Impediments to Timely Diagnosis of Alzheimer's Disease in African Americans

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The purpose of this study was to identify early patterns of care for Alzheimer's disease (AD) in a cohort of African-American patients and their caregivers presenting at an inner city clinic and a suburban memory assessment clinic. Caregivers (N = 79) of patients diagnosed with probable AD were interviewed. Data were collected about the delay from noticing first AD signs until recognition that a problem existed and delay from problem recognition until first physician consultation. Patients and caregivers had lower educational status, and patients had been diagnosed more recently at the inner city clinic than at the suburban clinic, although MMSE scores of patients at the two clinics did not differ; median delays in caregivers' recognizing a problem and in consulting a physician were also similar across clinics. Delay was as long as 7 years between noticing symptoms and problem recognition and between problem recognition and physician consultation. Although patients attending the suburban clinic were more likely to have previously seen a physician than those attending the inner city clinic, they were no more likely to have received a prior diagnosis of AD. Lack of physician contact is likely to be widespread in families caring for African Americans with AD. Physician consultation is more characteristic of more highly educated families but may not yield a correct diagnosis for the patient. Intensive efforts are needed to connect African-American families with physicians and to achieve more timely diagnosis of AD to enable families to understand the illness, plan for patient safety, and make long-term plans. **J Am Geriatr Soc 53:2012–2017, 2005.**

Key words: Alzheimer's disease; ethnicity; diagnosis

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Early identification of Alzheimer's disease (AD) provides opportunities to initiate treatment that may slow a patient's disease progression and connect family members with supportive services. AD is more prevalent in African Americans than in whites,[1,2] and the number of African Americans entering the age of risk will more than double over the next 30 years.[1] At the time of AD diagnosis, measured cognitive impairment is more severe in African-American patients, and there is less opportunity for patients and families to benefit from early intervention.[3–5]

To examine early patterns of care in AD in African-American families, a cohort study was conducted of patients and their caregivers presenting at two memory assessment clinics affiliated with Emory University. AD was the focus rather than dementia in general or vascular dementia because the aim was to characterize caregiver awareness of a disorder that is due to an insidious onset and slowly progressive decline. An abrupt onset in which the symptoms are immediately apparent to family members frequently characterizes vascular dementia. Outcomes of primary interest were the reported interval between the caregiver first noticing AD symptoms and recognition that a problem existed and the reported interval between the caregiver's problem recognition and first contacting a physician. The two data collection sites served different segments of the population by virtue of their inner city and suburban locations; participant characteristics and outcome variables were therefore compared between clinics.

METHODS

Study Design and Sample

The original setting was an inner city memory assessment clinic (Clinic A) that primarily serves African-American patients. A second clinic (Clinic B) with a suburban location that serves a smaller number of African-American patients was added to facilitate subject enrollment.

A cohort of 79 eligible, self-identified African-American caregiving family units (a patient and a primary caregiver) was enrolled between January 2002 and August 2003.

African-American patients presenting for the first time at either of the memory assessment clinics were eligible if

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they had a clinical diagnosis of probable AD from clinic physicians using National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association criteria,[6] had a self-identified primary caregiver, and resided in the community. The patient's primary caregiver was defined as an individual serving as "personal representative"[7] or the individual who "spent the most time taking care of the person."[8] The Emory University institutional review board approved the study, and all caregivers provided written informed consent.

During the study interval, Clinic A served 380 new patients, of whom 327 (86.0%) were African American. At Clinic A, 109 African-American caregivers were approached to participate in the study, and 46 were enrolled (42.2%). Clinic B served 409 new patients, of whom 61 (14.9%) were African American. Fifty-four African-American caregivers were approached to participate in the study, and 33 were enrolled (61.1%). The primary reasons for declining at both clinics were "not enough time" or "not interested."

