

An integrated model of comprehensive care for people with Alzheimer's disease and their caregivers in a primary care setting



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Abstract Most people with Alzheimer's disease and their families receive care in primary care. This article describes an integrated model of Alzheimer's disease care in a primary care setting serving a predominantly ethnic minority population. This model included: a comprehensive screening and diagnosis process; a multidisciplinary team approach to care, coordinated by a geriatric advanced practice nurse; and a proactive, longitudinal tracking system. The psychosocial intervention included specific responses to the treatment and management of behavioral and psychological symptoms of dementia, including caregiver directed interventions and pharmacological treatment if needed. Results suggest that this type of model can be implemented in primary care, particularly with the involvement of geriatric advanced practice nurses who can effectively manage the complex nature of Alzheimer's disease.

Keywords behavioral and psychological symptoms; caregiver-directed interventions; dementia; ethnic minorities; general practice

Alzheimer's disease (AD) represents one of the major public health problems facing the USA today, with enormous emotional and economic costs. Ernst and Hay (1994) estimated the total cost of AD care to be \$173,932 per individual, including unpaid caregiver costs. More recently, Harrow and colleagues (2004) calculated the formal and informal costs associated with AD and found that estimates vary greatly due to instrumental activities of daily living that the care recipient needed help with and also varied by geographic region. Nonetheless, the cost of care associated with AD is high and expected to continue to increase. The emotional cost to family members, who also manage the physical demands of providing care over many years while watching their relative lose the very essence of their being, is also noteworthy (Guerriero Austrom & Hendrie, 1990). Stress levels reported by family caregivers are high, particularly for depressive symptoms. For example, among community-dwelling caregivers of persons with AD, these have ranged from 40 percent to 70 percent (Friss & Whitlatch, 1991; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Gitlin et al., 2003; Pruchno & Resch, 1989; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Thomas et al., 2006; Whitlatch, Feinberg, & Sebasta, 1997) versus 8 percent to 16 percent among community-dwelling non-caregiving older adults (Blazer, Burchett, Service, & George, 1991; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Owen et al., 2002).

Psychosocial interventions for caregivers have received much attention in the literature, with evidence that some of these interventions are effective in reducing both caregiver distress and behavioral disturbances in people with AD (Coon, Ory, & Schulz, 2003).

In an effort to comprehensively evaluate and examine the most promising home- and community-based interventions for alleviating the problems associated with caregiving, including ethnic minority caregivers, the US National Institutes of Health (NIH) funded the REACH project (Resources for Alzheimer's Caregivers Health). Six regional sites participated in this unique project with the primary purpose of carrying out behavior and social research on interventions designed to enhance family caregiving. The six sites developed and evaluated a variety of multi-component interventions for family caregivers of people with AD at the mild or moderate level of impairment. Efforts were made to recruit ethnic minority caregivers, especially African American and Hispanic caregivers, because they are under-represented in the literature. While the results of the REACH study demonstrated that interventions that emphasized active engagement of the caregiver had the greatest impact in reducing burden

and caregiver depression, there remains at this time, no single easily implemented and consistently effective method for achieving the same clinically significant outcomes across caregivers (Schulz et al., 2003). Based on the results of REACH, REACH II is currently underway to test a single intervention at multiple sites with an ethnically diverse caregiver population.

It is not clear whether interventions that have been designed for primarily white populations attending AD specialist clinics would be as effective for minority families. They are less likely to attend these clinics and therefore interventions may be more acceptable if integrated into primary care settings (Dilworth-Anderson, Thaker, & Burke, 2005; Olin, Dagerman, Fox, Bowers, & Schneider, 2002). In fact, most people with AD and their families receive their care in primary care settings. Primary care often does not have the resources to provide the appropriate diagnosis, evaluation, education, treatment or long-term management for this population (Callahan, Guerriero Austrom, & Unverzagt, 2004; Callahan, Hendrie, & Tierney, 1995). For example, AD is frequently unrecognized by primary care physicians. In one study, nearly 75 percent of people found to have moderate to severe cognitive dysfunction did not have an AD diagnosis recorded in their medical record (Callahan et al., 1995). It has been suggested that improvements in primary care for older people can be achieved through system-level interventions such as collaborative care management (Katzelnick et al., 2000; Simon et al., 2001; Wells, Johnson, & Salyer, 1998). These interventions, such as those designed for late-life depression, provide additional resources for the management of people with depression and demonstrate improved outcomes. However, the efficacy of these system-level interventions is unproven for older people with AD.

