An Integrated Program for Dementia Evaluation and Care Management

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Alzheimer’s disease (AD) is the leading cause of dementia in the United States (U.S. Congress, 1987). It is estimated that more than 11% of the population older than 65 is affected (Evans et al., 1989, 1992), with annual costs for patient care exceeding $90 billion in the United States alone (U.S. Congress, 1987). As the elderly population continues to expand, the magnitude of the problem posed by AD will increase dramatically in the decades to come (U.S. Bureau of the Census, 1993). Given these facts, management of AD is a critical issue for health care policy as well as quality of life for patients and caregivers. Cost-effective methods for diagnosis and management are clearly needed.

It is vital that families and clinicians recognize the early symptoms of dementia that call for an initial assessment for several reasons (U.S. Department of Health and Human Services, 1996; Larson, 1997). First, some causes of dementia are treatable. An appropriate diagnostic evaluation in these cases can result in dramatic (and, in some cases, immediate) improvements in quality of life. Second, given the prevalence of AD and the resulting care management issues, early diagnosis becomes critical, especially in terms of quality of life for the patient and caregiver. For example, decisions related to legal and financial affairs, driving an automobile, and independent living depend on an accurate diagnosis and appraisal of dementia severity. In addition, timely referral for dementia-related education, caregiver counseling, and social services (e.g., home health, senior transportation, Meals-on-Wheels) is also dependent upon an early diagnosis of AD.

It is widely recognized that the currently available prescription medications for the treatment of AD (i.e., Cognex and Aricept) are only marginally effective, with only a relatively small percentage of patients demonstrating clinically significant improvement. Side effects of available medications and their cost also serve to limit their utility. Psychotropic medications are widely used in severe AD in an attempt to control behavioral disturbances, with response to specific treatments highly variable and side effects prominent in some individuals. As a consequence, management of AD currently must focus on caregiver education, counseling, and community-based support services. Unfortunately, clinicians, families, and policy makers underestimate the positive impact of caregiver support and social services (Larson, 1997; Thomson, 1997).

Studies have shown that a well-organized program of caregiver education and support can improve qual-
ity of life for patients and caregivers. Barusch and Spaid (1991) demonstrated that six training sessions, in the context of weekly caregiver support groups, increased effective coping responses as well as reduced caregiver burden. In terms of caregiver support, Bass, Noelker, and Rechlin (1996) found that the use of community services provided through a case management program reduced depression, health deterioration, and social isolation in elderly caregivers of community-dwelling dementia patients. Mittelman and colleagues (1993, 1995, 1996) conducted a 42-month longitudinal study comparing routine caregiver support to a comprehensive program that included six individual and family counseling sessions, weekly support group participation, and dementia-related education. In the first year of the study, the treatment group had half as many nursing home placements as the control group (Mittelman et al., 1993) and caregivers in the treatment group were significantly less depressed than those in the control group (Mittelman et al., 1995). In addition, participation in the comprehensive program of caregiver support and education delayed nursing home placement by an additional 329 days relative to a control group that did not receive these services (Mittelman et al., 1996).

It is important to note that the effect demonstrated by Mittelman and colleagues is far greater than that provided by available medications or observed in widely cited studies of Vitamin E and selegiline (Sano et al., 1996, 1997). Furthermore, Mittelman's intervention was not intensive and associated costs were similar (or even less) relative to medication studies. Given that nursing home care costs approximately $40,000 per year, the delay of nursing home placement demonstrated in Mittelman's study represents substantial cost savings.

These studies suggest that the development of new social service interventions that target caregivers represent a sound investment, not only in terms of quality of life for both patients and caregivers but also in terms of cost savings realized through delayed need for institutionalization. It is clear that a fresh look and new models are required. The purpose of this article is to outline our experiences with an integrated model of dementia evaluation and management.

