

**Providing Dementia-Specific Services to Family Caregivers:  
North Carolina's Project C.A.R.E. Program**

**ABSTRACT**

While options for family caregivers in the United States have expanded, many families are not reached by support services, due to geographical and cultural isolation. North Carolina, one of 38 states participating in the Alzheimer's Disease Demonstration Grants to the States (ADDGS) program, targets underserved rural and minority caregivers through Project C.A.R.E. (Caregiver Alternatives to Running on Empty). Under this program, families can receive up to \$2000 annually for services ranging from community-based respite to more comprehensive care (in-home and overnight respite, training and emotional support). Services are coordinated by a family consultant (FC) at each of the program's three sites (Asheville, Charlotte, and Winston-Salem). Since the program's inception in 2001, the FC's have successfully developed a network of support services where none previously existed. Project C.A.R.E. serves as a model to other states in delivering dementia-specific services to vulnerable populations.

## INTRODUCTION

In the United States, family members provide the majority of care received by persons with Alzheimer's disease and other dementias. National policies designed to alleviate the burden of family caregivers are a relatively recent development and dementia-specific services are not offered through Medicare, Medicaid, or the National Family Caregiver Support Program. The states are left to their own devices to provide these services. Since 2001, North Carolina has targeted dementia-specific services to rural and minority caregivers through Project C.A.R.E. (Caregiver Alternatives to Running on Empty). This program uses a consumer-directed family consultant model to deliver comprehensive respite care at three sites: Asheville, Winston-Salem, and Charlotte. Project C.A.R.E.'s success in developing a grass-roots network of dementia-specific services where none previously existed provides officials in North Carolina and other states a model for reaching underserved caregivers.

## BACKGROUND

### **Family Caregivers: Demographics and Vulnerable Populations**

Alzheimer's disease is the most common cause of dementia in older adults (Katzman, 1995). The number of people with dementia is expected to quadruple in 50 years (Brookmeyer, Gray, & Kawas, 1998). The United States is expected to witness a 44 percent increase in individuals with Alzheimer's disease by 2025. States with a rapidly increasing older population, such as North Carolina, are expected to face the greatest challenges (Hebert, Scherr, Bienias, Bennett, & Evans, 2004). In 2000, an estimated 130,000 older adults in North Carolina had mild, moderate or severe Alzheimer's disease. By 2025, the total number is expected to increase by 91% to 250,000 (Alzheimer's Association, 2006).

Most people with dementia live at home and are cared for by their family members and friends (Dilworth-Anderson, Williams, Gibson, 2002). As dementing illness progresses, affected individuals increasingly rely

on family members for basic personal care. Although some research recognizes positive benefits of caregiving (Haley, Gitlin, Wisniewski, Mahoney, Coon, Winter, et al., 2004; Picot, 1995), it is well-understood that dementia caregivers need instrumental and psychosocial support (Sörensen, Pinquart, & Duberstein, 2002). Caring for a loved one with dementia requires long hours of continuous supervision and response to increasing dependence. Dementia caregivers experience high levels of emotional and physical stress, leading to high levels of perceived burden and poorer well-being (Hooker, Bowman, Coehlo, et al., 2002; Schulz & Beach, 1999). They provide care that is more challenging physically and emotionally and more time consuming, which takes a heavier toll on work and family life (National Alliance for Caregiving, 2004). Most importantly, they are more isolated than other caregivers, and limited in their access to available support in the community.

There is a growing realization that institutionalization of the demented older adult may be reduced by increasing the range of services available in the community (Kosloski & Montgomery, 1993; Montgomery, Marquis, Schaefer, & Kosloski, 2002). Professional health and human services are needed to supplement the care provided by family members (Toseland, McCallion, Gerber, & Banks, 2002). Identifying underserved family caregivers is an important first step. First, few programs target the needs of minority caregivers (Cox & Monk, 1996), despite a desire to access culturally relevant programs (Dilworth-Anderson et al., 2002). A second group of dementia caregivers underutilizing support services are families who live in rural areas are often limited regarding choice of services available.

