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Development and Implementation of Nonpharmacologic Protocols for the Management of Patients With Alzheimer's Disease and Their Families in a Multiracial Primary Care Setting

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Purpose. Most patients and families with dementia are cared for in primary care clinics. These clinics are seldom designed to provide the necessary comprehensive care. The purpose of this article is to describe nonpharmacologic protocols for the management of patients with Alzheimer's disease and their families that are administered as part of a multifaceted care-management intervention program in a multiracial primary care clinic. **Design & Methods.** The nonpharmacologic component for the integrated program of collaborative care was developed based on a literature review and previous clinical experience. The care is coordinated by a geriatric nurse practitioner who meets with patients, families, and

the primary care physicians. The nonpharmacologic protocols included general educational guidelines about Alzheimer's disease. Specific protocols to treat the common behavioral disturbances associated with Alzheimer's disease also were developed. A major component of the intervention is a monthly psycho-educational support group for caregivers. **Results.** The intervention has been well accepted by patients, families, and physicians. Approximately one-half of the treatment group has participated in the support group regularly. **Implications.** The integration of behavioral interventions and team care within the primary care environment has been successful.

Key Words: Behavioral disturbances, Nonpharmacological interventions, Primary care, Minority elderly, Psychosocial-educational support group

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and behavioral disturbances in patients with Alzheimer's disease (Bourgeois, Schulz, & Burgio, 1996; Coon, Ory, & Schultz, 2003; Gallagher-Thompson et al., 2000; Hébert et al., 2003; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996; Pinkston & Linsk, 1984; Pinkston, Linsk, & Young, 1988). In an effort to comprehensively evaluate and examine the most promising home- and community-based interventions for alleviating the burdens associated with caregiving including minority caregivers, the National Institutes of Health have funded the REACH (Resources for Alzheimer's Caregivers Health) project (Coon, Schulz, & Ory, 1999).

Despite these efforts, there remains, at this time, no single easily implemented and consistently effective method for managing patients with Alzheimer's disease and their families (Coon et al., 2003). It is even more difficult when the interventions are targeted to racially and ethnically mixed populations. Traditionally, minority groups have been understudied in Alzheimer's disease research. They are less likely to attend specialty clinics, and therefore interventions may be more acceptable if they are integrated into the primary care settings where minority elders are receiving medical care. In fact, most patients with dementia and their families receive their care in primary care settings. These clinics often do not have the resources to provide appropriate diagnosis, evaluation, education, treatment, or long-term management for this population (Callahan, Austrom, & Unverzagt, 2004; Callahan, Hendrie, & Tierney, 1995).

Previous efforts to improve late-life depression in primary care using screening and health-care practitioner feedback and education have not been consistently successful, suggesting that a more comprehensive intervention strategy may be necessary for this population (Callahan, 2001; Callahan, Hendrie, Dittus, Brater, Hui, & Tierney, 1994). Recently, a collaborative stepped-care management intervention program was developed that had more success in managing late-life depression in primary care than previous efforts (Unutzer et al., 2002). This intervention contained key components of evidence-based models for chronic illness care (Hegel, Imming, Cyr-Provost, Hitchcock, Arean, & Unutzer, 2002; Wagner, 2000). These key components included collaboration between primary care practitioners, patients, and specialists; a personalized treatment plan; proactive follow-up and outcomes monitoring by a case manager; targeted use of specialty consultation; and protocols for stepped care (Unutzer et al., 2002).

We are currently conducting a randomized trial of a primary care-based care-management program to improve outcomes of care for patients with Alzheimer's disease and their caregivers, which is based on this model. One important feature of the model is the application of specialty-based state-of-the-art diagnostic and management guidelines to a primary care setting. The study site is a large primary care practice serving an urban population of vulnerable

older adults. The study intervention includes three basic components: (a) a comprehensive screening and diagnosis protocol, (b) a multidisciplinary team approach to care coordinated by a geriatric nurse practitioner (GNP), and (c) a proactive longitudinal tracking system. A major component of the team approach to care includes intervention strategies directed primarily, but not exclusively, toward family caregivers. The primary outcomes of this study are reductions in behavioral disturbances, caregiver stress, and health-care utilization.

The purpose of this article is to describe the development and implementation of nonpharmacologic protocols for the management of patients with Alzheimer's disease and their families that is part of this care-management program. It also includes a description of the psychosocial-educational support group intervention for the caregivers. Of particular relevance is the application of these protocols in a busy, multiracial primary care clinic. This population has been underrepresented in the literature.