Our interdisciplinary research team participated as a site in the Improving Mood Promoting Access to Collaborative Treatment (IMPACT) Program. The IMPACT Program included collaborative care among primary care physicians, patients, geriatric medicine specialists, geriatric psychiatrists and a depression care manager. The depression care manager implemented a personalized treatment plan and provided proactive follow-up care guided by protocols of stepped care. This model proved highly successful in the treatment of late-life depression, where 45 percent of intervention patients had a 50 percent or greater reduction in depressive symptoms from baseline, compared with only 19 percent of usual care participants (Unutzer et al., 2002). Based on the successful IMPACT program, we have designed a similar model to provide best practice dementia care in primary care clinics, using the most recent management guidelines in the USA for AD (Knopman et al., 2001; Doody et al., 2001; Small et al., 1997). Aspects of this model have been described elsewhere (Boustani et al., 2005;

Guerriero Austrom et al., 2004, 2005). The purpose of this article is to integrate these already published descriptions and, in particular, to describe the interactions between the primary care providers (PCPs) and the geriatric advanced practice nurse (GAPN).

Methods

The PREVENT study

Our NIH-supported PREVENT study (Providing Resources Early to Vulnerable Elders Needing Treatment for Memory Loss) was administered in a university-affiliated primary care practice serving a local population. The older population cared for in this practice is approximately 68 percent women, 63 percent African American and 43 percent with eight years of education or less. The essential components of the integrated program included: (1) a comprehensive screening and diagnosis protocol; (2) a multidisciplinary team approach to care coordinated by a GAPN; and (3) a proactive longitudinal tracking system. The design of this study has been described in detail elsewhere (cf. Guerriero Austrom et al., 2004, 2005).

People aged 65 years and over who consented to take part in this part of the study were screened for cognitive impairment during their regularly scheduled primary care visit, using a six-item screen (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Those scoring below the threshold on the screen were then given a more comprehensive 18-item instrument, the Community Screening Instrument for Dementia (CSI'D') (Hall et al., 2000). For those with evidence of cognitive impairment on the CSI'D', a comprehensive clinical assessment was performed using a structured informant interview, neuropsychological testing, neurological and physical evaluations, and chart review for relevant laboratory testing and brain imaging (Hendrie et al., 2001). Those with a diagnosis of probable or possible AD using the NINDS-ADRDA (McKhann et al., 1984) criteria were invited to participate in the project. Those who consented were then randomly assigned to the intervention or control group.

An interdisciplinary consensus team including the GAPN, the social psychologist who was responsible for the design and implementation of the caregiver-directed interventions, a geriatrician, and a geriatric psychiatrist, guided the treatment recommendations based on published best practice guidelines (Doody et al., 2001; Knopman et al., 2001). The guidelines included AD-specific pharmacological considerations such as the use of cholinesterase inhibitors, vitamin E, aspirin, or modifications of their existing drug regimen, to minimize central nervous system side effects. The recommendations of the interdisciplinary consensus team were presented in full by the GAPN. For the purposes of this article we are reporting on

findings at one site only with one GAPN. It is important to note that the GAPN was well known to the PCPs prior to this intervention study. In addition, the recommendations stressed psychosocial interventions for the day-to-day management of behavioral and psychological symptoms related to AD (Guerriero Austrom et al., 2004). The caregiver-directed psychosocial interventions were implemented through the education and support provided to family caregivers by the GAPN. In addition, the people with dementia and caregivers were invited to participate in monthly support group meetings that provided further support and education about the disease to caregivers, reinforced the caregiver-directed interventions and offered a moderate exercise program for people with dementia (Guerriero Austrom et al., 2004).

The minimum intervention that all treatment group caregivers and people with dementia received included: advice on communication skills; caregiver coping skills; legal and financial advice; exercise guidelines with a guidebook and videotape; and a 'Caregiver Guide' provided by the local chapter of the Alzheimer's Association. Based on the caregiver's responses, individualized recommendations were made regarding how to manage their relative's specific behavioral symptoms or how to deal with issues causing caregiver distress. One to two weeks following the initial meeting, the GAPN telephoned the caregiver to assess tolerance to medications, answer any questions related to the relative's behavioral symptoms and to reinforce the intervention recommendations. At one month following the initiation of the intervention, the GAPN met face-to-face with the person with dementia/caregiver to review progress and address new or continuing concerns. The face-to-face meetings and telephone contacts were repeated at four-week intervals. All problems identified during any interaction, changes in treatment and intervention recommendations were entered into the existing computerized medical record system, thus allowing the PCPs immediate access to all information.

