

**Promoting an Effective Partnership Between Families Coping  
with Alzheimer's Disease and Their Healthcare Providers**

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## Abstract

The primary objective of this project was to identify the needs of family caregivers and healthcare providers who care for persons with dementia. Participants included 128 self-selected caregivers, who completed a telephone or online survey, and 27 healthcare providers, who participated in a focus group and completed a survey. The hypothesis that primary care physicians were more likely to diagnose Alzheimer's disease than a specialist was not supported. Caregivers reported their primary source of information about the disease was the doctor; however, the majority reported they were not told about available resources. Healthcare providers identified time with patients and families, and awareness of community services as their main challenges. Policy implications include addressing these health literacy issues. Recommendations proposed: increased awareness of the local Alzheimer's Association; promotion of training programs for the dementia care triad; and utilization of technology for families and professionals to track the needs of persons with memory loss.

## **Promoting an Effective Partnership Between Families Coping with Alzheimer's Disease and Their Healthcare Providers**

Currently, nearly 4.5 million individuals in the U.S. have received a diagnosis of Alzheimer's disease (Alzheimer's Association, 2003a). The growth of the number of individuals with Alzheimer's disease (AD) in the Commonwealth of Virginia is expected to increase by 18% to 30,863 in 2010, up from 26,120 in 2000 (Evans, et al., 1989). More than 80% of individuals with AD are cared for at home by family members. Many family members are ill-equipped to provide for the needs of a loved one with increasing memory loss. Individuals can live as long as 20 years with the disease and due to the disease's progressive nature, family members often report their loved one loses many capabilities. These skills include the ability to drive, to manage personal hygiene, to converse, to recognize close friends and family, and ultimately to feed oneself.

### *Role of Healthcare Providers*

Many family caregivers depend on their loved one's primary care physician for direction in not only what to expect as the disease progresses, but how to physically and emotionally manage the changing conditions of their loved one (Miller, Glasser, & Rubin, 1992). A 1992 study, based on interviews with 88 family caregivers, found overall satisfaction with medical care. However, vague diagnoses and limited information about or referrals to support services were frequently reported (Haley, Clair, & Saulsberry, 1992). Similar experiences were reported in the 2002 national survey "Long-Term Care from the Caregiver's Perspective" conducted by Kaiser Family Foundation, Harvard School of Public Health, and the National Opinion Research Center (Gould, 2004).

According to a 2001 study conducted by Roper Starch Worldwide, Inc. for the Alzheimer's Association (2001), a communication gap exists between family caregivers and the care recipient's primary care physician. Based on telephone surveys with family caregivers (N = 376) and U.S. physicians (N = 500), physicians perceive they are providing more information about AD than family caregivers report they need. Researchers affiliated with the study developed and distributed a "Caregiver Survey" and a "Physician Alzheimer Survey." Fifty-eight percent of caregivers with suspicions about their relative's memory problems sought out a primary care physician for information about AD. Other commonly reported sources of information included magazines/newspapers (30%) and family/friends (29%). Approximately half (53%) of the caregivers reported the doctor as being very knowledgeable about the disease and about treatments.

A particularly startling finding from the study was related to the physician's attitude about the disease. More than three-quarters (80%) of doctors reported their belief that the disease can be stabilized, if treated early, and a treatment regimen including medication, support services, and lifestyle changes, is recommended. Less than one-third (32%) of caregivers reported that the doctor told them about these possibilities. Likewise, 45% of caregivers reported wanting more information about where to find help and services and approximately one-third (31%) of the caregivers reported that the doctor provided this information. Nearly 90% (88%) of the primary care physicians reported that they provided this information. This study demonstrates the disparity that can exist between family caregivers and primary care physicians with respect to a number of care-related issues, including treatment plans and referral to support services (Alzheimer's Association, 2001). Clearly, factors such as the doctor's amount of time per patient and denial of the disease on the part of the family caregiver or patient can create

barriers to meeting the needs of the person with AD (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Teel & Carson, 2003).

An interesting paradox emerges: “The physician is prepared to stake expertise on diagnosis of dementing disorders, while the family caregiver expects physician intervention at the level of management and treatment (Miller, Glasser, & Rubin, 1992, p. 136). How then, are support systems put in place so that caregivers and healthcare providers can achieve a balance between what is needed and what is provided in order to maintain optimal care for the person with dementia throughout the course of the disease?

The Alzheimer’s Association (2003b) developed a brief manual entitled “Partnering with Your Doctor: A Guide for Persons with Memory Problems and Their Care Partners” to facilitate discussion between the family caregiver and the physician providing care to the person with AD. This manual explains how the diagnosis is made, provides communication strategies for working with the care recipient’s doctor, and offers a guide and checklist for follow-up doctor visits. This and similar materials, place the responsibility for communication with healthcare professionals on the family caregiver. Most family caregivers desire to be advocates for their loved one and thus, seek out information to help them navigate through the day-to-day maze of this disease (Mittelman & Epstein, 2003). In fact, several studies have documented that family members are the ones that raise the issue of memory loss with their loved one’s family doctor (Boise, et al., 1999; Connell, Boise, Stuckey, Holmes, & Hudson, 2004).

Clearly, many older adults view their primary care physician as their primary point of contact for information about medical-related issues, both physical and psychological. Butler (2002) expresses concern for the lack of board-certified geriatricians and physicians with specialties in geriatric medicine in the U.S. Butler (2002) reports that, due to these shortages,

older adults are more likely to experience inadequate or even inappropriate health care from their doctor. In addition, a 2003 study concluded that greater recruitment efforts need to be initiated in order to enroll and retain more physicians in the geriatric psychiatry fellowship programs (Lief, et al., 2003). Barry (2003) notes that Continuing Medical Education (CME) credits delivered via a formal program or conference on geriatrics have been found to be relatively ineffective. Rather, educational programs that integrate multifaceted interventions including discussion and practice of new techniques, have shown more consistent positive outcomes in changing healthcare provider behaviors and outcomes for geriatric patients (Barry, 2003). By engaging physicians in focus group discussions, Boise and colleagues (1999) have found that knowledge about AD is only part of the issue. Rather, the physician's attitude, which may include views that the disease is too challenging to treat or manage or that there are no effective treatment options, inhibits the assessment, diagnostic and referral process.

Currently, the Southeastern Virginia Chapter of the Alzheimer's Association (The Chapter) estimates that there are 30 geriatricians to serve a population of more than 195,000 persons 65 years of age and older in the 7,400 square-mile service area. More than 25,000 of these seniors are estimated to have Alzheimer's disease (Alzheimer's Association, 2006). Therefore, it is not surprising that many persons with dementia, and their primary caregivers, must rely on their primary care physician for not only a diagnosis, but for follow-up and treatment. Even when persons with AD are referred to a specialist, primarily a neurologist, they continue to visit their primary care doctor to address other medical issues (e.g., influenza, hypertension); thus memory problems will continue to be present in the primary care physician's practice. Evidence suggests that physicians are more comfortable providing a diagnosis of a number of diseases, including cancer, than they are of informing a patient that the memory

problems are likely due to AD (Boise, et al., 1999).

Mittelman & Epstein (2003) explain that few studies have attempted to identify the source of the diagnosis and those that have observe 50% of dementia cases, or fewer, are diagnosed by primary care physicians (Callahan, Hendrie, & Tierney, 1995). However, several studies have examined the disclosure of the diagnosis and its impact on physicians and caregivers (Carpenter & Dave, 2004). What happens following the diagnosis is of great concern to healthcare professionals, persons newly diagnosed, and family caregivers alike. A 2004 study gathered data from focus groups with both caregivers (N = 52) and physicians (N = 39). Family caregivers generally reported they experienced resistance in obtaining a diagnosis and some were told the condition was dementia while others were told more specifically, that the memory loss was due to Alzheimer's disease. Physicians reported they felt pressured to make a diagnosis, that there was limited time to assess the patient, and that they found it disconcerting to provide bad news (Connell, et al., 2004). Physicians also reported a challenge with trying to obtain a balance between patient confidentiality and keeping the family fully informed. The researchers identified a discrepancy in how the diagnosis was received by family members, who reported a more negative experience, as compared to the physicians, who generally reported that families handled it well.