Measures and Data Collection

The data collectors were a senior research nurse at Clinic A (VG) and a social worker at Clinic B (SPH), both experienced in clinical and research interactions with African-American patients. Demographic and clinical characteristics of patients, including Mini-Mental State Examination (MMSE) scores,[9] were obtained from clinic medical records. Caregiving information was obtained using structured in-person interviews with caregivers, caregivers' self-completion of the Physical Self-Maintenance Scale (PSMS)[10] and Instrumental Activity of Daily Living (IADL) scale[10] (patient's functional status), and the Memory and Behavior Problems Checklist (patient).[11] Caregivers were recruited and interviewed at the time of the patient/caregiver unit's first visit to the clinic or at the first follow-up visit. When the caregiver could not remain at the clinic to complete all of the instruments, the research assistant followed up to obtain the information.

Interview questions addressed the caregiver's sociodemographic characteristics and health status and the caregiving unit's medical use. In addition to the delay variables of primary interest, caregivers were asked to name the first observed signs of AD, symptoms that led to the first physician evaluation, reasons for delay in consulting a physician, type of physician seen first, and first diagnosis received. Interview questions were modeled after questions used in a mailed questionnaire of a nationwide consumer panel of primarily white AD caregivers.[12] Caregivers were given an opportunity to add responses not included in structured response lists.

Data Analysis

Sociodemographic characteristics of patients and caregivers were compared using *t* test for continuous variables and chi-square test for categorical variables. Delay variables (time in months) for participants and time in months from diagnosis to study enrollment were described using medians and means and compared using Wilcoxon test. Within-group (caregiver relation to patient) comparisons for delay variables were conducted using analysis of variance. Spearman correlation examined the association between the delay variables. Finally, for all patients who had seen a physician before presenting at the memory clinic, a chi-square test was used to compare receipt of AD diagnosis versus receipt of other diagnosis by physician type. All tests were two-tailed.

RESULTS

Patient and Caregiver Characteristics

Eighty-five percent of the patients in the study were female. The average age ± standard deviation of the patients was 75.3 ± 8.2, and most lived with their caregiver (73%). Patients seen at Clinic A were less likely than those seen at Clinic B to be high school graduates (Table 1). Average

Table 1. Characteristics of African-American Participants by Clinic

Participants	Clinic A (Inner City) (n = 46)	Clinic B (Suburban) (n = 33)	*P*-value
Patients			
Age, mean ± SD	74.5 ± 9.3	76.4 ± 6.4	.30
Female, %	84.8	84.9	.99
High school graduate, %	39.1	71.0	.006
Mini-Mental State Examination, mean ± SD	13.6 ± 5.6	13.0 ± 7.2	.67
Physical Self-Maintenance Scale, mean ± SD	20.1 ± 3.6	18.7 ± 3.9	.12
Instrumental activities of daily living, mean ± SD	15.1 ± 3.8	14.0 ± 4.7	.26
Memory and behavior problems, mean ± SD	12.2 ± 4.6	14.5 ± 5.2	.04
Caregivers			
Age, mean ± SD	53.3 ± 10.2	55.2 ± 11.8	.44
Female, %	82.6	72.7	.29
High school graduate, %	82.6	100	.01
≥1 major health problems*	56.5	62.5	.60
Annual income ≤ $30,000, %	43.2	37.9	.66
Adult child of patient, %	69.6	54.6	.17

Note: Total n varies from 77 to 79, except income; n = 73.
* e.g., heart disease, hypertension, diabetes mellitus, arthritis.
SD = standard deviation.

MMSE[8] scores of patients were not significantly different. Clinic A patient characteristics are consistent with a published report of African-American patients previously evaluated at the same clinic (average MMSE score 15.4 ± 6.8).[13] Average PSMS and IADL scores of patients were not significantly different, but patients from Clinic B scored higher than patients from Clinic A in total memory and behavior problems.