At two months, the GAPN reviewed the person with dementia/caregiver's progress with the clinical treatment team. All family members were encouraged to call the GAPN when they wished. If the person with dementia remained stable after three months of the intervention, the face-to-face meetings were scheduled at three-month intervals. The intervention lasted for 12 months. Caregivers were given updated handouts for their individual protocol binders based on information received from the semi-structured interviews. Specific protocols activated for the person with dementia were discussed with the caregiver and a corresponding handout was given to them for reinforcement (Guerriero Austrom et al., 2004). People with dementia and their caregivers were only provided with these protocols if the behavioral symptom was a current problem. These

protocols addressed: depression/anxiety; aggression/agitation; repetitive behavior; and delusions/hallucinations/paranoia. Information on managing personal care, mobility and sleep disturbances was also developed. The key components of each of the protocols are described in Table 1.

All of the protocols included a corresponding handout for caregivers that was developed to be very user friendly. They were written at a fifth-grade reading level (10–12 years) and incorporated graphics and large print. Each handout was color-coded and placed in a corresponding color-coded section of their binder. The binder also contained in the inside cover a list of important contact information. (A complete protocol package may be obtained from the first author.)

Results

Screening and diagnostic process

The results of the screening and diagnostic process have been described in detail elsewhere (cf. Boustani et al., 2005). Briefly, 3340 patients were screened, 434 scored positive and, of these, 227 agreed to a formal evaluation. Among those completing the diagnostic assessment, 47 percent were diagnosed with AD, 33 percent had cognitive impairment/no dementia and 20 percent were considered to have no cognitive deficit. People with AD had an average of two to three chronic or long-term conditions and were taking approximately five medications. Of the 127 people who received AD diagnoses and were offered the opportunity to participate in the study, 27 (21.3%) refused. The refusal rate for African Americans was 18.6 percent (16 out of 86), somewhat but not significantly lower than the Caucasian participants (26.8%, 11 out of 41) ($p = 0.354$).

Fifty-five patients and their caregivers were enrolled in the intervention arm of the PREVENT study. They were predominately female and African American. The mean age of the patients was 76 years and mean years of their education was approximately eight years. The caregivers were predominately daughters, approximately 54 years of age with 12 years of education, and the majority lived with their relative. The demographic characteristics of the patients and caregivers are summarized in Table 2.

The results of the intervention are not yet available; however, it has become clear that the effectiveness of this intervention depends on the key role played by the GAPNs, who are well trained in dementia management practices and familiar with primary care settings. They coordinate the care between patients, family members and the PCPs, while implementing the intervention and providing closely monitored follow-up with each patient and their family members. In addition, they attend the regularly scheduled

Table 1 **Content of the educational protocols for the caregiver-directed interventions**

Problem behavior	Main elements of intervention
Depression/anxiety	Maintain a cheerful and bright environment; encourage mild to moderate exercise; promote positive social interactions; redirect the patient when he or she expresses negative thoughts; validate feelings and comfort when he or she is in distress.
Aggression/agitation	Identify potential triggers of emotional outbursts; attempt prevention of outbursts; establish a calm environment; use non-threatening and gentle approach; reassure the patient; avoid arguing, confronting or trying to reason with him or her; redirect his or her attention; encourage flexibility regarding schedule, e.g. meals, medications or bath time.
Repetitive behavior	Reassure person that he or she is safe; ignore repetitive questions; recognize patient may no longer remember how to gain attention; recognize non-verbal cues; redirect attention when possible; find repetitive tasks that are enjoyable based on person's needs and social history.
Delusions/hallucinations/paranoia	Avoid direct confrontation; avoid reasoning and rationalizing with the person; give non-committal answers; attempt to distract and redirect.
Managing personal care	Maintain and encourage the person's independence in activities of daily living (ADLs); simplify directions as needed; maintain a consistent and predictable daily routine, including advice about bathing, dressing, mealtimes, dental care, toileting and incontinence.
Mobility	<p>Wandering: Register all patients for Safe Return (Alzheimer's Association, 1998); appropriate environmental modifications such as locks; surround the patient with familiar objects; provide people with a safe place to wander; provide constant reminders about time and place; offer appropriate levels of exercise.</p> <p>Fall prevention: Provide safe and secure environment; avoid throw rugs; install grip bars in bathrooms and kitchens.</p> <p>Shadowing: promote tolerance and patience of the behavior; encouraging respite relief for the caregiver.</p>
Sleep disturbances	Implement a bedtime routine that includes a consistent toileting regimen; ensure comfortable sleeping arrangements; encourage a regular activity program; keep day-time naps short and somewhere other than the bedroom.