Background

The Alzheimer's Disease Education Program (ADEP) is located in the Department of Neuropsychiatry at the Texas Tech University Health Sciences Center (TTUHSC) in Lubbock, Texas. ADEP was established to improve the quality of care received by individuals with AD and to reduce the burden of caregiving experienced by their families. This mission is achieved by means of caregiver education and counseling coordinated through the program's six Regional Resource Centers (RRCs) and affiliated clergy in West Texas, Eastern New Mexico, and the Oklahoma Panhandle. The RRCs are housed in nursing homes located in Abilene (TX), Amarillo (TX), Hobbs (NM), and Lovington (NM). The RRCs are staffed by people who are knowledgeable about AD and able to counsel caregivers, train clergy, give presentations and distribute educational materials. ADEP is a service demonstration project supported by TTUHSC and a coalition of national and regional foundations. All program services are provided free of charge.

ADEP's service area encompasses 108 predominantly rural counties in West Texas, occupying 137,637 square miles, not including the natural service areas outside of the state. The service area has a population of more than 2.9 million, including an elderly population of more than 344,000 (U.S. Bureau of the Census, 1991; Saenz & Murguia, 1995). Of the elderly population, more than 53,700 adults are in need of dementia-related services, not including the second victims of the disease—the caregivers and families (Evans et al., 1989).

A major objective of ADEP is early detection of AD through dementia screening clinics (DSCs). The DSCs serve as a starting point for caregivers and family members to utilize the educational and counseling services available through the program. Caregivers continue to access staff members throughout the course of the disease for information, referrals, and support. In this article we will describe the procedures that have developed out of more than 36 clinics held throughout the service area in Alzheimer's Association chapter offices, churches, nursing homes, physicians' offices, and university medical centers. More than 1,200 patients and family members have participated to date, demonstrating the utility of the DSC model. Although this model of dementia evaluation and subsequent care management was developed in a rural setting, we believe that it can be adapted to urban locations and may serve as an effective tool within a managed care environment.

Method

Staffing the Clinic Team

The clinic supervisor is responsible for overseeing the entire screening process from initial contact through the care management follow-up to guarantee that clinic staff are providing accurate information and appropriate care to clinic participants. The clinic supervisor should be a psychologist who has demonstrated expertise in the diagnosis and care of individuals suffering from a dementing illness. The remaining clinic team includes a coordinator and evaluation staff. The coordinator is responsible for establishing a location, advertising, and scheduling participants for the clinic. Evaluation staff are responsible for conducting initial interviews, performing evaluations at the clinic, giving feedback to caregivers, and conducting follow-up interviews. Frequently, the coordination and evaluation duties are performed by the same individual(s), although these duties could be divided among different clinic staff members. Like the clinic supervisor, clinic staff should be familiar with the characteristics of dementia and be trained in the use of the interview form and evaluation materials. Moreover, clinic staff need to be aware of common issues facing families caring for someone with a dementing illness. Clinic staff can
include masters-level psychologists, nurses, psychiatric social workers, psychology graduate students, and others in related health care fields who have experience in geriatric assessment.

Volunteers from local community service agencies can also be utilized at the clinic. Volunteers can be trained to provide caregivers and participants with information regarding community resources. Additionally, volunteers can sit with participants suffering from a dementing illness to prevent them from wandering while their caregivers are with clinic staff. Potential volunteer sources include community service agencies such as the Alzheimer’s Association, dementia caregiver support groups, and senior citizen centers.

Establishing Locations for the Clinics

The clinics should be held in locations that are familiar or easy to locate for clinic participants who live in the surrounding areas. Furthermore, each clinic location should be accessible for participants who have physical impairments. Sites chosen for the clinic should have a comfortable waiting area and several testing rooms. It may also be helpful to have a quiet room available in case a clinic participant becomes agitated. All rooms should provide privacy to protect confidentiality and to minimize any distractions that may occur during testing.

The clinic site should be established prior to any advertisement. In addition, coordinating staff should visit the site to ensure that it will be adequate for clinic use. During this visit, it is beneficial for the clinic coordinator to provide the facility contact person(s) with a thorough explanation of the clinic procedures and requirements so an appropriate location within the facility can be chosen. It is useful to hold the clinic in the same location in a community each time to reduce the amount of coordinating effort required from clinic to clinic. Possible locations for clinics include churches, community service agencies (e.g., Alzheimer’s Association chapter offices), long-term care facilities, senior citizen centers, community centers, and university medical centers.