### *Physician Education*

In a recent survey of fellowship-trained geriatricians (N = 490) conducted by Medina-Walpole and her colleagues (2002), the researchers found that 80% maintained a Certificate of Added Qualifications in Geriatric Medicine (CAQ-GM). In order to obtain the CAQ-GM, good for 10 years, physicians completing the fellowship must then pass an examination. The survey focused on trainees from 1990 to 1998, where the fellowship requirements were reduced from

two years to one year. Jointly, the American Board of Internal Medicine and the American Board of Family Practice, who oversee the examination, initiated the change. This change took effect in 1995 in response to growing concerns about the shrinking number of geriatricians and the belief that reducing the requirement period would attract more physicians.

The researchers reported the median age at completion of the fellowship was 34, and the most commonly reported factor for pursuing a career in geriatrics was “societal needs for more physicians to care for the elderly.” The researchers found that, when analyzing the 1996-1998 subcohort, the period when trainees first completed the one-year fellowship option, that those fellows who completed two or more years of training had significantly more advanced career development (e.g., principal investigator on research project, authored articles, professional membership). Interestingly, those fellows who opted for the lengthier training period were more likely to have reached a decision about a career in geriatrics before or during medical school than those participating in the one-year fellowship. Medina-Walpole and her colleagues (2002) note that there has been an increase in applicants since the change in certification requirements but that more studies will need to be conducted to evaluate the impact.

Numerous medical books have been published which detail AD, in terms of its causes and in techniques for making a diagnosis. However, information is less readily available that provides healthcare providers, particularly primary care physicians, with recommended steps to follow in ensuring that a treatment plan, including medication and support services, is established once the diagnosis has been made (Foster, 2001). Two particular challenges impacting both physicians and family caregivers include the time available to spend with patients and caregivers during doctor visits, and awareness of available resources, such as the Alzheimer’s Association (Finifter, et al. 2003).

A recent pilot study conducted by The Chapter found only limited success in distributing packets of information about the Alzheimer's Association to area physician practices, including family practice and specialists (Guriloi, 2006). The outreach packets included a referral pad where physicians could check applicable services (e.g., support group, family orientation) available through The Chapter. There was a slight increase in the number of referrals shortly after the distribution of materials, but The Chapter has been cautious to ascertain a direct connection. There are a variety of educational materials made available to physicians (e.g., Merck Institute of Aging and Health Toolkits) but less is known about how healthcare professionals would like to receive and utilize this information, including how to incorporate ancillary staff into the process.

#### *Present Study*

The present investigation was undertaken to: 1) identify the primary source (e.g., primary care physician, neurologist) of the diagnosis of Alzheimer's disease (AD); 2) determine the needs of healthcare providers with respect to supporting families caring for relatives with AD; 3) characterize the needs of family caregivers as they interact with the care recipient's healthcare provider; and 4) propose solutions to address the identified needs and strengthen the family caregiver – healthcare professional partnership.

This study examined several hypotheses. The first hypothesis was that the primary source of the diagnosis of memory loss was more likely to be given by the person's primary care physician than by a specialist. The second hypothesis was that local family caregivers would report there is information they have not received, but would find helpful to receive from the care recipient's healthcare provider. The third hypothesis stated that healthcare professionals, including doctors and nurses, would report certain types of materials and tools more helpful to

them in working with family caregivers.

## Method

### *Participants*

*Family Caregivers.* Recruitment of participants for the Family Caregiver Survey began in July 2005. The survey closed July 2006 and 128 primary caregivers for relatives with diagnosed memory loss participated<sup>1</sup>. Primary caregivers were defined as those family members providing more than 50% of the needed care for the individual with the disease.<sup>2</sup> In cases (n = 12) where the care recipient was deceased, caregivers were eligible for inclusion in the telephone survey if the care recipient had passed away within the past twelve months. This inclusion of individuals, those whose relative has recently died, served two purposes; 1) it acknowledged that many caregivers do not view their caregiving role as complete once the care recipient passes away; and 2) it allowed these individuals to disclose experiences related to the recent care of their relative, including the last phase of the disease.

Participants were self-selected and contacted the principal investigator in order to enroll in the study and complete the survey. Participants were recruited from The Chapter's 7,400 square-mile service area. This service area included Hampton Roads, Greater Williamsburg, Eastern Virginia, and South Central Virginia.<sup>3</sup> Recruitment involved a variety of measures including invitations to participate in the survey in The Chapter's quarterly newsletter (*The Reminder*) and in the *Cortical Connections* (medical) newsletter. A record of all recruitment contacts (N = 204) was maintained in FileMaker Pro 5.0 (version 3).

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<sup>1</sup> The project proposal identified 175 as the target number of caregivers to participate. After extensive recruitment efforts, the research team was confident 128 participants served as an ample sample size to evaluate statistically.

<sup>2</sup> The terms primary caregiver and family caregiver are being used interchangeably to refer to the same individuals.

<sup>3</sup> An additional 39 caregivers contacted the principal investigator and were ineligible to enroll because they resided outside the study area (e.g., calls and emails were received from California and Canada) or the care recipient had passed away more than 12 months ago.

The study announcement, with a direct link to the online version, was posted on several web sites including ones with SeniorNavigator, The Chapter, the Center for Excellence in Aging and Geriatric Health (CEAGH), and the Senior Services Coalition. The study announcement was circulated to support group facilitators, newspapers, local religious organizations, senior service providers, doctors' offices, long-term care facilities, and respite and home health agencies. In addition, staff members at the Glennan and the CEAGH Memory Assessment Centers were informed of the study. In November (2005), in recognition of Alzheimer's Awareness Month, the principal investigator hosted an informational session on brain fitness where caregivers were recruited. Also in November, The Chapter sent a special mailing to approximately 300 persons on their "chapter advocate" list to enlist their assistance with recruiting caregivers to participate. In addition, a modified snowball sampling approach was used as some participants knew other caregivers performing similar duties.

Demographic data for the caregivers are presented in Table 1. The mean age of the caregivers was 62.5 years ( $SD = 12.5$ ), range of 29 to 88 years. Females accounted for 76% of the participants, with 47.6% adult children/children-in-law, and 36.5% spouses. The majority of participants (68.3%) reported that they had been caring for their relative for three years or longer, with the most common response being "between 3-5 years" (38.9%). Nearly 15% of the participants ( $N = 17$ ) reported they have been serving as the caregiver for eight or more years. More than half (54%) of respondents explained that they were involved in caregiving duties for more than 30 hours each week, with the most common response being "more than 79 hours each week" (34.7%).

Table 1. Categorical Descriptive Variables for Caregivers.

