Caregiver Education and Service Utilization in African American Families Dealing with Dementia

Constance L. Coogle, Ph.D., Virginia Center on Aging, Virginia Commonwealth University

Introduction

For more than a decade attention has been focused on Alzheimer's family caregivers in African American communities. The Fourth Report of the Advisory Panel on Alzheimer's Disease to the U. S. Congress and the U.S. Department of Health and Human Services calls for "…public education and outreach efforts specifically targeted to ethnic elders and their families and communities through the development and dissemination of culturally relevant materials emphasizing both the established facts about [Alzheimer's Disease and Related Disorders] and the efficacy of seeking treatment." (Advisory Panel on Alzheimer's Disease, 1993, p. 50). While federal financing and state initiatives have addressed some of the inequities, minority family caregivers remain underserved.

Evidence suggests that African Americans and Hispanics are disproportionately at risk for developing Alzheimer's disease (Tang et al., 1998). The relationship between serum cholesterol, genetic factors (Apolipoprotein E genotype) and the risk for Alzheimer's disease in a population-based study of elderly African Americans has also been examined (Evans et al., 2000). Researchers have suggested that this evidence of differential risk should be used to develop specific counseling strategies (Green et al., 2002) and guide interventions targeted to the specific causes likely to be encountered in different racial populations (Miles, Froehlich, Bogardus, & Inouye, 2001; Shadlen, McCormick, & Larson, 2002).

Caregiver Education and Support

Although the importance of providing services for and encouraging service utilization among minority families dealing with dementia is receiving renewed attention, the need for culturally sensitive care has been well-articulated for more than twenty years (e.g., see Valle, 1981; Valle, 1998). Numerous conditions specific to African Americans present challenges in providing care to elders with dementia. African American family caregivers have a great need for information about Alzheimer's disease, affordable respite services, and counseling to resolve major family conflicts (Segall & Wykle, 1988). Another study found that despite a greater need for services and more unmet service needs among African American caregivers, they did not differ from White caregivers in terms of professional help-seeking behavior (Hinrichsen & Ramirez, 1992). One study comparing callers to a local Alzheimer's

Association Chapter found that African American caregivers had a greater interest in home health and daycare services than Caucasian caregivers (Cox, 1999). There was also a greater need for referrals, identification bracelets, and respite. The results of a one-year follow-up investigation, however, revealed that neither African American nor Caucasian caregivers had pursued their stated plans to take advantage of Chapter services. Other evidence shows that informal caregivers of elders with Alzheimer's disease in rural African American communities may be particularly unlikely to seek eldercare information or services (Wood & Parham, 1990). Although this may partly stem from privacy issues, data suggest that it is mainly a consequence of frustration with their health care providers (Lampley-Dallas, 2002), since African American family caregivers have complained about their ability to obtain appropriate information and referrals for service from their physicians (Lampley-Dallas, Mold, & Flori, 2001).

Formal health care resources are not considered a priority support option for African American caregivers, and this is likely a consequence of the need for improved cultural awareness among health care providers (Sterritt & Pokorny 1998). It is important when considering an apparent trend toward an underutilization of community service resources (see e.g., Deimling & Noelker, 1989), to examine the availability and accessibility of services. In addition, cultural values and beliefs about illness and disease among different ethnic groups can shape the meanings they assign to dementia (Farran, Miller, Kaufman, & Davis, 1997). These values and beliefs can influence who gives care and why, as well as whether caregivers seek help outside the family system (Dilworth-Anderson & Gibson, 2002). Ethnic and cultural variations may influence family perceptions about the acceptability of seeking help from outside the family (Holmes, Teresi, & Holmes, 1983). Some researchers have pointed to the lack of cultural relevance of many existing services for African Americans (Dilworth-Anderson & Gibson, 1999; Navaie-Waliser et al., 2001; Wallace, Levy-Storms, Kington, & Anderson, 1998). Although there are regional (Chatters, Taylor, & Jackson, 1985) and socioeconomic (Cantor, 1979) variations in the familial support patterns in African American communities, in general the extended family is more involved in dementia caregiving, while the primary caregiver is more likely to receive help from others (Cox, 1993). Other comparisons have shown that in contrast to White caregiving families, the sources of informal support were more varied in African American families (Lawton, Rajagopal, Brody, & Kleban, 1992). Although the strength of these informal support systems does not seem to inhibit the use of formal services, family caregiving responsibilities typically diminish as outside assistance increases (Cox & Monk, 1990). It would be most advantageous if outside assistance could contribute to promoting the skills and continuity of family caregivers. At a minimum, such interventions must not conflict with cultural norms, threaten caregiver well being, or exacerbate caregiver strain. Successful educational efforts to reach African American caregivers should seek to reinforce the basic family infrastructure. There is a need to recognize the desire to