Table 2 **Demographic characteristics of PREVENT patients (N = 55) in the intervention**

Characteristics	% or mean
Patients	
% Female	70.9
% African American	58.2
% Married	25.5
Mean age (years) of patient	76.2
Mean years of education	8.2
Caregivers	
% Caregiver female	78.2
% Caregiver living with patient	52.7
Relationship to patient	
% Spouse caregiver	16.4
% Child caregiver	52.7
% Other relationship	30.9
Mean age (yrs) of caregiver	53.8
Mean years of education	11.6

patient exercise and family support group meetings (Guerriero Austrom et al., 2004).

Several factors are important to the nurses' success in establishing a good relationship with the primary care physician. It helps when the GAPNs are already familiar with the primary care settings and considered as part of the care team. The GAPN was responsible for interaction with 26 different PCPs. As indicated in Table 3, over half of the PCPs had only one patient in the study, while 27 percent had two patients enrolled and approximately 20 percent of the PCPs had three or more patients enrolled.

Physicians are trained to exchange complex, clinical information in brief, structured interactions. Thus, it is best when the GAPNs keep the initial meeting with the PCP brief, factual and face-to-face. As illustrated in Table 4, there were 99 documented interactions with the PCP for 48 of the 55 patients (seven patients had no documented interaction with the PCP). While the PCP and GAPN had only one interaction for 31 percent of patients, they had multiple interactions for approximately half of the people with dementia.

The mean number of contacts by the patients with the GAPN was 10.9 (SD 4.5). There were five patients whose only contact was the initial intervention visit. Otherwise the number of contacts for the other 50 patients ranged from four to 19. The majority of these contacts (61.3%) were face-to-face visits.

Table 3 **Number of people with AD seen by PCP**

Number of study patients	Number of PCPs	% of PCPs
1	14	53.9
2	7	26.9
3	2	7.7
6	1	3.9
7	1	3.9
8	1	3.9

Table 4 **Number of PCP and GAPN interactions per patient with AD**

Number of interactions	% of patients
0	12.7
1	30.9
2	34.5
3	12.7
4	5.5
5	1.8
6	1.8

Discussion

In this article, we have described an integrated program of collaborative care for older people with AD and their caregivers in a primary care setting serving a predominantly African American, medically indigent population.

The screening and diagnostic process highlighted some challenges regarding the diagnosis of AD in primary care. For example, almost half of the people who scored positive in the screening refused a formal diagnostic evaluation. The refusal rate, which is similar to previously reported rates, suggested that people may experience some ambivalence about the diagnosis of AD and, in fact, may perceive screening for AD as harmful (Boustani et al., 2005). To overcome this problem, we are now exploring the potential of a counselling service to accompany screening. Dementia was under recognized in this primary care setting. Only 19 percent of patients with confirmed dementia diagnosis had documentation of dementia in their medical records. These findings are consistent with previous studies (Callahan et al., 1995). Additionally, patients with AD presented with many other chronic conditions and were on multiple medications, some of which may be contraindicated in patients with cognitive impairment. Thus, the care of people with AD in primary care is very complex (Schubert et al., 2006). We can report so far that this model of

care has been well received by the patients and caregivers, as well as by the PCPs. In particular, caregiver-directed interventions, including education and advice about patient behavioral issues, are readily acceptable to both patient and caregiver dyads and health care providers. They appear to play a major role in the implementation of the intervention.

Over 90 percent of patients and their caregivers utilized the services of the GAPN frequently. The mean number of contacts between the GAPN and the caregivers was 10.9, most being face-to-face. Another indicator of this acceptability by the patients and caregivers is their ongoing attendance at the psycho-educational and exercise support group meetings. In contrast to the experience of other groups providing services to ethnic minority groups, approximately one-half of our treatment group caregivers and patients attended the monthly meetings regularly. All family members are encouraged to attend. Frequently, more than one family member will attend with their relative (Guerriero Austrom et al., 2004). In the majority of cases (58%), the PCPs also interacted frequently with the GAPNs. They welcomed particularly the additional resources provided to their patients by the GAPNs in the management of this complicated disorder. For example, the GAPNs need only verbal approval to begin the intervention process and could take responsibility for writing orders, implementation and follow-up. Many of the people with dementia in this study had complex psychosocial issues, which could be extremely time-consuming. The GAPNs provided unique psychosocial assistance to these 50 individuals and families, to help them cope with such stressors.