Advertising the Clinics

Advertisements should be initiated a minimum of three weeks prior to the clinic and discontinued approximately one week before the clinic. This will allow the clinic coordinator at least one week to complete initial interviews. Appropriate media for clinic advertisements include newspapers (medical or seniors’ section), community service agency newsletters (e.g., Alzheimer’s Association), and church bulletins. Letters to physicians and clergy can also be used to advertise the screening clinics.

Clinic advertisements should include several key elements. The advertisements should indicate that the clinic is provided for those persons who are experiencing memory difficulties that interfere with activities of daily living. The advertisements should also clearly state any basic criteria for participation such as age (e.g., persons 55 years or older). Furthermore, advertisements should include the name and phone number of the sponsor as well as the date of the clinic. Advertisements should also indicate that a limited number of appointment times are available. Those who cannot be accommodated by the clinic can be offered a place on a waiting list for future clinics and/or given referrals to appropriate community resources.

Letters to physicians and clergy should include a brief description of any services offered subsequent to the clinic (e.g., reports to physicians). Furthermore, these letters should also invite physicians or clergy members to contact clinic coordinators if they have any questions concerning the clinic. Finally, a flyer that can be posted at the physician’s office or at the church may also be included.

Initial Interview and Scheduling

When contacted by a caregiver or potential participant for the first time, the clinic coordinator should provide basic information about the screening clinic. This information should include a description of the phone interview and cognitive testing as well as the date of the clinic, time required for testing, name of the clinic supervisor, and the limitations of the screening evaluation. Once the caregiver or potential participant indicates an understanding of this information as well as a willingness to participate, the clinic coordinator will complete the phone interview to collect a symptom and medical history. If the caregiver is not prepared to complete the interview, the clinic coordinator will set an appointment time to gather this information. The information concerning symptom and medical history can be collected using the Caregiver Telephone Interview for Dementia (CTID; Freed & Elder, 1996). This semistructured interview is used to gather information about basic demographics, symptom course, behavioral problems, activities of daily living, prescription medications, and medical history. The information collected using the CTID can then be employed to determine the appropriate combination of clinical services for the participant and caregiver. The CTID is available from the first author upon request.

Clinic participation is determined based on several criteria. Primary criteria are a history of memory problems and age, usually 55 years or older. Additional criteria include the willingness to participate, the presence of mild to moderate memory difficulties (as suggested by the phone interview), rudimentary communicative abilities as well as the absence of uncomfortable health conditions (e.g., incontinence) and extreme behavioral problems (e.g., physical aggression). If it is determined that a potential participant would not benefit from attending the clinic, coordinating staff may offer a caregiver consultation in lieu of the screening. Briefly, these consultations include a review of the medical and symptom history as well as a discussion of management strategies for someone with a dementing illness. In addition, the caregiver is provided with information concerning the steps required to establish a diagnosis of dementia and given referrals to community resources that can provide caregiving support (e.g., respite, home health care).
Very few individuals are excluded from participation in the DSCs provided that they meet age guidelines. Generally, a caregiver is discouraged from bringing an individual who suffers from significant agitation, hallucinations, or incontinence. Instead, the caregiver is offered educational and counseling services in the absence of the affected individual. In this way, the safety and comfort of the affected individual is ensured while the caregiver is provided with needed services. Written reports and follow-up services are available to caregivers of severely demented individuals, just as with other DSC participants.

Following the completion of all initial phone interviews, the clinic supervisor and clinic staff should review the interviews. Information that needs to be more thoroughly explored on the day of the clinic should be noted on the phone interview. Following this review, coordinating staff should contact caregivers and potential participants by telephone to schedule an appointment. During this contact, the clinic coordinator should also provide directions to the clinic location.