### **Public Policy towards Family Caregivers**

In the United States, the responsibility for addressing the unmet needs of family caregivers has been devolved to the states, giving them the opportunity to become “laboratories of innovation” (Bovbjerg, Wiener, & Housman, 2003). The states have several avenues for expanding LTC services for family

caregivers (Wiener & Tilly, 2003). States can shift LTC expenses from Medicaid to Medicare, a practice known as Medicare maximization. States can create tax incentives for LTC insurance, providing coverage for expenses otherwise met out-of-pocket by family caregivers. States can integrate acute and LTC services, for example, through the Program of All-Inclusive Care for the Elderly (PACE). A fourth option is the National Family Caregiver Support Program (NFCSP), created under the OAA Amendments of 2000.

Finally, Alzheimer's Disease Demonstration Grants to the States (ADDGS) programs in 38 states provide families direct respite care and support services. There are several advantages to the ADDGS mechanism. First, this program supports families in their choice to provide care in their own homes. Second, it draws support from resources beyond Medicare and Medicaid, leveraging new sources of funding. Third, it fosters private-public partnerships between state and local governments and organizations within the aging network. Finally, in contrast to the NFCSP, the ADDGS program provides dementia-specific services (Montgomery, et al., 2002).

## **CURRENT STUDY**

### **Purpose**

The current study examines the implementation of the ADDGS program in North Carolina. In 1993, the State was awarded its first ADDGS grant, which led to the creation of Project C.A.R.E. in 2001. Project C.A.R.E. is designed to target dementia-specific services to family caregivers from rural and minority communities that have lacked access to adequate resources due to reasons including geographic isolation, economic distress, and historical racial and cultural biases. Project C.A.R.E. is administered by the state's Division of Aging and Adult Services (DAAS), in cooperation with the Western Carolina chapter of the Alzheimer's Association, Mecklenburg County Department of Social Services (DSS), and Duke Family Support Program (RTI International, 2006).

In this study, we examine Project C.A.R.E.'s implementation, service provision, and future goals through the perspective of the family consultants (FC's) at the program's three sites (Asheville, Winston-Salem, and Charlotte). We will demonstrate that while the FC's share core principles, each Project C.A.R.E. site is unique. This individuality is due in part to the organizational structure in which each FC operates. It is also due to the specific network of service providers, churches, and other institutions that each FC has developed. Finally, services are distinct at each site due to the needs of the target populations in each community, particularly those of rural and minority caregivers.

## **Methods**

We conducted face-to-face, semi-structured interviews with the FC at each of the three Project C.A.R.E. site offices (Asheville, Winston-Salem, and Charlotte) in order to discuss the program's implementation, service delivery, and future goals. The semi-structured questions became a guide to foster conversations so that the FC's could describe their experience in their own words. Interview questions were open-ended and were designed to explore particularly service delivery, the use of respite care as a portal for other services, and the target populations served at each site. Each interview lasted approximately 30 to 60 minutes.

We also used the interview process to identify larger themes that may have helped to determine the success of Project C.A.R.E. For example, we queried FC's at each site about the advantages and disadvantages of a consultant's location in an Alzheimer's Association chapter versus a county department of social services. We also asked FC's to describe partnerships with service providers, churches, and other institutions they have developed and sustained in Project C.A.R.E.'s first five years of operation. Finally, we

discussed with the FC's their expectations for the future of Project C.A.R.E. and the resources that will be needed to meet these goals.

In addition to these three interviews, we discussed Project C.A.R.E. with other informed individuals, including the program's director in the state's Division of Aging and Adult Services (DAAS), the director of the North Carolina Family Caregiver Support Program, other DAAS personnel, service providers in the respective communities, and the Director of the Duke Family Support Program. Follow-up interviews with the three FC's were also conducted as needed. Qualitative content analysis was used to analyze the data (Miles & Huberman, 1994). Research team members met to identify similar phrases, patterns and themes to construct a formalized body of knowledge from the generalizations derived by the data.