Perspectives

remain self-reliant, while simultaneously providing an acceptable mechanism for improving caregivers' knowledge and skills. Given the dynamics of dementia caregiving among African American families, the challenge is to develop educational interventions and services that are at once sensitive to and supportive of caregivers' sense of identity and independence.

Challenges Unique to African American Family Caregivers

There is consensus, nevertheless, that African American family caregivers face challenges that typically exceed those of non-minority caregivers. Although some comparative studies have not found significant differences in the amount of strain or burden experienced by African American caregivers (Cantor, 1983; Cox, 1999; Morycz, 1985; Morycz, Malloy, Bozich, & Martz, 1987; Wood & Parham, 1990), others have found evidence that White caregivers experience significantly greater levels of burden (Hinrichsen & Ramirez, 1992; Knight, Silverstein, McCallum, & Fox, 2000; Lawton et al., 1992; Macera et al., 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995). Still others found that African American caregivers expressed high levels of burden and distress during retrospective interviews, and suggest that studies to the contrary have not addressed the cultural-historical and sociopolitical factors (i.e., lifelong discrimination and economic exploitation) that influence the experience and expression of burden (Fox, Hinton, & Levkoff, 1999). It is important to distinguish between cognitive appraisals and related psychological constructs, however, and the results of structural equation modeling suggest that the influences of ethnic group membership on perceived burden, emotional distress, and coping processes are complex and multidirectional (Haley et al., 1996; Knight et al., 2000).

Some special strains and unique strengths may be rooted in the philosophical orientation of African American culture (Wood & Wan, 1993). Evidence indicates that African American caregivers tend to use more positive reappraisal when dealing with caregiving difficulties, and this factor may be an important intervening variable moderating the level of caregiver stress (Farran et al., 1997; Haley et al. 1996; Knight & McCallum, 1998; Knight et al., 2000; Roff, Burgio, & Chaplin, 2001; Wood & Parham, 1990). Several investigators have noted the prominent use of prayer as a means of coping among African American caregivers (Levkoff, Levy, & Weitzman, 1999; Picot, 1995; Segall & Wykle, 1988; Wood & Parham, 1990; Wykle & Segall, 1991). Wood and Parham (1990) found that while Caucasian caregivers reported more behavioral coping strategies, African American caregivers used more internal cognitive strategies for coping. These included reliance on religious belief systems and more frequent reframing of the situation in positive terms. Many of these cognitions (e.g., "I have to get through this; I've been through a lot before; I'll get through this, too") reflect determination to survive the caregiving experience. Similarly, Segall and Wykle (1988) found that African American caregivers of dementia patients selected two dominant styles of coping in caring for their confused relatives: (1) prayer and faith in God, and (2) accommodating

oneself to the situation. These types of coping strategies would seem to be adaptive for Alzheimer's caregivers who may be powerless to change the external and objective stressors in the caregiving situations (Wood & Wan, 1993). In the context of southern Black culture there is a tendency among families to focus on affective, rather than cognitive functioning, and role performance is valued above intellectual ability (Gaines, 1989). The implications of this difference in relation to the way dementia is perceived may partially explain the relative resilience to the caregiving burden noted among African American family caregivers (Haley et al., 1995; Miller et al., 1995; Morycz et al., 1987). It may also relate to the observation that in African American caregiving families the use of formal (Cox & Monk, 1990) and informal (Dilworth-Anderson, Williams, & Cooper, 1999) support is more likely to be a function of the dementia care recipient's impairment level and unrelated to caregiver burden.