After the appointment has been scheduled, the clinic coordinator should send a letter confirming the appointment time, date, address, and directions to the clinic. This letter should also include a contact phone number so that the caregiver or participant can change or cancel their appointment as needed. The decision concerning who should receive the confirmation letter should be determined by the nature of the referral. For example, the caregiver may wish to receive all correspondence given the memory impairments of the person they are referring to the clinic. All confirmation letters should be sent one to two weeks in advance of the clinic. Once the confirmation letter has been sent, a file for each participant should be prepared. This file should include initial interview information, consent forms, release of information forms, testing materials, and any other notes concerning the participant.

The number of supervisory and evaluation personnel available will determine the number of participants who can be evaluated in a day. Most appointments will require approximately 90 minutes. This allows enough time to complete the consent form, conduct the evaluation, review the results with the clinic supervisor as well as provide feedback and educational materials to caregivers. Consent to release information to the family physician or other family members can be obtained as well. Given one supervisory person and three evaluators, up to 12 participants may be evaluated in a day.

Day of the Clinic

On the day of the clinic, the caregiver and participant are greeted by clinic staff who will review the consent form with them. The consent form should include an explanation of the evaluation process, requirements (e.g., willingness to participate), and limitations. By signing the consent form, the participant and caregiver formally indicate their agreement to be evaluated and to receive services. The caregiver is offered the opportunity to observe the screening evaluation with the participant's consent as this can be an important part of the process. Once the participant and caregiver give consent, evaluation staff will escort the participant and/or caregiver to a testing room and begin the evaluation. The evaluation requires approximately 30 minutes. Instruments used in the evaluation include the Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975), Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983), Controlled Oral Word Association (Spreen & Benton, 1977), and Geriatric Depression Scale (Brink et al., 1982), as well as the CERAD Constructional Praxis and Word List (Morris et al., 1989).

Evaluation staff usually spend 15 minutes scoring evaluation material and consulting with the clinic supervisor. Evaluation staff then provide feedback about the evaluation and offer recommendations for care management, requiring approximately 30 minutes. Recommendations may include: detailed medical evaluation for dementia, medication review, pharmacologic treatment for depression, driving precautions, respite care, specific techniques for managing problem behaviors, legal arrangements, family meetings to discuss issues, and nursing home placement. Subsequent to feedback, the participant and caregiver are given the opportunity to sign a release of information so they or their physicians can receive a written summary of the evaluation results. If indicated, the caregiver is provided with educational material concerning dementing illnesses. The caregiver is also encouraged to call clinic staff if questions arise following the clinic. Prior to seeing the next participant, evaluation staff should spend 15 minutes making notes in the participant’s file about any conclusions and recommendations provided to the caregiver. Following the clinic, evaluation screening reports should be sent to the caregiver and/or physician within two weeks.

Care Management

The aim of the care management follow-up is to review with the caregiver the process that began at the clinic. The first follow-up telephone call should come within five working days after the clinic. Staff should verify report recipients requested by the caregiver (e.g., themselves, other family members, physicians). Further, staff should give the caregiver a reasonable time frame in which they can expect to receive a report of the clinic evaluation (this will vary according to clinic census and availability of staff completing reports). Staff will review recommendations for care management offered at the clinic as well. Finally, staff should offer to call the caregiver again within a month.

The next follow-up phone call should be made approximately 35 working days after the clinic. The general aim of this call is to assist the caregiver in implementing recommendations contained in the report, provide educational information concerning management strategies, and offer caregiver support. Accordingly, staff should ensure that requested reports were received by the caregiver and/or physician. Staff will also answer any questions or clarify the contents of
the report if asked by the caregiver. If needed, staff will attempt to assist the caregiver in implementing recommendations through problem-solving discussions. For example, staff may help the caregiver identify possible causes of difficult behaviors and possible behavioral management solutions. Staff should encourage the caregiver to seek emotional and instrumental support (e.g., home health care) from available community resources as well. Finally, staff should offer to call again in approximately 90 days.

The next follow-up telephone call should be made 125 days after the clinic. The general aim of this and subsequent calls (at 215 and 305 working days following the clinic) is to provide educational information concerning dementia as well as to encourage problem-solving techniques for behavior management. Additionally, the caregiver should be encouraged to seek assistance with caregiving from community resources.