## **RESULTS**

### **Project C.A.R.E. Site Visits**

Project C.A.R.E. services are coordinated by a FC at each of the program's three sites (Asheville, Charlotte, and Winston-Salem). Families enrolled in Project C.A.R.E. may receive up to \$2000 a year in assistance. This stipend is only used for direct respite care services, which are often a portal to more comprehensive programs and services for Project C.A.R.E. families. Project C.A.R.E. funds can be used by families for in-home care, adult day services, and overnight respite. Eligible clients, as defined by the guidelines of the program, are individuals with dementia who live in the areas served by these FC's and are not already receiving services through the North Carolina's Community Alternatives Program for Disabled Adults (CAP/DA), the state's Medicaid home and community-based waiver program for low-income disabled adults (Bratesman, 1997). The intent of the program is to serve people on fixed incomes with few resources as quickly and effectively as possible.

*Asheville*

**Implementation.** The FC for Project C.A.R.E. in Asheville is responsible for implementing the program across six counties in a rural, mountainous region in western North Carolina. Within this target population, the FC describes two types of families served by Project C.A.R.E. The first group consists of native North Carolina families who have lived in the state most of their lives, typically in economically depressed areas where most people were employed in industries like textiles and furniture. Many elders in these families have worked all their lives and have few resources to deal with Alzheimer's disease. Further, the adult children in these families are frequently suffering from their own economic stress, leaving the caregiving burden to the elder spouse. The second group of Project C.A.R.E. clients includes persons who have migrated to the Asheville region, who tend to have higher incomes and may be more comfortable in working with public and private agencies. However, these individuals may lack available family support and may not know how to navigate the local network of service providers.

For both types of families, the Asheville FC provides the same role: that of listener and mediator. Often, the primary caregiver has nobody to talk to. As the FC describes, this can "cause the floodgates to open" at the time of the initial assessment. The FC can facilitate necessary conversations that have not yet taken place. Often, family members will not listen to each other, but will listen to the FC. Project C.A.R.E. clients can find respite care services or they can be arranged and coordinated by the FC. According to the Asheville FC, the latter is more likely to occur, as beleaguered caregivers are often more than happy to have Project C.A.R.E. take the lead.

In 2005, the Asheville FC was promoted to the position of Director of Respite and Mountain Area Policy for the Western Carolina Alzheimer's Association. In this capacity, the FC has increased access to the resources and training materials of the state and national organizations. This dual role constitutes a

significant advantage; according to the Asheville FC, "Project C.A.R.E. gets me for free". Further, there is no significant disadvantage to this organizational structure, as the Alzheimer's Association allows this FC to provide caregivers in the Asheville area with core services such as the Safe Return program, a toll-free help line, support groups, training workshops, educational resources, and information and referral. Beyond these benefits, the Asheville FC adds that the support of colleagues at the Alzheimer's Association helps in shouldering an emotional burden that would be difficult to bear in a more isolated setting.

**Service delivery.** In the six-county area served by the Asheville FC, a total of 434 enrolled families have received direct services (home and community-based respite care) from Project C.A.R.E. in the program's first five years (see Table 1), with another 365 non-enrolled families receiving ancillary services such as information, counseling, and referral. A challenge for the Asheville FC has been in locating appropriate resources in a region in which public programs targeting persons with dementia are limited. For example, a single adult day center covers a four-county area in this part of the state (Transylvania, Henderson, Rutherford, and Madison). In addition, while one county has multiple home care agencies, in two other counties, in-home supportive services (IHSS) are not available. Due to these gaps in public programs, Project C.A.R.E. clients in the Asheville area may use the \$2000 in available funds to hire private in-home care or to pay for expenses such as transportation.