Culturally Sensitive Caregiver Education

The proliferation of culturally sensitive educational materials for Alzheimer's caregivers is remarkable given the preceding dearth of available resources. Some excellent materials and methods have been utilized at the grassroots level by local Alzheimer's Association chapters with guidance from the National organization (Alzheimer's Association, 1994). Most recently, the Association's website has added educational and outreach materials that focus on Alzheimer's disease in the Black/African American community (http://www.alz.org/ResourceCenter/ Diversity/BlackAfricanAmerican.htm). In 1995, the National Institute on Aging and the National Institute for Nursing Research launched Resources for Enhancing Alzheimer's Caregiver Health (REACH), a five-year initiative to characterize and test the most promising home- and community-based interventions for helping caregivers. Because of the historical lack of attention to caregiving in ethnic communities, all six of the REACH sites included substantial minority participation and responded to complex diversity issues that required special attention (Burgio et al., 2001). Four of the sites (Birmingham/Tuscaloosa, Boston, Memphis, and Philadelphia) targeted African American caregivers. At the University of Alabama at Tuscaloosa and Birmingham, the culturally sensitive intervention combined care-recipient focused behavior management skill training and caregiver focused problem-solving skills training (Burgio, 1999). Assessing appraisals of problem behaviors (i.e., behavioral bother), these investigators (Burgio, Stevens, Guy, Roth, & Haley, 2003) found the greatest improvements among African American caregivers participating in the skills training intervention, and among White caregivers who were provided minimal support (i.e., brief phone calls and written educational materials). This differential effect was obtained despite the investigators intention to develop interventions that addressed common needs while remaining responsive to cultural issues. More information about this project and other REACH Research Groups can be accessed electronically (http://www.edc.gsph.pitt.edu/reach/). The *Families Who Care* project (Coogle, 2002; Coogle & Churcher, 1996; Coogle & Finley, 1994) pointed to the most critical psychoeducational needs of African

American and rural families dealing with dementia and suggested optimal strategies for breaching the barriers to the provision of services. The important training topics uncovered in this study also approximate the themes that emerged from qualitative analyses of focus group and interview data provided by African American and Caucasian caregivers of relatives with Alzheimer's disease (Loukissa, Farran, & Graham, 1999). A description of the multicultural outreach effort conducted by this research group in a large metropolitan area (Farran, Graham, & Hicks-Barlett, 1996) also reinforces the utility of the suggestions emerging from the *Families Who Care* project. Understanding the role of culture is essential to successful outreach efforts in minority communities. "Cultural humility incorporates a lifelong commitment to self-evaluation and critique to redressing [power imbalances], and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations." (Tervalon & Murray-Garcia, 1998, p. 123).

Now that national care guidelines for culturally and linguistically appropriate services in health care have been finalized by the Office of Minority Health, Department of Health and Human Services and the Center for Cross Cultural Health Care (http://www.omhrc.gov/inetpub/wwwroot/omh/programs/ 2pgprograms/cultural4.htm), it is time also to establish culturally-relevant programming as part of the residential services available to minority and rural families dealing with dementia (see also Wykle & Ford, 1999). In addition, to improve the access to services by traditionally underserved populations, community-based programs should be located within targeted ethnic communities, as suggested by the Advisory Panel on Alzheimer's Disease (1993) and others. The Panel also recommended that specialized training for paraprofessionals, as well as professionals, be offered to increase the number of culturally capable service providers at all levels of the system. The cultural competence module incorporated into the FOCUSED (F=face-to-face, O=orient to topic, C=continue the topic, U=Unstick communication blocks, S=Structure questions, E=Exchange the conversation, D=Direct) training program to improve communication skills for nursing assistants who care for patients with Alzheimer's disease (Ripich, Wykle, & Niles, 1995) serves as a prime example of how the Panel's recommendation can be followed on a wide scale basis.