	N	%
<b>Ethnicity</b>		
Caucasian	105	82.0
African American	11	8.6
Other	3	2.4
Not reported	9	7.0
<b>Education</b>		
Some high school/high school degree	17	13.3
Some college	34	26.6
College degree	33	25.8
Some graduate school/graduate degree	33	25.7
Not reported	11	8.6
<b>Marital Status</b>		
Married/Living with partner	92	71.8
Separated/Divorced	15	11.7
Widowed	6	4.7
Single/Never married	7	5.5
Not reported	8	6.3
<b>Employment</b>		
Retired	46	35.9
Employed full-time	26	20.3
Employed part-time	15	11.7
Self-employed	10	7.8
Unemployed/not working outside home	18	14.1
Other	4	3.1
Not reported	9	7.0
<b>Annual Household Income</b>		
Less than \$15,000	7	5.5
Between \$15,000 - \$24,999	6	4.7
Between \$25,000 - \$34,999	13	10.2
Between \$35,000 - \$49,999	24	18.8
Between \$50,000 - \$74,000	23	18.0
Between \$75,000 - \$99,999	9	7.0
Between \$100,000 - \$149,999	17	13.3
More than \$150,000	3	2.3
Don't know	5	3.9
Not reported	21	16.3
<b>Caregiver's Self-Rated Health</b>		
Excellent or Very Good	56	43.8
Good	48	37.5
Fair or Poor	17	13.3
Not reported	7	5.4

Diagnostic-related characteristics of the care recipients are presented in Table 2. The mean age of the care recipients was 79.3 years (SD = 8.0), range of 52 to 98 years. The majority of care recipients resided at home, either on their own or with family, with 18.5% residents at an assisted living facility, and 9.7% at a nursing home. Caregivers reported the overall health of care recipients to be generally good (30.5%), with 32.2% rated as fair or poor.

Table 2. Health-related Characteristics for Care Recipients.

	N	%
<b>Care Recipient's Diagnosis</b>		
Alzheimer's disease	68	53.1
Probable Alzheimer's disease	15	11.7
Dementia	33	25.8
Other (e.g., Parkinson's disease, unknown)	12	9.4
<b>Healthcare Provider Who Provided Diagnosis</b>		
Primary Care Physician	42	32.8
Neurologist	48	37.5
Geriatrician	11	8.6
Psychiatrist/Psychologist	5	3.9
Other	11	8.6
Not reported	11	8.6
<b>When Diagnosed</b>		
Within the past year	12	9.4
1-3 years ago	41	32.0
4-6 years ago	42	32.8
7-9 years ago	13	10.2
More than 9 years ago	12	9.4
Not reported	8	6.2

*Healthcare Providers.* The second group of participants included physicians and their nursing staff practicing in the 7,400 square-mile area previously identified. Three focus groups, consisting of 8 - 17 healthcare providers each, were organized with a total of 37 participants. All focus group participants were invited to complete a brief survey. Demographic data for healthcare providers are presented in Table 3. Of the 37 participants, 30 healthcare providers

completed the survey and those respondents consisted of specialists (N = 2), primary care physicians (N = 6), and other medical staff (N = 24) affiliated with doctors' offices (e.g., nurse practitioners, nurses).

Table 3. Characteristics of Healthcare Providers Completing Survey as Part of Focus Groups.

	N	%
Type		
Primary care physician	6	20.0
Specialist	2	6.7
Nurse/Nurse practitioner	11	36.7
Office Manager	2	6.7
Other (e.g., certified medical assistant, scheduler)	9	30.0
Proportion of patients 60 years of age and older		
40% or fewer	3	9.9
Between 50% - 70%	10	33.3
Between 75% - 85%	9	30.1
More than 85%	5	16.6
Not reported	3	10.0
Proportion of patients with dementia		
10% or fewer	9	30.0
Between 20% - 30%	6	20.0
Between 35% - 45%	6	20.0
50% or more	4	13.3
Not reported	5	16.7
Distinguish between dementia and AD diagnosis		
Always	8	26.6
Sometimes	11	36.7
Rarely	4	13.3
Never	2	6.7
Not reported	5	16.7
Tools utilized		
MMSE	27	90.0
Clock drawing test	19	63.3
Referral to specialist/assessment center	9	30.0
<i>The 36-Hour Day</i>	7	23.3
<i>The Merck Manual of Geriatrics</i>	5	16.7
Schedule additional time with patients with dementia	15	50.0
Schedule additional time with family caregivers	16	53.3

Healthcare providers were recruited to participate in the focus group sessions via The Chapter's Medical and Scientific Advisory Team, an active committee of local healthcare providers (e.g., physicians, researchers, and neuropsychologists). The committee's primary purpose has been in assuming responsibility for assessing and addressing the educational needs of physicians and other health professionals who treat persons with AD and related disorders and thus was well-suited to assist in convening these focus groups. In addition, two focus groups were organized in conjunction with Eisai Pharmaceuticals and educational programs the company was hosting for healthcare providers on memory loss and related issues.

#### *Procedure for Family Caregiver Survey*

When caregivers contacted the principal investigator and were determined to be eligible to complete the survey, they were provided with the option of completing the survey by telephone (36%), scheduled at their convenience, or online (64%) at their leisure. They were informed that either version of the survey was estimated to take 20 minutes to complete. Individuals who initiated contact with the principal investigator were informed that their agreement to participate in the survey indicated their consent to disclose information.

The online version was utilized for entering data from all participants. Those caregivers who requested to complete the survey by telephone were informed that they would be placed on speaker phone so that the researcher could enter their responses directly into the web-based survey. During the introduction of the survey, all participants were advised that at the conclusion of the survey, they would have the opportunity to request a copy of the survey results. All survey responses were stored in an Access database on the Principal Investigator's office computer, which is password-protected. A letter summarizing the results was mailed or emailed, depending

upon the request, in August 2006 to all participants who made such a request (N = 76).<sup>4</sup>

### *Instruments*

*The Family Caregiver Survey.* The Family Caregiver Survey (see Appendix A) was developed by the research team<sup>5</sup> and was administered both via telephone and online.<sup>6</sup> The purpose of the Family Caregiver Survey was to identify the source of the diagnosis (e.g., primary care physician, neurologist) of memory loss. In addition, the survey provided details regarding the types of information family caregivers receive from their relative's physician with respect to the diagnosis and the disease.

Data from Access was coded and transferred to SPSS 13.0. Descriptive statistics and frequency distributions were calculated on all variables, and where possible, cross-tabulations were conducted to examine frequencies and percentages of individuals when considering two variables. Correlational analyses were conducted to determine the degree of relationship between specific variables (e.g., length of time caregiving and caregiver and care recipient's health status). Where qualitative information was obtained (e.g., types of information and advice provided by doctor) responses were transferred to Word to examine patterns and themes.

*The Healthcare Provider Focus Group.* The Focus Groups of Healthcare Providers consisted of two items asked of each group (see Appendix B). The research team had originally proposed to ask eight items but determined that response time was estimated at 30 minutes or more and would make the recruitment of healthcare providers more challenging. The purpose of the focus groups was to identify the scope of care, challenges in care, and recommendations to

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<sup>4</sup> A number of non-participants (N=25) who contacted the principal investigator about the project also requested to receive the study findings and were sent a summary.

<sup>5</sup> All references to the research team include the principal investigator, Christine J. Jensen, Ph.D., Lou Rossiter, Ph.D., Gino Colombara, Ed.D., Patricia Lacey, MBA, and Lara Whittaker, MPP.

<sup>6</sup> The original project proposal stated that the survey would be administered by telephone. The research team decided to hire a web developer to create an online version.

strengthen the caregiver – healthcare provider relationship. Response times to address these items ranged from 10 – 25 minutes. Because one objective of the study was to determine the types of tools and sources doctors and their staff are utilizing in working with persons with memory loss, this information was gathered via a brief survey (see Appendix C), which took approximately five minutes to complete.

Hand-written notes and audio recording were utilized at each focus group session to assure that all responses were accurately documented. Participants were asked to place their name and position (e.g., primary care physician, nurse) on a sign-in sheet in order to determine the number of participants and the medical positions represented. Participants were also asked to sign an Informed Consent Form. Responses to the questions presented during the focus groups were recorded on paper and were also audio-taped. Three independent reviewers listened to the audio recordings and reached consensus on the identified themes. Responses to the survey items were entered into SPSS 13.0 and frequencies were conducted.