The Asheville FC has addressed these gaps in public programs by forming partnerships with local providers. Provider agencies (such as Hospice) are among the principal sources of referrals for Project C.A.R.E. The NFCSP allocates some funds for direct respite services. In addition, local LTC providers, including the Veterans Administration and the Black Mountain Center (a state-sponsored Alzheimer's and Developmental Disabilities program) offer overnight respite for caregivers, with secure units for persons with dementia. Finally, Project C.A.R.E. utilizes the resources and expertise of the State Division of Aging

and Adult Services and the Duke Family Support Program. In total, the Asheville site has utilized 45 different provider agencies during Project C.A.R.E.'s first five years.

**Future goals.** The Asheville FC describes longevity and teamwork among collaborators as key accomplishments of Project C.A.R.E. Another is the volume of families that have been helped by Project C.A.R.E., which includes approximately 500 additional families who have received consultation and referral. The day-to-day challenge, as he sees it, is keeping up with the rising demand for dementia-specific services. With 70-80 families in the program at any given time, and new referrals constantly arriving, the "ripple effect" for Project C.A.R.E. continues to grow. This Asheville FC is concerned that current federal support for Project C.A.R.E. will not match the future rise in demand. According to this FC, the primary objective for Project C.A.R.E. in the future is finding the necessary state and local funding to sustain and grow the program. The FC would like to see Project C.A.R.E. explore new partnerships, as well as find new ways to continue working with existing partners.

#### *Winston-Salem*

**Implementation.** The FC at the Winston-Salem site oversees a three-county area (Forsyth, Stokes, and Surry counties), where Project C.A.R.E. addresses the needs of two distinct groups of clients. In Forsyth County, Project C.A.R.E. was initially targeted to families in Winston-Salem's African American community, a historically underserved population prioritized in the original ADDGS program. The Winston-Salem FC described the early implementation of the program through community outreach, particularly through educational and training programs centered in the city's African American churches. Over the past two years, the scope of Project C.A.R.E. in Winston-Salem has expanded to serve clients in the neighboring rural counties of Stokes and Surry, which are largely white.

Working with these two distinct groups has created unique challenges for the Winston-Salem FC, some by virtue of race, others due to the rural nature of the area being served. An initial obstacle in working with African American and white caregivers alike is defining the problem of dementia and the services Project C.A.R.E. has to offer. As the Winston-Salem FC describes, educational materials explaining Alzheimer's disease are often unclear to this clientele, as is an understanding of what is meant by terms such as "respite". In addition, the increased diversity of clients has prompted changes in how this FC implements Project C.A.R.E. For example, among African American families in Winston-Salem, enrollment of caregivers was frequently initiated in the churches, which are a trusted presence in the community. However, among white families in Stokes and Surry counties, referrals have largely come from service providers, such as the local Area Agency on Aging and word of mouth referrals. As the Winston-Salem FC explains, established agencies are often the only way to gain entry in these counties.

Project C.A.R.E.'s FC in Winston-Salem also helps coordinate the services of the Triad Area office of the Western Carolina Alzheimer's Association chapter. As is the case in Asheville, this dual responsibility gives the Winston-Salem FC access to a wealth of dementia-specific programs and resources from both the state and national organization. The Winston-Salem FC agrees that this constitutes a significant advantage for the population served by Project C.A.R.E. in terms of the depth and variety of programs that the Alzheimer's Association offers. This is particularly vital in rural areas, where there may not be health professionals experienced in diagnosing dementia. However, the FC also notes that the placement of Project C.A.R.E. within an Alzheimer's Association chapter may represent a disadvantage initially, as families may not readily identify the unique and comprehensive services Project C.A.R.E. offers, such as in-home assessment and connections to community resources. These services would be difficult for the Alzheimer's Association to replicate, if Project C.A.R.E. funding is not continued.

**Service Delivery.** The Winston-Salem FC describes the provision of relief to caregivers at this site as “referral first, then respite”. Through training and public speaking events, this FC has worked over the past five years to create an increased public awareness of dementia, a problem that is often perceived as a private family matter. Once an understanding within the community has been established, the FC can help, beginning with the initial assessment. This is performed by one or more trained individuals (the FC, social workers, etc.), depending on the need. These assessments allow the FC to direct families either to home and community-based respite services available through Project C.A.R.E. or to services through existing county DSS programs with which they may not have been familiar. As Table 1 demonstrates, 359 families were enrolled in Project C.A.R.E. from 2001 to 2006 in Forsyth, Stokes, and Surry counties. In addition, another 284 families have received information, consultation, and referral without respite funding. As this FC notes, the number of families enrolled in Project C.A.R.E. “only scratches the surface” of the number of people that are helped in some way through the program.