Caregivers were about 20 years younger than patients (54.1 ± 10.9) and primarily female (78.5%), and similar to patients, Clinic A caregivers were less likely than those at Clinic B to be high school graduates. Average annual income of caregivers was not significantly different. Caregivers' relationship to the patient did not differ between clinics, with about 60% of all caregivers being daughters and daughters-in-law.

Delay Before Caregiver Recognized a Problem

The median delay between caregivers noticing AD symptoms and recognizing a problem did not differ between clinics (Table 2), and the lag time did not vary by caregiver's relationship to the patient. Almost 60% of caregivers reported that forgetfulness (lapses in memory) was the main symptom they noticed that led them to suspect something was wrong with the patient; the remainder cited confusion, personality or behavior change, problems at home or work, trouble communicating, or difficulty doing complicated tasks.

Delay Before Caregiver Consulted a Physician

The median delay between caregivers' recognizing a problem and consulting a physician was not significantly different between the clinics, and the lag time did not vary by caregiver's relationship to the patient. Forgetfulness (cited by 50.7%), confusion (cited by 17.8%), and personality/behavior change (cited by 14%) were the main factors that led caregivers to have the patient see a doctor.

The two delay variables (Table 2) were significantly related (Spearman rho = 0.47; $P < .001$). Caregivers who reported a longer lag time to problem recognition also indicated a longer delay in consulting a physician.

Factors that Impeded Physician Consultation

Caregivers indicated from a list of possible reasons why they had delayed seeing a doctor. Most caregivers indicated multiple reasons. More than half said they thought that the changes were normal aging (57.0%), were unsure how severe the problem was (55.7%), and that it was difficult to discuss this with the patient (53.2%). In addition, 41.8% said it was difficult to face the possibility that the patient might have dementia or AD, 38.0% said the patient became angry, and 16.5% said the patient refused to see a doctor.

Table 2. Delay in Seeking Treatment

Delay (Months)	Clinic A	Clinic B
	Median (Minimum–Maximum)	
From caregiver noticing symptoms and recognizing a problem	9 (1–84)	6 (0–72)
Before caregiver consulted a physician	3 (0.2–84)	2 (0.1–48)

Note: No significant differences between clinics.

Diagnosis of AD by First Physician Consulted

When participants were categorized by the number of months before study enrollment that the patient had received a diagnosis of AD, the time was significantly shorter for participants from Clinic A than for Clinic B (0.8 ± 1.9 months vs 13.2 ± 20.9 months). Participants from the two clinics also differed with regard to timing and type of first physician contact ($P < .001$). For half of all Clinic A caregiving units, compared with only 6% of Clinic B caregiving units, there had been no previous consultation with a physician regarding the patient's problem. In addition, most Clinic A participants who had previously consulted a physician saw a family physician, whereas Clinic B participants who had seen a physician were more likely to have seen an internist; some saw a neurologist or a psychiatrist.

Of participants who had previously seen a physician, Clinic B patients were no more likely than Clinic A participants to have received a diagnosis of AD. Of patients who had previously seen a physician before coming to the memory clinic, 61% of Clinic B patients and 48% of Clinic A patients had first received a diagnosis other than AD. In addition, the type of physician seen first was not related to the likelihood of receiving the diagnosis of AD. As Table 3 indicates, if the diagnosis of AD was not made at the time of first physician consultation, it was likely that the patient received a multiple diagnosis or no diagnosis or that the patient's problems were attributed to normal aging. Of the eight different multiple diagnosis combinations that were reported, dementia (but not AD) was included in four; the remaining multiple diagnoses included some combination of the diagnoses usual aging, depression, anxiety, and stroke.