Discussion

AD is devastating for its victims and their families; the financial and emotional costs are staggering (Schulz, O’Brien, Bookwala, & Fleissner, 1995). At a societal level, the explosive growth of the geriatric population and the emergence of managed care dictate new approaches to dementia care.

The methods outlined in this article were designed to serve a variety of functions including: (a) early detection of dementia in previously unscreened cases, (b) provision of assistance to physicians in obtaining a diagnosis of AD (or other illness), (c) counseling and education of caregivers and families about the disease process, and (d) an entry point for subsequent follow-up and care management. It should be noted that the DSCs function as one component of a larger program model that includes public education, development of clergy as a resource for parishioners, and long-term care staff training in addition to diagnostic services. Although services are provided free of charge in the current context, the DSCs could be billed to private insurance and/or Medicare as are other psychological services.

Of particular importance to this model of care management is the accuracy and thoroughness of the initial assessment. The CTID is used to obtain a detailed history of the patient’s memory and medical problems during an interview with the primary caregiver or other reliable informant. Several previous studies have demonstrated the reliability and validity of historical information obtained through a telephone interview with an informant (Gatz et al., 1995; Kawas, Segal, Stewart, Corrada, & Thal, 1994; Korner-Bitensky & Wood-Dauphinee, 1995). Other authors have demonstrated that an informant questionnaire is at least as valuable as a brief cognitive evaluation in screening for dementia (Jorm, Scott, Cullen, & MacKinnon, 1991; O’Connor, Politt, Brook, & Reiss, 1989; Van der Cammen, Van Harskamp, Stronks, Pashcier, & Schudel, 1992). One of the important aspects of the current model concerns the use of the CTID in conjunction with cognitive screening in case ascertainment. Initial symptoms, activities of daily living, and current problem behaviors have proven particularly useful in the identification of dementia cases, particularly when coupled with objective neuropsychological test data. The comprehensive symptom and medical history, when summarized in the DSC reports, is a valuable asset for physicians called on to conduct further diagnostic evaluation. The CTID also includes an assessment of social resources and caregiver coping strategies that can be used as part of care management planning.

The DSCs are modeled after mobile health clinics, which have developed as a method for providing services in areas lacking an adequate health care infrastructure. Bloodmobiles, mobile CT scanners, and mammography services have been provided in this way. Mobile DSCs represent a cost-effective way to provide diagnostic services in support of family practitioners and have the added benefit of familiarizing caregivers with local social service providers in a comfortable community setting. The personal experiences of families as well as staff members conducting the DSCs clearly support the positive impact that these services have on quality of life. Feedback received from families during DSC counseling sessions and follow-up calls has been predominantly positive. Families have reported that the information about AD and recommendations for care provided at the DSCs have helped them understand the disease, deal with behavioral problems, find needed support services, obtain a diagnosis, and provide better care. To quantify these observations, a study of client satisfaction with services is currently underway as part of program evaluation.

Managed care can be defined as a system of health care delivery that is designed to manage costs and access to care through the coordination of medical services, utilization review, and standards of care. One of the primary goals of managed care is to contain costs by reducing unnecessary hospitalization, specialty care, and emergency services. Health promotion, preventive care, early intervention, and education are important tools for cost containment and also the goals of the DSCs. For managed care to be successful in containing costs while promoting quality of care, new programs will have to be developed that focus on preventive care and the philosophy that you invest a little in order to save a lot. Access to care and quality of care must not be lost in the push for cost containment.

The tools and procedures that have been developed through the DSCs may be useful to the general practitioner for improving diagnostic accuracy and increasing the effectiveness of services. The DSCs may also be a cost-effective model for delivering dementia-related diagnostic and counseling services in a managed care environment. In the current environment of health care reform and cost containment, cost savings must be demonstrated in order to promote the widespread adoption of the methods described in this article. Until such time as effective medical treatments for AD are available, caregiver education, counseling, and support services must be provided, not only because it is the humane thing to do but also because cost savings will result in the long run (Mittelman et al., 1996; Toseland et al., 1997). Hopefully, the model
outlined in this article will serve as a starting point for new dementia care programs that are both rational and humane in a managed care environment.

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