The overall outcomes of the PREVENT study are currently being analysed. Our preliminary analyses suggest that an integrated model of AD care can be implemented in a primary care setting. It should be noted that most patients attending the primary care clinics involved in this study are a highly vulnerable ethnic minority population (63% African American). Some authors 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 AD in primary care clinics with large percentages of ethnic minority patients. The intervention described in this article, however, was designed to be implemented in PCP clinics in the USA. It is unclear whether this particular design could be implemented in other countries with different models of health care.

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References

- Blazer, D., Burchett, B., Service, C., & George, L.K. (1991). The association of age and depression among the elderly: An epidemiologic exploration. *Journal of Gerontology*, 46(6), 210–215.
- Boustani, M., Callahan, C.M., Unverzagt, F.W., Austrom, M.G., Perkins, A.J., Fultz, B.A., et al. (2005). Implementing a screening and diagnosis program for dementia in primary care. *Journal of General Internal Medicine*, 20, 572–577.
- Callahan, C.M., Guerriero Austrom, M., & Unverzagt, F.W. (2004). The older adult: Recognizing and treating dementia and late life depression. In L.J. Haas (Ed.), *Handbook of psychology in primary care* (pp. 263–278). New York: Oxford University Press.
- Callahan, C.M., Hendrie, H.C., & Tierney, W.M. (1995). Documentation and evaluation of cognitive impairment in elderly primary care patients. *Annals of Internal Medicine*, 122(6), 422–429.
- Callahan, C.M., Unverzagt, F.W., Hui, S.L., Perkins, T., & Hendrie, H.C. (2002). Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Medical Care*, 40, 771–781.
- Coon, D.W., Ory, M.G., & Schulz, R. (2003). Family caregivers: Enduring and emergent themes. In D.W. Coon, D. Gallagher-Thompson and L.W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress: A clinical guide* (pp. 3–27). New York: Springer.
- Dilworth-Anderson, P., Thaker, S., & Burke, J.M.D. (2005). Recruitment strategies for studying dementia in later life among diverse cultural groups. *Alzheimer's Disease and Associated Disorders: An International Journal*, 19(4), 256–260.
- Doody, R.S., Stevens, J.C., Beck, C., Dubinsky, R.M., Kaye, J.A., Gwyther, L., et al. (2001). Practice parameter: Management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, 56(9), 1154–1166.
- Ernst, R.L., & Hay, J.W. (1994). The US economic and social costs of Alzheimer's disease revisited. *American Journal of Public Health*, 84(8), 1261–1264.
- Friss, L.R., & Whitlatch, C.J. (1991). Who's taking care? A statewide study of family caregivers. *American Journal of Alzheimer's Care Related Disorders Research*, 6, 16–26.
- Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L.W. (1989). Prevalence of depression in family caregivers. *Gerontologist*, 29(4), 449–456.
- Gitlin, L.N., Belle, S.H., Burgio, L.D., Czaja, S.J., Mahoney, D., Gallagher-Thompson, D., et al. (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multisided initiative at 6-month follow-up. *Psychology and Aging*, 18(3), 361–374.
- Gonzales, E., Gitlin, L.N., & Lyons, K.J. (1995). Review of the literature on African American caregivers of individuals with dementia. *Journal of Cultural Diversity*, 2(2), 40–48.
- Guerriero Austrom, M., & Hendrie, H.C. (1990). Death of the personality: The grief response of the Alzheimer's disease family caregiver. *American Journal of Alzheimer's Care and Related Disorders and Research*, 5(2), 16–26.
- Guerriero Austrom, M., Damush, T.M., Hartwell, C.W., Perkins, T., Unverzagt, F., Boustani, M., et al. (2004). The development and implementation of non-pharmacological protocols for the management of patients with Alzheimer's disease and their families in a multi-racial primary care study. *Gerontologist*, 44, 548–553.