The Role of the Church

There is also a need to address the importance of engaging church leaders in outreach efforts. In African American communities, the church is probably the most important institution, and religious involvement tends to reduce the effect of stressors such as financial difficulties and health problems (Krause & Tran, 1989). It has also been instrumental in helping families manage elders with various forms of dementia (Copeland & Pollard, 1989). More recent studies have found that African American caregivers ranked God or religion as their first source of informal support (Picot, 1995; Sterritt & Pokorny, 1998). Yet, additional qualitative data from Levkoff and colleagues

Perspectives

(1999) indicates that although African American caregivers are more likely to seek support from religious organizations, many report being dissatisfied with the support they received. In the *Families Who Care* project, the inclusion of prominent members of the clergy on the project advisory group provided entree to an organization of local churches and led to the involvement of trusted church leaders who served as trainers and engaged family caregivers. The approach had been previously suggested by our colleagues (Ballard, Nash, Raiford, & Harrell, 1993; Chadiha, Morrow-Howell, Darkwa, & McGillick, 1994) and was being simultaneously employed by still others (Farran et al., 1996). Although this methodology was fruitful, anecdotal reports suggested that, because of insufficient understanding and education about Alzheimer's disease, families are not being supported by their fellow parishioners to the extent they might be.

Conclusions

Future research into the most effective methods for accomplishing caregiver education and service programs will need to incorporate what we have learned about the factors that influence caregiving outcomes and processes for African American families dealing with dementia. It is time now to test more complex models that: 1) acknowledge the imperatives of cultural sensitivity, 2) reinforce the informal infrastructure of support, and 3) build on the resiliency characteristic of family caregivers. In addition, the work needs to be conducted within a contextual framework that considers the sociocultural, interpersonal, situational, temporal and personal domains relevant to the experience of dementia caregiving in African American families (Dilworth-Anderson & Anderson, 1994). Finally, efforts must always be cognizant of the lessons evident in the literature about the barriers to service utilization, the interaction between the application of formal and informal supports, and the strategies for maximizing the acceptability and accessibility of educational outreach and intervention. It will be advantageous to employ mulitmethod approaches (Dilworth-Anderson & Burton, 1999) that use culturally relevant and sensitive instruments and specific measures of cultural variation, along with variables that capture the sociocultural characteristics and rich diversity among African American caregivers (Dilworth-Anderson, Williams, & Gibson, 2002).

Please direct all correspondence to Constance Coogle, Ph.D.; Virginia Center on Aging; Virginia Commonwealth University; P.O. Box 980229; Richmond, VA 23298-0229. 804.828.1525; clcoogle@vcu.edu.

References

Advisory Panel on Alzheimer's Disease. (1993). *Fourth report of the Advisory Panel on Alzheimer's Disease, 1992*. NIH Publication No. 93-3520. Washington, DC: U.S. Government Printing Office.

Alzheimer's Association. (1994). *Multicultural outreach program manual*. Chicago, IL: Author.

Ballard, E. L., Nash, M. A., Raiford, K., & Harrell, L. E. (1993). Recruitment of black elderly for clinical research studies of dementia: The CERAD experience. *The Gerontologist*, *33*(4), 561-565.

Burgio, L. D. (1999). Skill training for African American and Caucasian caregivers. In REACH progress report (pp. 6-15). Pittsburgh, PA: REACH Coordinating Center. Retrieved March 3, 2000, from http://www.edc.gsph.pitt.edu/reach/.

Burgio, L., Corcoran, M., Lichstein, K. L., Nichols, L., Czaja, S., Gallagher-Thompson, D., Bourgeois, M., Stevens, A., Ory, M., & Schulz, R. (2001). Judging outcomes in psychosocial interventions for dementia caregivers: The problem of treatment implementation. *The Gerontologist*, *41*(4), 481-489.