Methods

Population

The program is administered in a university-affiliated primary care practice serving a medically indigent population. The older population cared for in this practice is approximately 68% women and 63% African American, and 43% have <8 years of education (Callahan et al., 1995). Well-screened and well-characterized patients with possible or probable Alzheimer's disease are enrolled and randomly assigned to the treatment or control (usual care) group.

Measures

Caregivers are administered the Memory and Behavior Problems Checklist (MBPC) and the Patient Health Questionnaire-9 (PHQ-9) during the initial interview with the nurse practitioner and at 4-week intervals thereafter. The MBPC is a standard reliable measure of the frequency of behavioral disturbances in the patients as well as a measure of the caregiver's reaction (Zarit, Orr, & Zarit, 1985). The PHQ-9, a nine-item self-report measure, is used as the measure of severity of the caregiver's depression (Kroenke, Spitzer, & Williams, 2001). These two measures are used to design the individualized intervention protocols.

Nonpharmacologic Protocols

A major premise of our study is that nonpharmacologic methods are the intervention of first choice for behavioral disturbances. The nonpharmacologic protocols used in this study are based on a literature review and those previously used in

clinical and educational settings (by the first author). The protocols included interventions designed to address both patient and caregiver issues. Notably, the interdisciplinary team also evaluates the patients for chronic conditions (e.g., pain) or medications that may be contributing to the behavioral disturbance. Because the program is integrated with primary care, the nurse practitioner can work with the primary care physicians to evaluate symptoms or change medications. Education about some behaviors applies to all patients with dementia.

All participants receive the Alzheimer's Disease and Related Dementia Guide for Caregivers (Alzheimer's Association, Central Indiana Chapter, 2002). In addition, all treatment participants receive an educational intervention at the first contact meeting with the GNP following enrollment, consisting of information and handouts about understanding Alzheimer's disease, common misunderstandings about the disease and patient behaviors, and advice about how to communicate with a loved one with Alzheimer's disease (Austrom & Hendrie, 2001). At this initial meeting, the nurse practitioner also stresses the importance of obtaining advice about basic legal and financial issues such as living wills, guardianship, and power of attorney. Patients and families are referred to the local Legal Services Organization, a not-for-profit group. The director of the Senior Law Project presents the information to participants attending the support group as well.

In addition to the educational information provided to all intervention patients as described above, specific protocols have been designed for the common behavioral disturbances associated with Alzheimer's disease. Patients and their caregivers are provided with these protocols only if the behavioral disturbance is a current problem. These protocols address the following: depression/anxiety, aggression/agitation, repetitive behavior, and delusions/hallucinations/paranoia. Information on managing personal care, mobility, and sleep disturbances also has been developed. Following is a description of the key components of the protocols:

Depression/anxiety.—These include maintaining a cheerful and bright environment, encouraging mild to moderate exercise, promoting positive social interaction, redirecting patients when they express negative thoughts, and validating feelings and comforting patients when they are in distress.

Aggression/agitation.—Identifying potential triggers of emotional outbursts and attempting prevention of outbursts, establishing a calm environment, using a nonthreatening and gentle approach and reassuring the patient, avoiding arguing, confronting, or trying to reason with patients, redirecting patients' attention, and encouraging flexibility regarding medications or bath time.

Repetitive behavior.—Reassuring patients that they are safe, ignoring some of the repetitive questions, and redirecting patients' attention when possible.

Delusions/hallucinations/paranoia.—Avoiding direct confrontation, avoiding reasoning and rationalizing with the patient, giving noncommittal answers, and attempting to distract and redirect the patient.

Personal care.—Maintaining and encouraging the patient's independence in activities of daily living and simplifying directions as needed, maintaining a consistent and predictable daily routine, and advice about bathing, dressing, mealtimes, dental care, toileting, and incontinence.

Mobility (includes wandering, balance/falls, and shadowing behavior).—Strategies for wandering include registering all patients for Safe Return (Alzheimer's Association, 1998); appropriate environmental modifications including locks, surrounding the patient with familiar objects, providing patients with a safe place to wander; continual reminders about time and place; and offering appropriate levels of exercise. The protocol for preventing falls includes providing a safe and secure environment, avoiding throw rugs, and installing grip bars in bathrooms and kitchens. Managing patients who shadow the caregiver include promoting tolerance and patience of the behavior but also encouraging respite relief for the caregiver.