- Guerriero Austrom, M., Hartwell, C., Moore, P.S., Boustani, M., Hendrie, H.C., & Callahan, C.M. (2005). A care management model for enhancing physician practice for Alzheimer disease in primary care. *The Clinical Gerontologist*, 29(2), 35–43.
- Hall, K.S., Gao, S., Emsley, C.L., Ogunniyi, A.O., Morgan, O., & Hendrie, H.C. (2000). Community screening interview for dementia (CSI 'D'): Performance in five disparate study sites. *International Journal of Geriatric Psychiatry*, 15, 521–531.
- Haley, W.E., LaMonde, L.A., Han, B., Narramore, S., & Schonwetter, R. (2001). Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hospice Journal*, 15(4), 1–18.
- Harrow, B.S., Mahoney, D.F., Mendelsohn, A.B., Ory, M.G., Coon, D.W., Belle, S.H., et al. (2004). Variation in cost of informal caregiving and formal-service use for people with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 19(5), 299–308.
- Hendrie, H.C., Ogunniyi, A., Hall, K.S., Baiyewu, O., Unverzagt, F.W., Gureje, O., et al. (2001). Incidence of dementia and Alzheimer disease in 2 communities: Yoruba residing in Ibadan, Nigeria, and African Americans residing in Indianapolis, Indiana. *JAMA: The Journal of the American Medical Association*, 285(6), 739–747.
- Katzelnick, D.J., Simon, G.E., Pearson, S.D., Manning, W.G., Helstad, C.P., Henk, H.J., et al. (2000). Randomized trial of a depression management program in high utilizers of medical care. *Archives of Family Medicine*, 9(4), 345–351.
- Knopman, D.S., DeKosky, S.T., Cummings, J.L., Chui, H., Corey-Bloom, J., Relkin, N., et al. (2001). Practice parameter: Diagnosis of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, 56(9), 1143–1153.
- McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E.M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's disease. *Neurology*, 34(7), 939–944.
- Olin, J.T., Dagerman, K.S., Fox, L.S., Bowers, B., & Schneider, L.S. (2002). Increasing ethnic minority participation in Alzheimer's disease research. *Alzheimer's Disease and Associated Disorders: An International Journal*, 16(Supplement 2), S82–S85.
- Owen, J.E., Roth, D.L., Stevens, A.B., McCarty, H.J., Clay, O.J., Wadley, V.G., et al. (2002). Association of life events and psychological distress in family caregivers of dementia patients. *Aging and Mental Health*, 6(1), 62–71.
- Pruchno, R.A., & Resch, N.L. (1989). The context of change: Disorientation following intra-institutional relocation. *Journal of Applied Gerontology*, 8(4), 465–480.
- Schubert, C., Boustani, M., Callahan, C.M., Perkins, A.J., Carney, C.P., Fox, C., et al. (2006). Comorbidity profile of dementia patients in primary care: Are they sicker? *Journal of the American Geriatric Society*, 54(1), 104–109.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA: The Journal of the American Medical Association*, 282(23), 2215–2219.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L.N., et al. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes, and future directions. *The Gerontologist*, 43, 514–520.
- Schulz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist*, 35(6), 771–791.

- Simon, G.E., Katon, W.J., VonKorff, M., Unutzer, J., Lin, E.H., Walker, E.A., et al. (2001). Cost-effectiveness of a collaborative care program for primary care patients with persistent depression. *American Journal of Psychiatry*, 158(10), 1638–1644.
- Small, G.W., Rabins, P.V., Barry, P.P., Buckholtz, N.S., DeKosky, S.T., Ferris, S.H., et al. (1997). Diagnosis and treatment of Alzheimer disease and related disorders. Consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society. *JAMA: The Journal of the American Medical Association*, 278(16), 1363–1371.
- Thomas, P., Lalloue, F., Preux, P.M., Hazif-Thomas, C., Pariel, S., Inscale, R., et al. (2006). Dementia patients caregivers quality of life: The PIXEL study. *International Journal of Geriatric Psychiatry*, 21(1), 50–56.
- Unutzer, J., Katon, W., Callahan, C.M., Williams, J.W. Jr, Hunkeler, E., Harpole, L., et al. (2002). Collaborative care management of late-life depression in the primary care setting: A randomized controlled trial. *JAMA: The Journal of the American Medical Association*, 288(22), 2836–2845.
- Wells, N., Johnson, R., & Salyer, S. (1998). Interdisciplinary collaboration. *Clinical Nurse Specialist*, 12(4), 161–168.
- Whitlatch, C.J., Feinberg, L.F., & Sebesta, D.S. (1997). Depression and health in family caregivers: Adaptation over time. *Journal of Aging and Health*, 9(2), 222–243.

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