Burgio, L., Stevens, A., Guy, D., Roth, D. L., & Haley, W. E. (2003). Impact of two psychosocial interventions on White and African American family caregivers of individuals with dementia. *The Gerontologist*, *43*(4), 568-579.

Cantor, M. H. (1979). The informal support network of New York inner city elderly. In D. Gelfan, & A. Kuzik (Eds.), *Ethnicity and Aging* (pp. 153-177). New York: Springer Publishing.

Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist*, *23*, 597-604.

Chadiha, L. A., Morrow-Howell, N., Darkwa, O., & McGillick, J. (1994). Targeting the Black church and clergy for disseminating knowledge about Alzheimer's disease and caregiver's support services. *American Journal of Alzheimer's Care and Research*, *9*(3), 17-20.

Chatters, L., Taylor, R. J., & Jackson, J. S. (1985). Size and composition of the informal helper networks of elderly Blacks. *Journal of Gerontology*, *5*, 605-614.

Coogle, C. L. (2002). The Families Who Care Project: Meeting the educational needs of African American and rural family caregivers dealing with dementia. *Educational Gerontology: An International Journal*, *28*(1), 59-71.

Coogle, C. L., & Churcher, C. (1996). Implementing and evaluating multicultural outreach programs: The Families Who Care project. *Proceedings of the Alzheimer's Association Fifth Annual Alzheimer's Education Conference*, Section B2.

Coogle, C. L., & Finley, R. B. (1994). *Families who care: Assisting African American and rural families dealing with dementia*. Richmond, VA: Virginia Center on Aging.

Copeland, J., & Pollard, M. C. (1989). *The black church and the aging network: A helping hand for the elderly.* Final report (AoA Grant 06AM0414). Washington, DC: U. S. Public Health Service, Administration on Aging.

Cox, C. (1993). Service needs and interests: A comparison of African American and white caregivers seeking Alzheimer's assistance. *American Journal of Alzheimer's Disease*, *8*(3), 33-40.

Cox, C. (1999). Service needs and use: A further look at the experiences of African American and Caucasian caregivers seeking Alzheimer's assistance. *American Journal of Alzheimer's Disease*, *14*(2), 93-101.

Cox, C., & Monk, A. (1990). Minority caregivers of dementia victims: A comparison of Black and Hispanic families. *Journal of Applied Gerontology*, *9*(3), 340-354.

Deimling, G. T., & Noelker, L. (1989). *Respite use by African American family caregivers of dementia patients: Patterns of attrition and utilization*. Paper presented at the 42nd Annual Scientific Meeting of the Gerontological Society of America, Boston, MA.

Dilworth-Anderson, P., & Anderson, N. (1994). Dementia caregiving in Blacks: A contextual approach to research. In E. Light, N. Niederehe, & B. Lebowitz (Eds.), *Stress effects on family Alzheimer's patient* (pp. 385-409). New York: Springer Publishing.

Dilworth-Anderson, P., & Burton, L. (1999). Critical issues in understanding family support and older minorities. In T. Miles (Ed.), *Full color aging: Facts, goals, and recommendations for America's diverse elders* (pp. 93-105). Washington, DC: The Gerontological Society of America.

Dilworth-Anderson P., & Gibson, B. E. (1999). Ethnic minority perspectives on dementia, family caregiving and interventions. *Generations*, *33*, 40-45.

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease & Associated Disorders: An International Journal. 16*(Suppl. 2), S56-S63.

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist*, *42*(2), 237-272.

Dilworth-Anderson, P., Williams, S. W., & Cooper, T. (1999). Family caregiving to elderly African Americans: Caregiver types and structures. *Journal of Gerontology: Social Sciences*, *54B*(4), S237-241.

