues, respite care, future care needs and options. Organizations include:

Alzheimer's Association	1-800-272-3900	www.alz.org
Family Caregiver Alliance	1-800-445-8106	www.caregiver.org

(or your own social service department)

- Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.
- Discuss the intensity of care and end-of-life care decisions with the person with AD and the family.

REPORTING REQUIREMENTS

- Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment) to Adult Protective Services, your local police department, or the appropriate state agency, as required by law.
- Driving: Report the diagnosis of AD in accordance with applicable state law.

Table 3: System Changes Reflected in Chart Audit Quality Indicators

Quality Indicator	% Documented Prior to Project N = 42	% Documented After-Project N = 42	Chi-Square p-value
Diagnostic Guideline			
Mini-Mental Status Exam	16%	93%	<. 001
Management Guidelines			
Referral to Alzheimer's Assoc.	3%	76%	<. 001
Referral to Safe Return™ Program	0%	29%	<. 001
Functional Assessments			
Activities of daily living	13%	93%	<. 001
Decision-making capacity	3%	19%	<. 001
Depression	11%	57%	<. 001
Wandering	8%	74%	<. 001

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Alzheimer's | GREATER LOS ANGELES

4221 Wilshire Blvd, Ste 400
Los Angeles, CA 90010
(323) 938-3379

alzgla.org | 844.HELP.ALZ
844 4357 259

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