Sleep disturbances.—Implementing a bedtime routine that includes a consistent toileting regimen, ensuring comfortable sleeping arrangements, and encouraging a regular activity program.

All of the protocols include corresponding handouts for caregivers that were developed to be very user friendly. They were written at a fifth-grade reading level and incorporate graphics and large print. Each handout is color-coded and placed in a corresponding color-coded section of a binder. The binder also contains in the inside cover a list of important contact information. (A complete protocol package may be obtained from the first author.)

Intervention Process

Following the completion of the diagnostic process, the clinical treatment team, which includes a GNP, a social psychologist, a geriatrician, and a geriatric psychiatrist, reviews the information on the patients assigned to the treatment group, and treatment recommendations are made. These include pharmacologic considerations of the use of cholinesterase inhibitors, vitamin E, aspirin, and other

modifications of the existing drug regimen and the nonpharmacologic psychosocial interventions.

All treatment group caregivers and patients receive the educational intervention described above. Based on the caregivers' responses to the MBPC and PHQ-9, individualized recommendations are made regarding specific behavioral disturbances or caregiver distress. Any item checked on a subscale of the MBPC activates a specific behavioral intervention protocol. The specific intervention is determined by an item-by-item evaluation of all of the responses on the subscale.

Individualized Care Plan

During the week following the initial assessment, the nurse practitioner meets separately with the primary care physician and with the patient and family members. This provides the nurse practitioner the opportunity to discuss issues and answer questions or address concerns related to the diagnosis, prognosis, and treatment recommendations with both the primary care physician and the patient and family caregiver(s). At this meeting, the intervention recommendations are presented.

Implementation Phase

In the week following the initial meeting, the nurse practitioner telephones the caregiver to assess tolerance to medications, to answer any questions related to the patient's behavior, and to reinforce the intervention recommendations. At 1 month following the initiation of the intervention, the nurse practitioner meets face to face with the patient and family, reviews progress, and addresses any new or continuing concerns they may have. The nurse practitioner readministers the MBPC and PHQ-9 and updates the primary care physician by e-mail or telephone regarding the patient's progress. The face-to-face meetings and telephone contacts are repeated at 4-week intervals. At 2 months, the nurse practitioner reviews the patient's and caregiver's progress with the clinical treatment team. This includes a review of MBPC and PHQ-9 data. It should be noted that the nurse practitioner has the option of contacting the clinical treatment team at any time at his/her discretion. All family members are encouraged to call the nurse practitioner at any time with questions or concerns. If the patient remains stable after 3 months of the intervention, the face-to-face meetings are scheduled at 3-month intervals. The intervention lasts for 12 months. The nurse practitioner coordinates patient and caregiver contact with other clinic appointments and will make a home visit to accommodate participants' schedules and needs. The MBPC and PHQ-9 are administered at each contact. Caregivers are given updated handouts for their individual protocol binders based on information received from the MBPC and the PHQ-9. Specific

protocols activated for the patient are discussed with the caregiver, and a corresponding handout is given to them for reinforcement.

Caregiver psychosocial-educational support group.—In addition to the implementation of individualized behavioral intervention protocols, patients and caregivers in the treatment group are encouraged to attend monthly meetings. The meetings are held twice a month, at noon and in the early evening, to accommodate caregivers' schedules. Round-trip transportation is provided if necessary. The group meetings are 1.5 hours in length, with the first 10 minutes used for checking in and brief introductions. The patients are then escorted to an exercise group, which will be described in a separate article. The first 30 minutes of the caregiver meeting are devoted to an educational forum designed to educate the family about some aspect of Alzheimer's disease and caregiving issues. Educational topics are presented by the first author and invited faculty. Following the formal educational presentation, caregivers are encouraged to share any concern that they are currently experiencing about the patient and the patient's impact on the family. Caregivers are also encouraged to discuss any issue of concern in their lives at the current time. Some of the families have complicated life situations to cope with, including family and marital strife, poverty, and providing care simultaneously for multiple generations. During the last 30 minutes, the patients join the caregivers for snacks and socialization. During this time, the nurse practitioner meets briefly with each patient and caregiver, readministers the MBPC and PHQ-9, and reviews medications. The following case report illustrates the care-management process.