Evans, R. M., Emsley, C. L., Gao, S., Sahota, A., Hall, K. S., Farlow, M. R., & Hendrie, H. C. (2000). Serum cholesterol, APOE genotype, and the risk of Alzheimer's disease: A population-based study of African Americans. *Neurology*, *54*(1), 240-2.

Farran, C. J., Graham, K. L., & Hicks-Bartlett, S. (1996). Multicultural outreach efforts in a large metropolitan area. *Proceedings of the Alzheimer's Association Fifth National Alzheimer's Disease Education Conference*, Section B2.

Farran, C. J., Miller, B., Kaufman, J. E., & Davis, L. (1997). Race, finding meaning, and caregiver distress. *Journal of Aging and Health*, *9*, 316-33.

Fox, K., Hinton, W. L., & Levkoff, S. (1999). Take up the caregiver's burden: Stories of care for urban African American elders with dementia. *Culture, Medicine, and Psychiatry*, *23*, 189-198.

Gaines, A. D. (1989). Alzheimer's disease in the context of Black (southern) culture. *Health Matrix*, *6*(4), 33-38.

Green, R. C., Cupples, L. A., Go, R., Benke, K. S., Edeki, T. Griffith, P. A., Williams, M., Hipps, Y., Graff-Radford, N., Bachman, D., & Farrer, L. A. (2002). Risk of dementia among white and African American relatives of patients with Alzheimer disease. *Journal of the American Medical Association*, *287*(3), 329-336.

Haley, W., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A., Collins, R. P., & Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology*, *64*, 121-129.

Haley, W., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., & Roth, D. L. (1995). Psychological, social and health impact of caregiving: A comparison of black and white dementia caregivers and noncaregivers. *Psychology and Aging*, *10*(4), 540-552.

Hinrichsen, G. A., & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of their adaptation, adjustment, and service utilization. *The Gerontologist*, *32*, 375-381.

Holmes, D., Teresi, J., & Holmes, M. (1983). Differences among African American, Hispanic, and Caucasian people in knowledge of long-term care services. *Health Care Financing Review*, *5*(2), 51-67.

Knight, B. G., & McCallum, T. J. (1998). Heart rate reactivity and depression in African-American and white dementia caregivers: Reporting bias or positive coping? *Aging and Mental Health*, *2*(3), 212-221.

Knight, B. G., Silverstein, M., McCallum, T. J., & Fox, L. S. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *Journal of Gerontology: Psychological Science*, 55(3), P142-150.

Krause, N., & Tran, T. (1989). Stress and religious involvement among older blacks. *Journal of Gerontology: Social Sciences*, *44*, S4-S13.

Lampley-Dallas, V. T. (2002). Research issues for minority dementia patients and their caregivers: What are the gaps in our knowledge base? *Alzheimer Disease and Associated Disorders: An International Journal*, *16*(Suppl. 2), S46-S49.

Lampley-Dallas, V. T., Mold, J. W., & Flori, D. E. (2001). Perceived needs of African-American caregivers of elders with dementia. *Journal of the National Medical Association*, *93*(2), 47-57.

Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology: Social Sciences*, *47*, S156-S164.

Levkoff, S., Levy, B., & Weitzman, P. F. (1999). The role of religion and ethnicity in the help seeking of family caregivers of elders with Alzheimer's disease and related disorders. *Journal of Cross-Cultural Gerontology*, *14*(4), 335-356.

Loukissa, D., Farran, C. J., & Graham, K. L. (1999). Caring for a relative with Alzheimer's disease: The experience of African-American and Caucasian caregivers. *American Journal of Alzheimer's Disease*, *14*(4), 207-216.

Macera, C. A., Eaker, E. D., Goslar, P. W., Deandrade, S. J., Williamson, J. S., Cornman, C., & Jannarone, R. J. (1992). Ethnic differences in the burden of caregiving. *The American Journal of Alzheimer's Care and Related Disorders & Research*, *7*(5), 4-7.