#### *Survey on Geriatric Certification*

A pilot project was initiated as part of this larger study to gauge the impression of several area physicians on the geriatric certification process. The brief survey (see Appendix D), completed by 4 physicians, inquired about the timing of the training within one's medical career, incentives for completing the certification, and recommendations for recruiting physicians to become credentialed. Two physicians who reside in the study area and are currently credentialed were invited to complete the survey. The survey was also sent to the four medical facilities that offer the fellowship required to complete the certificate. Three surveys were returned by fax and one by email.

## Results

An initial step of the data analysis was the calculation of frequencies and cross-tabs among the caregiver and care recipient characteristics identified in the Family Caregiver Survey. Chi-squares were calculated for dichotomous variables and correlations, independent groups t-tests, and regressions were conducted, where applicable. Frequencies and cross-tabs were calculated with data from the Survey of Healthcare Providers.

### *Hypothesis 1*

The researchers hypothesized that primary care physicians would be more likely to provide a diagnosis of Alzheimer's disease than a specialist; however, this hypothesis was not supported (see Table 2). Of those caregivers identifying the healthcare provider who made the memory loss diagnosis (N = 117), 34.4% reported it was the primary care physician, while 39.3% were given the diagnosis by a neurologist, and the remaining were told by a geriatrician (9.0%), psychiatrist or psychologist (4.1%), or another healthcare professional(s) (e.g., assessment team) (9.0%)<sup>7</sup>. Because not all caregivers were informed that the diagnosis was specifically "Alzheimer's disease," an additional cross-tab was conducted to determine if primary care physicians were more or less likely to deliver a diagnosis of AD or probable AD than dementia. The chi-square analysis for this cross-tab was not significant.

Further analyses were conducted to examine if the primary care physician or a specialist was more likely to have provided the diagnosis of memory loss in suburban versus rural sections of the study area.<sup>8</sup> The chi-square was also found to be non significant and the groups were uneven, with very few caregivers (N = 11) reporting they resided in a rural area. Caregiver

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<sup>7</sup> The percentages reported in the text are slightly different than those reported in Table 2. The percentages reported in the text are based on a slightly smaller subsample of those caregivers who identified a specific healthcare provider. Table 2 identifies percentages for the entire sample including those not identifying the healthcare provider.

<sup>8</sup> The Chapter divides its territory into suburban and rural areas. No areas are considered urban.

residence was also examined based on the population density of the reported city or county. These groups were more evenly distributed between those with low ( $N = 65$ ) and high ( $N = 63$ ) densities but again, the chi-square analyses between density and who provided the diagnosis yielded insignificant results.

There was a strong correlation ( $r = .665^{**}$ ) between how long ago the caregiver started providing care for their loved one and the length of time since the diagnosis. Caregivers reported their overall health to be poorer, the longer time that they had been providing care, ( $r = -.188^*$ ) and based on the length of time since the diagnosis ( $r = -.229$ ). The independent samples t-test was not significant, but it is worth noting that care recipients' health was reported as poorer if the primary care physician ( $M = 2.88$ ,  $SD = 1.0$ ) provided the diagnosis than if a specialist did ( $M = 3.13$ ,  $SD = 1.35$ ). The t-test was significant when examining care recipient age and which healthcare provider delivered the diagnosis. Care recipients were more likely to be older ( $t(123) = 2.254$ ,  $p = .026$ ) if the diagnosis was provided by the primary care physician ( $M = 81.54$ ,  $SD = 5.28$ ) than by a specialist ( $M = 78.15$ ,  $SD = 8.86$ ). In a regression analysis of caregiver's health as either good (originally reported as good, very good, or excellent) or poor (originally reported as fair or poor), several predictors accounted for 16.2% of the variance. The predictors identified in this model included: care recipient's age, number of hours per week providing care, the length of time providing care, services that were needed but were not being utilized, and the medical professional who provided the diagnosis.

The final survey item invited caregivers to share any additional comments about their experiences. When reviewing and categorizing the types of responses, these were the following themes:

- Better awareness of available resources is needed for both family caregivers and healthcare providers.

- Additional knowledge and training about the disease is needed including:
  - Caregiver training;
  - Educational programs for healthcare providers;
  - Training for aides in long-term care facilities.
- Caregiving is stressful and adequate coping skills are important to help with the day-to-day variability of AD.

### *Hypothesis 2*

Caregivers reported their primary source of information about the disease and about community services was their doctor; however, the majority of caregivers (64.5%) reported that the doctor was more likely to provide information about medications than about the course of the disease, available community resources, or long-term care planning. Other sources of information identified by caregivers included: the Alzheimer's Association, support groups, books/magazines, and websites. Table 4 identifies the most common responses caregivers reported when asked to identify their primary, secondary, and tertiary sources of information about memory loss and about related services. When caregivers were asked to identify the resources (e.g., adult day services, home healthcare) they were currently utilizing to assist their role, the Alzheimer's Association (44.5%), the Internet (33.6%), and support groups (35.9%) were the most commonly reported.

When asked about information or advice they would like to have been provided about the care recipient's memory loss, caregivers reported a variety of items. These items included general information about the disease and disease progression, types of services to utilize (e.g., adult day care, support groups), how to handle the care recipient's other health problems, and financing the care over an extended period of time. Many caregivers engaged in the opportunity to explain their challenges when interacting with the medical community.

Table 4. Sources of Information Utilized by Caregivers.

	N	%
<b>Primary Source</b>		
Doctor	35	28.7
Books/Magazines	26	21.3
Alzheimer's Association	23	18.9
<b>Secondary Source</b>		
Doctor	27	24.1
Alzheimer's Association	17	15.2
Books/Magazines	13	11.6
<b>Tertiary Source</b>		
Alzheimer's Association	18	17.5
Doctor	17	16.5
Books/Magazines	11	10.7

One husband, caring for his wife, explained, “I think the medical community takes a hands-off approach. I have some experience with this as I have lost two sisters with memory problems. There aren’t even any geriatricians in our area. I’ve really had trouble getting any reports or information from the doctors she has seen. Another thing that concerns me is the change in administration in the long-term care facility where my wife is.” Another caregiver responded, “I guess I really didn’t expect the doctor to have a lot of resource information to deal with things on a day-to-day basis. The support group has provided a wealth of information on how to cope and keep your loved one safe.” Another caregiver explained her situation with the following, “I think generally the doctors do a very poor job of the dynamics of the disease on the family. There is very little advice or even what to expect given to the family. It is kind of...I have even had doctors be a little flippant saying everyone is different. It has been a major source of frustration that you are left out there hanging.”

When asked if they were more comfortable interacting with their loved one's doctor or nurse, the majority of respondents (69.3%) reported the doctor than the nurse (15.8%), with an additional 15% of caregivers reporting this issue was not applicable to them (i.e., care recipient resides in long-term care facility). Several caregivers reported they had very little interaction with the nurse when taking the care recipient to the doctor. Others reported frustration with both, with one caregiver explaining, "The nurse doesn't have the answers, and the doctor doesn't take the time and is always rushing through." And others reported the nurse was more accessible, with a respondent explaining, "Often the nurse was more accessible than the doctor, so there were more opportunities to make contact with the nurse, who might consult with the doctor on some occasions and get back with me."

### *Hypothesis 3*

Physicians and nurses who participated in the focus groups and completed the survey reported that time to spend with patients, and their families, and awareness of community services were their biggest challenges. Healthcare providers who completed the survey detailed ways in which the primary care doctor's staff (e.g., nurses, nurse practitioners) could provide support to families including:

- Make sure that patients are referred to a specialist in a timely fashion;
- Communicate with family members about the disease and available resources;
- Assess the caregiver's level of understanding about the disease in order to aid the physician in the treatment;
- Be a good listener;
- Provide encouragement, support and explain what to expect.