The Winston-Salem FC also stresses the importance of relationship-building. This FC has had particular success in expanding services to family caregivers through the area’s existing long-term care providers, utilizing 27 different agencies. Currently, short-term or overnight respite is available at three assisted living facilities and at 32 skilled nursing facilities. However, in the rural counties where Project C.A.R.E. has recently expanded, establishing a network of providers is a greater challenge due to the relative scarcity of professional resources. For example, Stokes and Surry counties are each served by only two senior centers.

**Future Goals.** The FC hopes to sustain Project C.A.R.E.’s growth in Winston-Salem and surrounding areas, building upon the relationships and trust that have been established, particularly with the African American community. The expansion of Project C.A.R.E. to Stokes and Surry counties has also created the

need for the development of new partnerships. In order to effectively serve this new clientele, the Winston-Salem FC plans to work closely with the AAA. This FC has expressed concern for the continuation of services unique to Project C.A.R.E. in the event that federal funding ceases. The Winston-Salem FC emphasizes the importance of establishing contacts with advocacy groups and legislative allies to help secure annual state funding to support the existing program infrastructure and service capacity.

### *Charlotte*

**Implementation.** The Charlotte FC is based within the Mecklenburg County Department of Social Services (DSS). As this FC describes, Project C.A.R.E. has filled the gap in respite and dementia care services in the Charlotte area since the program's inception. Project C.A.R.E. has been the "first responder" in Mecklenburg County to families seeking dementia-specific services. The Charlotte FC describes Project C.A.R.E. as being targeted to the city's low income and minority populations; for example, over 75% of the caregiver and dementia training events held in Charlotte are conducted in lower-income areas. Much of this outreach is performed in African American churches, with an increasing number of events addressing the city's growing Latino population. Unlike other DSS programs, which restrict services to clients with limited resources, Project C.A.R.E. does not employ means testing, serving families both just above and below the Medicaid income limit.

According to the Charlotte FC, the location of this Project C.A.R.E. office within the Mecklenburg County DSS is imbued with several unique advantages. The FC describes an innovative organizational culture supportive of the DSS taking the local lead in concerns such as family caregiving and senior-friendly community planning. Further, DSS personnel provides a pool of experienced social workers, who are knowledgeable of local service providers and specifically trained and experienced in accessing dementia-specific resources. This has resulted in an organization with renewed energy and dedication, one in which

individual staffers have willingly taken ownership of different aspects of Project C.A.R.E. At the same time, the presence of the Project C.A.R.E. FC within the DSS raises challenges, such as maintaining the visibility of the program. The FC concedes that there can be an identity problem, in that families may not distinguish Project C.A.R.E. services from others provided by DSS.

**Service Delivery.** In Mecklenburg County, 232 families have been enrolled in Project C.A.R.E. (see Table 1), with another 63 non-enrolled families receiving services as well. According to the Charlotte FC, Project C.A.R.E. adheres to the original intent of the ADDGS grant at this site by directing its resources towards direct services, specifically home and community-based respite care. In conjunction with the local Alzheimer's Association Chapter based in Charlotte, the FC provides education and training in dementia care to families as well as to Mecklenburg County DSS staff. These indirect services are particularly vital to the city's growing Hispanic population. An increasing proportion of these families are providing long-distance caregiving, according to the Charlotte FC.