Miles, T. P., Froehlich, T. E., Bogardus, S. T., & Inouye, S. K. (2001). Dementia and race: Are there differences between African Americans and Caucasians? *Journal of the American Geriatrics Society*, *49*(4), 477-484.

Miller, B., Campbell, R. T., Farran, C. J., Kaufman, J. E., & Davis, L. (1995). Race, control, mastery, and caregiver distress. *Journal of Gerontology: Social Sciences*, *50B*, S374-S382.

Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. *Research on Aging*, *7*, 329-361.

Morycz, R. K., Malloy, J., Bozich, M., & Martz, P. (1987). Racial differences in family burden: Clinical implications for social work. *Journal of Gerontological Social Work*, *10*(1-2), 133-154.

Navaie-Waliser, M., Feldman P. H., Gould, D. A., Levine, C., Kuerbins, A. N., & Donclan, K. (2001). The experiences and challenges of informal caregivers: common themes and differences among whites, blacks, and Hispanics. *The Gerontologist*, *41*(6), 733–741.

Picot, S. (1995). Rewards, costs, and coping of Black American caregivers. *Nursing Research*, *44*, 147-152.

Ripich, D. N., Wykle, M., & Niles, S. (1995). Alzheimer's disease caregivers: The FOCUSED program. *Geriatric Nursing*, *16*(1), 15-19.

Roff, L., Burgio, L., & Chaplin, W. (2001). Positive aspects of caregiving: Differences between African American and Caucasian dementia caregivers. *The Gerontologist*, *41*(Special Issue 1), 12.

Segall, M., & Wykle, M. (1988). The African American family's experience with dementia. *Journal of Applied Social Sciences*, *13*(1), 170-191.

Shadlen, M.-F., McCormick, W. C., & Larson, E. B. (2002). Research agenda for understanding Alzheimer's disease in diverse populations: Work group on cultural diversity, Alzheimer's Association. *Alzheimer Disease & Associated Disorders: An International Journal*, *16*(Suppl. 2), S96-S100.

Sterritt, P., & Pokorny, M. (1998). African American caregiving for a relative with Alzheimer's disease. *Geriatric Nursing*, *19*, 127-134.

Tang, M. X., Stern, Y., Marder, K., Bell, K., Gurland, B., Lantigua, R., Andrews, H., Feng, L., Tycko, B., & Mayeux, R. (1998). The APOE-epsilon4 allele and the risk of Alzheimer disease among African Americans, Caucasians, and Hispanics. *Journal of the American Medical Association*, *279*(10), 751-755.

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, *9*(2), 117-125.

Valle, R. (1981). Natural and support systems, minority groups, and the late life dementias: Implications for service delivery, research, and policy. In N.E. Miller, & G.D. Cohen (Eds.), *Clinical aspects of Alzheimer's disease and senile dementia* (pp. 277-298). New York: Raven Press.

Valle, R. (1998). *Caregiving across cultures: Working with dementing illness and ethnically diverse populations*. Philadelphia, PA: Brunner/Mazel.

Wallace, S., Levy-Storms, L., Kington, R. S., & Andersen, R. M. (1998). The persistence of race and ethnicity in the use of long-term care. *Journal of Gerontology: Social Sciences*, *53B*, S104–S113.

Wood, J. B., & Parham, I. A. (1990). Coping with perceived burden: Ethnic and cultural issues in Alzheimer's family caregiving. *Journal of Applied Gerontology*, *9*, 325-339.

Wood, J. B., & Wan, T. T. H. (1993). Ethnicity and minority issues in family caregiving to rural African American elders. In C. M. Barresi, & D. E. Stull (Eds.), *Ethnic elderly and long-term care* (pp. 39-56). New York: Springer Publishing.

Wykle, M., & Ford, A. B. (Eds.). (1999). *Serving minority elders in the 21st century*. New York: Springer Publishing.

Wykle, M., & Segall, M. (1991). A comparison of black and white family caregivers' experience with dementia. *Journal of the National Black Nurses Association*, *5*, 29-41.