Table 5 identifies healthcare providers' perceptions of the helpfulness of tools they use when treating their patients with memory loss. The materials and tools most commonly used were documented in Table 3 and include the Mini Mental State Exam (MMSE), the clock

drawing test, referrals to specialists, and *The 36-Hour Day*. Better than two-thirds of the respondents identified these tools as “very helpful” in delivering care from diagnosis to treatment, including communication with the patient and/or family.

Table 5. Degree of helpfulness of tools utilized in providing treatment to persons with dementia.

	<b>Not at all helpful % (n)</b>	<b>Somewhat helpful % (n)</b>	<b>Very helpful % (n)</b>	<b>N/A % (n)</b>
Establishing the diagnosis		17.9 (5)	78.6 (22)	3.6 (1)
Providing a treatment plan	3.4 (1)	13.8 (4)	79.3 (23)	3.4 (1)
Prescribing medication	3.7 (1)	22.2 (6)	66.7 (18)	7.4 (2)
Communicating with the patient and/or family		20.0 (5)	76.0 (19)	4.0 (1)

Nearly 40% (39.3%) of healthcare providers responded that they have tools that are routinely distributed to assist family caregivers. Some of the identified tools included books (e.g., *The 36-Hour Day*), handouts, brochures, and websites. Other “tools” included referrals to an assessment center or the Alzheimer’s Association and the association-sponsored support groups. Other than *The 36-Hour Day*, there was no one specific tool recognized that was being routinely distributed. However, the majority of healthcare providers (80%) identified their interest in a checklist, similar to an order set, which could be available to offer to family caregivers. The checklist might include referrals, reminders, and itemized steps in a treatment plan.

Responses from the geriatric certification survey identified a number of practical issues and challenges with respect to the certification process. First, although the certification is a fairly simple process, the fellowship requirements are not designed to attract practicing physicians. No

financial incentives were identified and the time to complete the fellowship is considered a low-pay year of training. Therefore, the respondents generally agreed that they do not recommend their colleagues in family or internal medicine become credentialed but rather to explore Certified Medical Education credits (CMEs) in geriatrics. Second, incentives that were recognized included: increased knowledge about health conditions and needs of older patients; prestige; research purposes; and camaraderie with other geriatricians. Third, no recommendations were acknowledged specifically related to the credentialing process but rather that a change in the market place is needed with respect to how geriatricians are viewed. Finally, disagreement remains as to which type of physician is considered a geriatrician, with some defining this based solely on the successful completion of the CAQ-GM, while others defined a geriatrician as one who “devotes his practice to evaluating and treating the elderly.”

## Discussion

Although the central hypothesis that the primary care physician would be more likely to diagnose the memory loss was not supported, the issue remains that persons with memory loss will continue to see their primary care physician (for management of diabetes, high blood pressure, etc) and that the doctor and his/her office staff should be informed of the diagnosed memory loss. Foster (2001) notes that physicians have the opportunity to fulfill a very positive role in treating patients with dementia; however, many times physicians are reluctant to treat the patient. It is well-known that the prognosis is not a desirable one and this coupled with the fact that there is great inter-individual variability in the course of AD makes the disease extremely challenging for many doctors to treat. Furthermore, dementia care is not profitable and “there is a significant disincentive to spend adequate time with patients, and important elements of dementia care such as coordination of care with community services and education and support

of caregivers are almost entirely unreimbursed” (Foster, 2001, p. 195).

This issue of low reimbursements is clearly related to the amount of time many physicians report they need to adequately diagnose and treat a person with AD. This was evident from the results of the Healthcare Provider Survey and focus groups. Interestingly, 50% of healthcare providers responding to the survey reported that they allow extra time to meet with their patients with memory loss and 53.3% reported additional time was scheduled for meeting with family members. These percentages indicate a positive development in that physicians and their staff are acknowledging the need for, and attempting to incorporate, additional time in to meeting with patients and families. Several participants in the focus groups explained that they meet with family members outside of regular business hours, where there is no opportunity for reimbursement.

When considering why more caregivers reported the specialist was more likely to have diagnosed the care recipient’s memory loss than a family doctor is worth additional exploration. This finding is somewhat surprising and could represent encouraging news. Perhaps this suggests that persons with memory loss are receiving the appropriate referrals to specialists. It is also possible that the caregivers, who were a self-selected group, were self-motivated and found ways to access specialty care. Many of the caregivers sought information and education about memory loss as noted by the many respondents who identified sources of information other than the doctor. Furthermore, these caregivers considered themselves advocates and explained that if they had not been the ones to ask for an assessment, it might not have taken place. It would be interesting to learn if other regions of the Commonwealth of Virginia are experiencing this greater emphasis on specialty care. Of course, emphasis does not imply access.

### *Promoting Partnerships*

The Council on Scientific Affairs of the American Medical Association (1993) has recommended that physicians be reimbursed for time spent providing education and counseling caregivers. The Council has also acknowledged that an effective relationship model would identify the key linkages and interdependence between primary care physicians and family caregivers. One specific partnership approach is that of a dementia care triad; to include the primary care physician, the person with memory loss, and the family advocate. Foster (2001) questions why pediatrics has routinely utilized a triad approach while this technique is not practiced in geriatrics. Fortinsky's (2001) research on triads identifies the significance of bringing all three parties together, as he notes that a recent push to pair physicians with family caregivers marginalizes the patient. Likewise, pairing the physician with the patient reduces the value of the family members' contributions to the care. It was not unusual for caregivers in the present study to identify with this experience and either perceive that they, or the person with memory loss, was being discluded from the medical evaluation.

Adams and Gardiner (2005) challenge the biomedical approach to dementia care and concur with Fortinsky that a psychosocial approach, particularly focused on communication strategies, among the members of the triad, be developed. This approach promotes open communication and joint decision-making within the dementia care triad. The Alzheimer's Service Coordinator Program was implemented in Ohio to support family caregivers by linking primary care practices with community services. Community agencies, such as the Alzheimer's Association, collaborated with primary care physician in offering educational and support services to family caregivers (Fortinsky, Unson, & Garcia, 2002). The intervention was effective in that a significant number of caregivers reported increased self-efficacy in the management of

their relative's dementia. A majority of participating physicians (65%) reported that their participation increased their awareness of available resources. More importantly, 45% of physicians responded that they were more confident in their skills to direct families and patients in suitable dementia care.

### *Enhancing Education*

The Commonwealth of Virginia offers three sites (i.e., University of Virginia, Eastern Virginia Medical School, and Virginia Commonwealth University) by which to obtain the CAQ-GM for physicians board-certified in internal medicine. One site (i.e., Roanoke Carilion Health System) is currently available for those board-certified in family medicine (Accreditation Council for Graduate Medical Education, 2005). SeniorNavigator.com, "Virginia's resource for health and aging," is considering the addition of a provider side to their web site. This would allow physicians to connect with a variety of community resources as well as to connect with other physicians meeting the needs of their aging patient population. SeniorNavigator.com recently produced materials that are made available for physicians entitled "SeniorNavigator helps you help your patients" (2005). This literature is intended to assist medical professionals with ways that SeniorNavigator can answer their patients' questions and direct them to services (e.g., home-delivered meals, transportation) or offer caregiver support resources. Healthcare providers who completed the survey were asked about the types of services or resources they typically refer. Only 10% (N = 3) referred to SeniorNavigator, while 43.3% referred to both the Alzheimer's Association and to other books and educational literature. The majority of participants (80%) expressed interest in a checklist, similar to an order set, which could be provided to family caregivers. The checklist might include such things as: 1) additional information on the treatment plan; 2) reminders about medical appointments; 3) referral to

specific resources, such as the Alzheimer's Association; and 4) reminders to keep a log documenting changes in the care recipient's cognitive status.