Community partners both within and outside the Mecklenburg County DSS assist in the coordination of respite and support services. Project C.A.R.E. works closely with several of the Department's programs, including In-Home Supportive Services and Meals-on-Wheels. Supplemental services are also provided to Project C.A.R.E. clients through the National Family Caregiver Support Program (NFCSP), Hospice, the Alzheimer's Association, Love Inc. (an information clearinghouse for a number of area churches) and others. The parish nurse program in Charlotte is a consistent source of referrals for Project C.A.R.E. The Charlotte FC also cites widespread support in Charlotte's faith community for Project C.A.R.E., particularly among the city's African American clergy. Eighteen different provider agencies have been utilized by the Project C.A.R.E. in Charlotte over the past five years.

**Future Goals.** The Charlotte FC identifies a lack of resources and funding as the greatest challenge presently faced by Project C.A.R.E. The program is often faced with the dilemma of whether to help a limited number family caregivers to the fullest extent or to help as many caregivers as possible. In response to possible budget shortfalls in the future, the Charlotte FC has prioritized the continued development of local partnerships to explore new community resources as well as writing letters to ministers, business leaders, and city and county employees to aid in advocacy and fundraising efforts. When attempting to expand the resources available to Project C.A.R.E. within Mecklenburg County, the FC notes that Project C.A.R.E. is somewhat restricted by its location within the county DSS; departmental approval is required for every action that is taken to expand the profile of the program.

## **DISCUSSION**

Since its inception in 2001, Project C.A.R.E. has enabled North Carolina to target dementia-specific services to some of the state's most vulnerable citizens. Project C.A.R.E. is designed to be more responsive to the specific needs of each family and community the program serves. Consequently, in certain aspects, the three FC's have diverged from each other in their implementation of this program. For example, the Winston-Salem FC has refrained from using the term "respite", a term this FC describes as having little meaning for the target population in this community. The FC's also vary in the number and type of community partners they have enlisted. The Charlotte FC has accessed a variety of public resources in Mecklenburg County, while the Winston-Salem FC has made inroads in this city's faith community. Finally, the selection and use of services at each site differ, which is partly due to the individual needs and preferences of caregivers as well as the availability of the different types of respite and support services within each community.

Beyond these external differences in service provision, several common themes emerged from our interviews with the Project C.A.R.E. FC's. These included the following:

**Building relationships.** The three FC's have identified local partnerships as integral components of the growth of Project C.A.R.E. Each consultant has raised awareness of the availability, need for and value of dementia-specific services in communities in which families lacked access to these resources. Establishing initial contacts required patience, persistence and flexibility; these efforts resulted in strong community partnerships that helped to address the needs of the underserved target populations. Enlisting local provider agencies has enabled the FC's to connect beleaguered caregivers directly to community-based respite support without duplicating existing services. This builds upon the trust established by the FC during the initial in-home assessment.

**Use of existing infrastructure.** Project C.A.R.E. FC's have maximized the strengths of the organizations in which they are based. In terms of the Alzheimer's Association, these include this organization's educational resources and support programs, as well as the experience and expertise of management and staff specific to dementia. At the same time, the location of Project C.A.R.E. within the infrastructure of county government in Charlotte has afforded unique advantages as well, such as the availability of trained social workers and the opportunity to coordinate directly with other public health and social service providers. The successful integration of Project C.A.R.E. into both types of organizations indicates that the program can be successfully implemented in a variety of public and private models.

**Emerging populations.** A third common theme identified in the interviews with the FC's is the expansion Project C.A.R.E. beyond its initial target population. In Asheville, an influx of retirees from other states has increased the demand for dementia-specific services. The Winston-Salem site office now enrolls rural

caregivers from primarily white communities in Stokes and Surry counties. In Charlotte, Project C.A.R.E. services are increasingly directed towards the city's growing Hispanic population. In each instance, the Project C.A.R.E. FC has broadened the program's outreach to encompass a more heterogeneous population. The successful adaptation of Project C.A.R.E. across distinctions such as race, economic class, and geographic location at its three existing sites augur well for future expansion of the program.