Clinical Case Report

Mrs. X. is a 78-year-old African American woman who was diagnosed with Alzheimer's disease. In addition to her Alzheimer's disease diagnosis, she was previously diagnosed with hypertension, for which she was on atenolol, and hypothyroidism, for which she received Synthroid. Her primary caregiver is her daughter. The family was under considerable stress. A son who was living with Mrs. X died just as she entered the study. Mrs. X was now living alone. The daughter was very anxious and distressed about assuming total care for her mother. She was also providing help for an elderly aunt with severe dementia and a close family friend who was seriously ill. She is currently working at a job she loves but has contemplated retirement in order to manage her caregiving role. The caregiver is married and has one adult son who lives out of state.

Initially there was some difficulty in establishing contact with the patient and daughter. Following

the consent visit, the GNP attempted to contact the family on seven occasions over a 7-week period. At the initial visit, in addition to the caregiver information, the patient was started on Aricept and vitamin E, which she has tolerated well. It was suspected that the patient had not been taking her thyroid medication regularly. The daughter was advised to monitor this carefully with both the patient and primary care physician.

After the initial visit, the daughter faithfully attended meetings with the GNP every month. Both Mrs. X and her daughter became enthusiastic participants in the group process, attending every monthly session. In fact, they would often attend two sessions per month, even though the educational components were repeated.

The initial focus of the intervention was addressing the daughter's feelings of being overwhelmed with caregiving responsibilities and grief at the loss of her brother. Her other brother had also died some years previously, and she now found herself an only child. Her PHQ-9 score at that time was 6, indicating depressive symptoms. We recommended that she discuss her depressive symptoms with her physician and suggested antidepressant medications. He subsequently prescribed Paxil. The daughter was particularly concerned about the future of her mother, given her experience with her aunt. The daughter was encouraged to distinguish the plight of her aunt from her mother's current condition and to concentrate on the positive aspects of her mother's relatively high level of functioning. The daughter was grateful for this help. In fact, she was so pleased with the group process that she invited her cousin, Mrs. X's niece, to attend as well. When the niece attended, she expressed her gratitude for the help her cousin was receiving and recognized immediately the group's facilitators and participants from the daughter's descriptions. The daughter has now been attending the group for 10 months, and her PHQ-9 score is 0.

Meanwhile, Mrs. X enthusiastically responds to the exercise program. She still manages to live alone with daily help from her daughter and additional assistance from her niece.

Discussion

In this article, we have described the nonpharmacologic protocols for the management of patients with Alzheimer's disease and their families that are part of an integrated program of collaborative care for older adults with Alzheimer's disease and their caregivers in a primary care setting. The program has several unique features. It includes a multidisciplinary approach to care with an emphasis on providing a caregiver support program. A nurse practitioner working with the primary care physician in a primary care clinical setting coordinates this care. Although it is too early to gauge the success of this intervention, we can report so far that it has

been well received by the patients and caregivers as well as by the primary care physicians.

One indicator of acceptability by the patients and caregivers is their ongoing attendance at the psychosocial-educational and exercise support group meetings. In contrast to the experience of other groups providing services to minorities, approximately one-half of our treatment group caregivers and patients attend the monthly meetings regularly. All family members are encouraged to attend. Frequently, more than one family member will attend with the patient.

Although the care-management program described here is innovative in its integration of care for patients with Alzheimer's disease within the primary care system, it is resource intensive. To replicate this program, primary care practices would need to implement a screening program, train the various interdisciplinary team members in the care protocols (including the GNP), and provide ongoing support for longitudinal coordination and tracking of care. Most of these required resources are not currently directly reimbursable by Medicare or other third-party payers. Thus, in many health care systems, such a program would have to demonstrate not only clinical effectiveness but also cost-effectiveness. Given the high cost of care for patients with Alzheimer's disease, including the cost of skilled nursing care, a program that supported caregivers and patients in a manner to delay nursing home placement could indeed prove to be cost-effective. Notably, the program we have implemented is taken directly from current recommendations for the care of patients with Alzheimer's disease. Although the program is costly, it does match current treatment guidelines. Before we assess cost-effectiveness, we must first test whether these treatment guidelines are effective.

It should be noted that most patients attending the primary care clinics involved in this study are a highly vulnerable minority population (63% African American). Some researchers have suggested that African American caregivers may be reluctant to participate in research or clinical services (Gonzales, Gitlin, & Lyons, 1995). We hope that this program, if successful, will become a model for intervention for the treatment and management of Alzheimer's disease in primary care clinics with large percentages of minority patients.

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