### *Limitations*

There are several limitations to the present study that should be addressed. First, the caregivers who completed the Family Caregiver Survey were a self-selected sample of caregivers. They may have been more motivated to seek out information about memory loss, about ways to care for their loved one, and about accessing specialty care than other non-responders. Second, there may have been a difference in those caregivers who completed the online versus the telephone version of the survey. Since all survey responses were entered into the same template regardless of the way in which they responded to the items, it was not possible to specifically track each response with whether the caregiver was participating by telephone or online. Because the majority (64%) of surveys were completed online, one wonders then if this will become a more common way to reach caregivers. Based on a thorough search of the literature, the number of online caregiver surveys is limited. The largest survey to date, the I CAN, or Investigating Caregivers' Attitudes and Needs survey, examined the experiences of 539 U.S. adults serving as the primary caregiver to loved ones with AD, conducted for the Alzheimer's Foundation of America (2006). With the present study, caregivers from California and Canada, just to identify a few, contacted the principal investigator inquiring about participation. Therefore, interest in online surveys is growing among caregivers across the country and across all ages.

A third limitation of the study was the small number of physicians who participated in the focus groups and completed the healthcare provider survey. The majority of participants were nurses, nurse practitioners, and office managers. Perhaps the participation of these healthcare

professionals is more telling in that nurses and other ancillary staff may truly be more available and accessible than physicians.

### *Recommendations*

A number of recommendations were discussed by the research team in connection with the aforementioned results. Simply put, it appears that there are literacy issues impacting the current delivery of dementia care. First, a health literacy issue is preventing caregivers from “consuming” the information physicians present. Second, a lack of literacy about Alzheimer’s disease and related dementias, community resources, and support services for caregivers appears to exist among physicians. Several of the most plausible options for addressing these literacy issues are identified below.

*Education and Training.* A variety of educational programs are needed. Training programs for family caregivers exist, including ones delivered by the Alzheimer’s Association, and ones developed by the National Family Caregivers Association (2002) entitled “Communicating Effectively with Healthcare Professionals”; however, more emphasis needs to be placed on interactive training where caregivers are more than passive recipients of information about memory loss and about ways to handle challenging behaviors. Many participants in the caregiver survey responded that their attendance at support groups was beneficial. This type of give-and-take educational forum should be more widely available. Becker and Webbe (2006) have been investigating means by which caregivers can record their questions for the physician and log behaviors of the care recipient utilizing hand-held computer technology, known as the “Pocket Buddy.” With this technology, caregivers can receive recommendations and reminders about specific tasks they can engage in with the person with memory loss. This information can be shared via the Internet with healthcare providers and

family. This line of research is promising.

Additional educational programs for primary care physicians are also needed. Although more curriculum, both traditional and online formats, is geared towards geriatrics syndromes, few truly go in-depth into dementia and AD. For example, very little attention has been devoted to dementia at the semi-annual meetings of the Virginia Academy of Family Physicians. During one of the focus group sessions, participants noted that one of the recent four-day meetings included a 45-minute session on dementia. Focus group participants reported that an entire morning session should have been dedicated to this topic. The findings from the present study suggest that the health literacy issues are not just about dementia per se but rather about how to offer support to the family members who serve as caregivers. Recently, the National Center on Caregiving of the Family Caregiver Alliance introduced an online toolkit entitled, “Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers.” Utilizing a family-centered perspective, sections of the toolkit include explanations about the vulnerabilities of family caregivers and how to conduct a caregiver assessment (Family Caregiver Alliance, 2006). It will be most interesting to see how this toolkit is shared with medical professionals and how they incorporate the caregiver assessment into their delivery of care.

Based on the responses received from the pilot survey of the geriatric certification process, a detailed cost-benefit analysis is in order. Respondents reported that although it was desirable professionally for them to attain the credentials, that there was essentially no financial incentive. Perhaps medical schools should assist in increasing awareness and recognition of the CAQ-GM so that junior physicians would more seriously consider its significance. In addition, it may be possible to have the certification fellowship and examination fees waived through the institution of the Geriatricians Loan Forgiveness Act H.R. 3046. This bill has been initiated by

Senator Reid (D-NV) and Representative DeLauro (D-CT) and currently awaits action in the Energy and Commerce Committee (American Association for Geriatric Psychiatry, 2005).

Because many physicians simply cannot take time away from their practice to complete the fellowship requirements, it would be worth exploring the establishment of a mentoring program for junior physicians. These junior physicians could partner with more established primary care physicians, neurologists, and geriatricians. This partnership may be established in person, via telephone, or online and would facilitate more opportunities for medical professionals to share their expertise outside of conference and meeting environments. It is also evident from the focus group discussions and the healthcare provider survey responses that more attention needs to be given to training programs for ancillary staff (e.g., nurses, office managers, schedulers). As Teel and Carson (2003) explain, “nurses are in an opportune position to educate families about dementia and caregiving and to ease the considerable challenges they face by providing more active support during the diagnosis and care process” (p. 38). Perhaps a nurse well-versed in dementia care could become a shared resource and serve as a dementia care coordinator who travels to family practice offices within a specified geographic region.

*Support for Primary Care Physicians.* As more and more physicians take advantage of technological advances to support their delivery of care, it seems a favorable time to introduce prompts into clinical standards following an AD or related-dementia diagnosis. The Veterans Administration has already established clinical standards whereby physicians, by use of electronic medical records, are prompted to ask about driving and gun safety when a diagnosis of memory loss is documented. Once a diagnosis is established, it would be extremely beneficial to the patient and the family if the primary care physician, specialist, or nurse would direct them to the Alzheimer’s Association. Conceivably, the computerized patient record might include a

prompt for the medical professional, such as, “Can the Alzheimer’s Association call you with additional information and resources?” If the patient and/or family member responds affirmatively, a HIPAA form would be generated so that they could indicate their consent with the information being shared (e.g., diagnosis, contact information). Once signatures were obtained, an automated message would be sent to the Alzheimer’s Association with the contact information needed for follow-up. The principal investigator is currently exploring a pilot of this technology with the Veterans Administration which integrates the triad approach. Once connections are established with the local chapter of the Alzheimer’s Association, support for both the caregiver and the person with memory loss are accessible.

Furthermore, the research team recommends the development and distribution of a “just in time” aid. This aid could essentially serve as a discharge/standing order for the primary care physicians and their staff to use. There was considerable interest in a checklist among the healthcare provider participants. Due to the overwhelming concerns regarding lack of the physician’s time documented in this study and others (e.g., Boise, et al., 1999; Iliffe & Wilcock, 2005), it is clear that physicians are in need of a checklist that could be provided to families caring for relatives with memory loss.

A final recommendation is to create a DVD with dementia material presented at Grand Rounds and other educational programs offered by Commonwealth of Virginia sites where the geriatric certification is available. This DVD could be made available to all primary care practices within the Commonwealth. CME credits could be connected to the educational material. The research team has confirmed availability of the archived materials at Eastern Virginia Medical School and the school’s interest in participating in such a project.

*Marketing and Promotion of the Alzheimer's Association.* As reported by caregivers, physicians were making some referrals to community services. However, a clear need exists for increased awareness of The Chapter Office and its support services. Only recently has the Alzheimer's Association, nationally, and its chapter affiliates, been able to advertise and market its services. Because it is more likely that families will seek out these services during times of crisis, and that these times of crisis likely include a visit to the physician, referrals to The Chapter should be more routinely incorporated. The research team recommends The Chapter establish a "When you run out of time" campaign to encourage physicians to make referrals. This campaign would recognize that many physicians are overburdened and do not have the time needed to adequately explain to persons with memory loss and their families what types of resources they might utilize, both in the near- and long-term. Physicians and their staff would refer their patients to The Chapter for a family orientation, whereby the person with dementia and their family would learn about the available community services and how to access them, including support groups and long-term care planning.