## **FUTURE DIRECTIONS**

The primary long-term goal for Project C.A.R.E. is to ensure the sustainability and expansion of the program. All three FC's have noted that as the visibility of Project C.A.R.E. has increased, so has demand, both from their original target clientele and from emerging populations in their respective service areas. The Asheville FC describes long waiting lists as the overriding daily concern. At times, Project C.A.R.E. seems like a "victim of its own success", as the Program's growing reputation brings an increase in inquiries and referrals, several from outside the geographic areas targeted by the original ADDGS grant.

Sustaining the current level of financial support at the three existing sites is critical in order for the program to continue to provide effective and comprehensive services to clients. The ultimate objective is to gradually expand Project C.A.R.E. statewide, particularly in counties in eastern North Carolina with large underserved rural and minority populations. However, uncertainty over future funding is a potential obstacle to the goals of sustaining and expanding Project C.A.R.E. Federal funding of the ADDGS program is due to expire in June 2007. If federal funding is not renewed, Project C.A.R.E. will have to turn to other resources to meet its objectives, such as state funding and support from private foundations.

The lessons of Project C.A.R.E are valuable for policy planners in North Carolina and in other states. In an era in which states are asked to do more with less, this program has successfully leveraged new sources of

funding to meet the needs of some of the state's most vulnerable citizens. At the same time, Project C.A.R.E. has fostered the development of a grassroots network of dementia-specific services in communities where help for caregivers had been fragmented and inaccessible. Public and private partnerships such as Project C.A.R.E. are critical as the number of Americans affected by dementia continues to grow.

## REFERENCES

- Alzheimer's Association (2006). *Alzheimer's Disease Statistics*. Chicago, IL: Alzheimer's Association.
- Bovbjerg, R.R., Wiener, J.M., & Housman, M. (2003). State and federal tolls in health care: Rationales for allocating responsibilities. Chapter 3 in J. Holahan, A. Weil, & J.M. Wiener (Eds.), *Federalism & Health Policy*. Washington, DC: The Urban Institute Press.
- Bratesman, S., Jr. (1997). North Carolina's CAP/DA population: Is CAP/DA on target? Durham, NC: Duke Long Term Care Resources Program.
- Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and public health impact of delaying disease onset. *American Journal of Public Health, 88*, 1337-1342.
- Cox, C., & Monk, A. (1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer' relatives. *International Aging and Human Development, 43*, 93-105.
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist, 42*, 237–272.
- Haley, W., Gitlin, L., Wisniewski, S., Mahoney, D., Coon, D., Winter, L., et al. (2004). Well-being, appraisal, and coping in African American and White dementia caregivers: Findings from the REACH study. *Aging & Mental Health, 8*, 316–329.
- Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2004). State-specific projections through 2025 of Alzheimer disease prevalence. [miscellaneous article]. *Neurology, 62*(9), 1645.
- Hooker, K., Bowman, S. R., Coehlo, D. P., Lim, S. R., Kaye, J., Guariglia, R., et al., (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journal of Gerontology: Psychological Sciences, 57B*, P453-P460.
- Katzman, R. (1995). Alzheimer's disease. *New England Journal of Medicine, 314*, 964-973.

Kosloski, K., & Montgomery, R. (1993). Perceptions of respite services as predictors of utilization.

*Research on Aging, 15*, 399-413.

Miles, M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis* (2<sup>nd</sup> edition). Thousand

Oaks, CA: Sage.

Montgomery, R.J.V., Marquis, J., Schaefer, J.P., & Kosloski, K. (2002). Profiles of respite use. *Home*

*Health Services Quarterly, 21* (3/4), 33-63.

National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S.* A report by the Alzheimer's

Association and National Alliance for Caregiving, 1-45.

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

152.

RTI International (2006). *Alzheimer's Disease Demonstration Grants to States Program:*

*North Carolina*. Final Report. Washington, DC: RTI International.

Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An

updated meta-analysis. *The Gerontologist, 42*, 356-372.

Toseland, R. W., McCallion, P., Gerber, T., & Banks, S. (2002). Predictors of health and

human services use by persons with dementia and their family caregivers. *Social*

*Science & Medicine, 55*, 1255-1266.