#### *Implications and Conclusions*

More and more families are being affected by AD. Patients, and their families, depend upon their doctor to be a resource for information about medications, the course of the disease, and community services. This study has identified a number of policy implications that must be incorporated to address the significant health literacy issues documented. Recognizing the value of triads in dementia care as well as the role of ancillary staff will prove most beneficial to caregivers and medical professionals alike. Finding creative ways to enhance knowledge of memory loss and of the resources available through the Alzheimer's Association will also be favorable for those providing care. Through greater use of technology, there are many

opportunities to assess the experiences of caregivers via online surveys and to support dementia care (e.g., clinical prompts, reminders) delivered by medical professionals. Ultimately, the goal in dementia care should be to enhance the healthcare provider – family caregiver partnership. Strengthening this partnership enables these care providers to access the resources needed to maintain the dignity and quality of life for persons with dementia.

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## **APPENDIX A**

### **Family Caregiver Survey**

This survey is part of a study being conducted by the Center for Public Policy Research at The College of William & Mary in cooperation with the Southeastern Virginia Chapter of the Alzheimer's Association and the Center for Excellence in Aging and Geriatric Health. Information from this survey will allow for a greater understanding of the needs of caregivers for persons with memory loss, particularly as the needs relate to the care recipient's healthcare providers. This survey includes 25 items and your participation in this survey will take approximately 20 minutes. All information that you provide will be treated in a confidential manner. This project was approved by the College of William & Mary Protection of Human Subjects Committee (Phone: 757-221-3901) on April 12, 2005 and expires on September 1, 2006.

As a family caregiver for a relative with memory loss, you are eligible to participate if:

- You provide or manage the majority of the needed care for your relative; AND
- The care recipient's doctor practices in the south central (e.g., South Hill, South Boston) or southeastern (Williamsburg to Virginia Beach) regions of Virginia, or the Eastern Shore.  
OR
- You were the primary caregiver and the relative with memory loss passed away within the past 12 months (PLEASE NOTE: If the person you have been caring for is deceased, please answer all questions based on your experiences prior to your loved one's passing).

If you have any questions about the survey or the study criteria, please contact the Project Manager.

#### **Contact Information**

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Project funded by the Alzheimer's and Related Diseases Research Award Fund.  
Thank you for agreeing to participate in this brief online survey.

#### **These questions apply to you, the caregiver:**

1. What is your sex?  
Male  
Female
2. Where do you currently reside (city/county)?

3. What is your relationship to the person you have been providing care for?

Spouse  
Partner  
Daughter  
Son  
Daughter-in-law  
Son-in-law

Granddaughter  
Grandson  
Sibling  
Friend  
Other, Specify:

3.a. Is the person you have been caring for still living?

Yes  
No

If no, please answer all questions based on your experiences prior to the individual's passing.

**The next few questions will focus specifically on the person you are caring for who is experiencing difficulties with his/her memory.**

4. Has the person you are caring for received, by a practicing physician, a formal diagnosis of "Alzheimer's disease," "probable Alzheimer's disease," or "dementia?"

"Alzheimer's disease"  
"Probable Alzheimer's disease"  
"Dementia"  
Other memory loss  
Not sure

4.a. If Other Memory Loss, please indicate diagnosis:

Dementia with lewy bodies  
Huntington's disease  
Multi-infarct dementia  
Parkinson's disease  
Pick's disease/Fronto-temporal dementia  
Vascular dementia  
Other, specify:

5. If the care recipient was diagnosed with "Alzheimer's disease," "probable Alzheimer's disease," or "dementia", when was the diagnosis made?

Within the past year  
1-3 years ago  
4-6 years ago  
7-9 years ago  
More than 9 years ago  
Not sure

6. Who provided this diagnosis?

Primary care physician  
Neurologist  
Geriatrician

Psychiatrist  
Clinical Psychologist  
Other, Specify:  
Not Sure

7. How long have you been providing assistance for the care recipient?

Less than six months	6-8 years
6-12 months	8-10 years
1-2 years	More than 10 years
3-5 years	

8. Please estimate how many hours per week you provide assistance for this individual.

Less than 5 hours	40 - 49 hours
5 - 9 hours	50 – 59 hours
10-19 hours	60 – 69 hours
20 - 29 hours	70 – 79 hours
30 - 39 hours	More than hours

9. Where does the individual you provide assistance for live?

Lives in his/her own house/apt  
Lives with me in my house/apt  
Lives with other family member(s)  
Lives in an assisted living facility  
Lives in a nursing home  
Other, Specify:

10. How old is the care recipient?

11. Compared to other people his/her age, how would you rate the overall health of the individual you are providing assistance to?

Excellent  
Very good  
Good  
Fair  
Poor  
Unsure

**The following questions are about sources of information and types of services you may be familiar with related to caregiving.**

12. Please rank the top three sources you use to find information on services this individual needs.

[1 = most frequently used]

Advertising from Radio, TV, or Newspaper

Alzheimer's Association

Another agency/organization, such as United Way or the hospital

[Name organization if marked \_\_\_\_\_]

Computer/Internet

Family Member(s)

Friend(s) or Neighbor(s)

Phone Book

Religious organization

The doctor

Other, Specify:

Other, Specify:

Other, Specify:

Don't know

13. What information or advice has the care recipient's doctor provided you or the care recipient with respect to his/her memory loss? (e.g., referral, long-range care plans, medication)

14. What additional information or advice related to the care recipient's memory loss do you wish the care recipient's doctor or nurse would provide to you or the care recipient?

15. Do you feel more comfortable interacting with the care recipient's doctor or with the nurse? Please explain why.

Doctor  
Nurse

16. What types of services or information do you currently use to assist in your care of this individual?  
[Check all that apply]

None	Home healthcare provider
Adult day care	Hospice
Alzheimer's Association	Information found on the Internet
Area Agency on Aging	Lawyer (Elder Law)
Assistance from neighbors	Nursing home
Assistance from religious organization/church	Respite services
Assisted living facility	Support group
Educational programs	Transportation services
Financial Planner	Other, Specify:
Geriatric case manager	

17. Are there services you are currently not using, but believe would assist you with your caregiving?  
[If no, skip question 17 a.]  
Yes  
No

17a. Why are you not using these services? (e.g., cost, unable to find the service, care recipient refuses)  
**Before we finish the survey, please answer just a few more questions about yourself so we can see how our sample compares with other samples of caregivers.**

18. What is your date of birth?  
MM/DD/YY

19. Compared to other people your age, how would you rate your own health right now?  
Excellent  
Very good  
Good  
Fair  
Poor  
Unsure

20. What is your marital status?

Married	Divorced
Living with Partner	Widowed
Separated	Never Married/ Single

21. What is the highest level of education that you have received?
- |                         |                      |
|-------------------------|----------------------|
| Grade/Elementary School | College Degree(s)    |
| Some High School        | Some Graduate School |
| High School Degree      | Graduate Degree(s)   |
| Some College            | Other, Specify:      |
22. What is your annual household pretax income from all sources?
- |                      |                       |
|----------------------|-----------------------|
| \$0 -- \$14,999      | \$100,000 - \$149,999 |
| \$15,000 -- \$24,999 | \$150,000 or more     |
| \$25,000 -- \$34,999 | Don't know            |
| \$35,000 -- \$49,999 | Prefer not to answer  |
| \$50,000 -- \$74,999 |                       |
| \$75,000 -- \$99,999 |                       |
23. Which of the following best describes your current work situation?
- Retired
  - Employed Full-time
  - Employed Part-time
  - Unemployed (seeking work)
  - Not working outside the home
  - Other, Specify:
24. What is your race/ethnicity?
- African-American / Black
  - Asian [including South Asian]
  - Hispanic or Latin American
  - Native American [including Eskimo/Aleut]
  - Pacific Islander
  - White /Caucasian
  - Other
  - Prefer not to answer
25. Are there any additional comments that you would like to make?

**That concludes this telephone/online survey. Thank you for taking time to participate. If you have any additional questions about this study, or would like a copy of the summary of the results of this study, please contact Christine Jensen, Ph.D. at (757) 221-1971, or via email at [cjjens@wm.edu](mailto:cjjens@wm.edu).**



**APPENDIX C**  
**Dementia Caregiver Project - Healthcare Provider Survey**

Please respond to each question. The information you provide could lead to improvements in the delivery of care to persons with dementia. Expected Completion Time: Less than 10 minutes.

**1. You are what type of healthcare provider:**

Primary Care Physician _____	Nurse Practitioner _____
Physician Assistant _____	Office Manager _____
RN/LPN _____	Specialist _____
Other, please specify: _____	

**2. Estimated percentage of patients:**      Age 60 or older \_\_\_\_\_%      With dementia \_\_\_\_\_%

**3. In communicating a diagnosis to the family, do you make a distinction between dementia and Alzheimer’s disease? (circle response)**

Always                      Sometimes                      Rarely                      Never                      N/A

**4. What tools (e.g., pamphlets, books, resource manuals, diagnostic techniques) are you currently using that assist you in the treatment of persons with dementia? (check all that apply)**

<i>Alz. Disease: A Physician’s Guide to Practical Mgt</i> _____	Referral to specialist or assessment center _____
<i>Geriatrics at Your Fingertips</i> _____	Other, please specify: _____
<i>The Merck Manual of Geriatrics</i> _____	_____
<i>The 36-Hour Day</i> _____	Other, please specify: _____
Mini-Mental State Exam _____	_____
Clock Drawing Test _____	Other, please specify: _____
Trails Test _____	_____

**5. Thinking of the tools identified in the previous question, please indicate the degree to which these tools are of help to you in providing treatment to persons with dementia in the following areas:**

	Not at all helpful	Somewhat helpful	Very helpful	N/A
Establishing the diagnosis				
Providing a treatment plan				
Prescribing medication				
Communicating with the patient and/or family				
Other, please specify:				
Other, please specify:				

**6. Are there any tools that you routinely distribute to assist or support the family caregiver(s)?**

Yes \_\_\_\_\_                      No \_\_\_\_\_

**If yes, please identify:**

**6.a. What area are you most in need of additional tools? (check all that apply)**

Establishing the diagnosis \_\_\_\_\_  
Providing a treatment plan \_\_\_\_\_  
Prescribing medications \_\_\_\_\_

Communicating with the patient and/or family \_\_\_\_\_  
Other, please specify: \_\_\_\_\_

**7. In your opinion, what should be the role of the primary care doctor's staff, including nurse practitioners and nurses, in providing support to family caregivers?**

**8. Do you allow more time in your scheduling for care provided to persons with dementia?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**If so, how much more time?**

**8.a. Do you allow more time in your scheduling for meeting with family caregivers of your patients with dementia?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**9. Do you refer your dementia patients and their families to services, such as respite or delivered meals, in the community?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**9.a. If yes, which types of resources/services do you refer (check all that apply)?**

Long-Term Care Facilities \_\_\_\_\_  
Adult Day Programs \_\_\_\_\_  
In-Home Respite Services \_\_\_\_\_  
Alzheimer's Association \_\_\_\_\_  
Area Agency on Aging \_\_\_\_\_  
Geriatric Case Management \_\_\_\_\_  
Legal/Financial Assistance \_\_\_\_\_  
Transportation \_\_\_\_\_  
Books/Manuals About Memory Loss \_\_\_\_\_  
SeniorNavigator.com \_\_\_\_\_  
Other Websites \_\_\_\_\_  
Other, please specify: \_\_\_\_\_

**10. Are you familiar with the Certificate of Added Qualifications in Geriatric Medicine?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**10.a. If you are a primary care physician, have you sought the Certificate of Added Qualifications in Geriatric Medicine? Why/Why not?**

**11. Would a checklist (similar to an “order set”) that you could provide to family caregivers be of help to you? This checklist might include items such as a treatment plan, reminders about medical appointments, reminders to keep a log to record changes in the care recipient, etc.**

Yes \_\_\_\_\_

No \_\_\_\_\_

**Thank you for your time. Please return the survey during the program, in the postage-paid envelope, FAX to 757-221-2390, or submit electronically to [cjjens@wm.edu](mailto:cjjens@wm.edu) BY March 8, 2006.**

*This project was approved by The College of William & Mary Protection of Human Subjects Committee (Phone: 757-221-3901) on November 23, 2005 and expires on September 1, 2006.*

**If you have further comments, please feel free to contact one of the Investigators:**

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**APENDIX D**  
**Dementia Caregiver Project - Survey on Geriatric Medicine Certification**

*Thank you for taking a few minutes to respond to these survey items. All information that you provide will remain confidential and will only be used as part of a College of William & Mary research project evaluating the CAQ-GM. By providing responses to these questions, you are consenting to participate in this project. If you prefer to discuss your responses via telephone, please contact Christine Jensen, Principal Investigator, 757-221-1971, or via email at [cjens@wm.edu](mailto:cjens@wm.edu) to arrange a time. You may enter the responses directly into this document, save, and then email to [cjens@wm.edu](mailto:cjens@wm.edu). Or, if you prefer, you can print a copy, fill in your responses, and then fax to 757-221-2390.*

1. Do you consider a physician with a CAQ in geriatric medicine to be a geriatrician?

\_\_\_\_ Yes                      \_\_\_\_ No

1.a. Why/why not?

2. What is your impression of the current certification process for obtaining the CAQ-GM?  
**Specifically---**

2.a. Do you believe that the material covered in the fellowship has been relevant to practicing geriatric medicine in Virginia?

*Use the following scale and circle/underline your response:*

*Strongly Agree (5)    Agree (4)    Uncertain (3)    Disagree (2)    Strongly Disagree (1)*

2.b. Do you believe the fellowship requirements are designed to attract new residents?

*Strongly Agree (5)    Agree (4)    Uncertain (3)    Disagree (2)    Strongly Disagree (1)*

2.c. Do you believe the fellowship requirements are designed to attract practicing physicians?

*Strongly Agree (5)    Agree (4)    Uncertain (3)    Disagree (2)    Strongly Disagree (1)*

3. Based on your knowledge, when do most doctors complete the fellowship training and obtain their certification?

- \_\_\_\_ during medical school
  - \_\_\_\_ early-career (within the first 10 years of completing medical school)
  - \_\_\_\_ mid- or late- career (more than 10 years beyond completion of medical school)
  - \_\_\_\_ other, please explain:
-

4. Do you recommend changes to the certification process in order to encourage more physicians to become certified? If so, what recommendations do you propose?

5. What do you perceive are the incentives for a doctor to obtain this certification? (**check all that apply**)

- Higher earnings potential
- Increased knowledge about the health conditions of older patients
- Better ability to recognize the needs of older patients
- To increase number of older patients served by the practice
- Other, please explain:
- Other, please explain:

6. Do you recommend to other family physicians or internists that they become credentialed? Why/why not?

**For Physicians with Certification in Geriatric Medicine:**

7. Since completing the certification in GM, what benefits have you experienced?

7.a. When the time comes to renew your certification, will you complete the renewal process? Why/why not?

**Thank you for your time. Please return the survey electronically to [cjens@wm.edu](mailto:cjens@wm.edu) or FAX to 757-221-2390 BY June 14, 2006.**

*This project was approved by The College of William & Mary Protection of Human Subjects Committee (Phone: 757-221-3901) on April 25, 2006 and expires on September 1, 2006.*

**If you have further comments, please feel free to contact one of the Investigators:**

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