DISCUSSION

Researchers focusing on ethnicity and dementia have attempted to disentangle differences that reflect socioeconomic status from those that are more closely linked to ethnicity or race.[14] The current study included African-American caregiving units presenting at inner city and suburban memory assessment clinics. The educational status of patients and caregivers was significantly higher in participants recruited from the suburban clinic than those recruited from the inner city clinic. Patients seen at the suburban clinic had been diagnosed with AD for a significantly longer time period, an average of just over 1 year, compared with an average of less than 1 month for patients at the inner city clinic, and caregivers at the suburban clinic reported more patient memory and behavior problems. Patients and caregivers at the suburban clinic were also more likely to have consulted a physician before coming to the clinic and to have consulted a specialist rather than a family physician, although patients presenting at the suburban clinic who had previously consulted a physician were no

Table 3. Caregiver's Report of First Diagnosis by First Physician Seen

	First Physician Seen				
	All Physicians n = 54	Family Doctor n = 29	Internist n = 17	Neurologist n = 6	Psychiatrist n = 2
First Diagnosis	%				
AD	44.4	41.4	41.2	66.7	50.0
Other than AD	55.6	58.6	58.8	33.3	50.0
Dementia	7.4	6.9	5.9	16.7	0
Depression	1.9	0	5.9	0	0
Anxiety	0	0	0	0	0
Stroke	1.9	3.5	0	0	0
Usual aging	11.1	20.7	0	0	0
No diagnosis	13.0	10.3	17.7	0	50.0
Other diagnosis*	1.9	0	0	16.7	0
Multiple diagnoses†	18.5	17.2	29.4	0	0

* Parkinson's disease; hypertension; referred for neuropsychological testing at the family's request; does not remember what the doctor said, but doctor referred patient to memory assessment clinic.
† Dementia and depression; dementia and anxiety; dementia and usual aging; dementia, depression, and usual aging; depression and anxiety; depression, anxiety, and usual aging; anxiety and other diagnosis; stroke and usual aging.
AD = Alzheimer's disease.

more likely than patients at the inner city clinic to have been diagnosed with AD by the first physician contacted.

Participants at the two clinics did not differ in lag time between noticing AD symptoms and recognizing a problem or between problem recognition and consulting a physician. Reported lag time between noticing AD symptoms and recognizing a problem was as long as 6 to 7 years, and reported lag time between problem recognition and consulting a physician was as long as 4 to 7 years. Forgetfulness was the symptom most likely to make caregivers think that something might be wrong and was also the reason most often given for having the patient see a physician. More than half the caregivers attributed delays in consulting a physician to thinking that the observed changes were normal aging, being unsure how severe the problem was, and finding it difficult to discuss the problem with the patient; more than one-third also found it challenging to face the possibility of dementia, and they experienced anger on the part of the patient about a possible physician visit. Of caregivers who indicated that it was problematic to discuss the issue with the patient, most (69%) reported angry responses from the patient.

Questions similar to those asked were included in a previous study in a mailed survey of approximately 1,500 persons who reported having a household member with AD.[12] Patients and caregivers in that survey were predominantly white (88%), and the investigators reported no findings specific to African Americans. In their survey, more than 80% of respondents reported that the patient's diagnosis had occurred more than 1 year before,[12] whereas only 30% of African-American patients in the current study had been diagnosed more than 1 year before. For almost one-third of the patients in the current study, their evaluation at the clinic as a new patient was their first contact with a physician regarding symptoms that might signal AD.

African-American caregivers in the current study were more likely to name several impediments to physician consultation than were white caregivers in the other study.[12] The difference was especially pronounced for the impediment finding it hard to face the possibility of dementia, which almost 42% of African-American caregivers in the current study but only 9% of white caregivers surveyed previously[12] mentioned. In a different survey of 452 adults that included 39% African Americans, African Americans were less aware of facts about AD, reported fewer sources of information, and viewed AD as less of a threat than whites.[15] In another study, African Americans, as well as Latinos and Asians, were found to have lower overall knowledge of AD than older white adults.[16]

There are important caveats about this study. The response rate from the potential participants was limited (48.5%), although this was considerably higher than the 13% response rate reported in the Knopman et al. study.[12] The majority of caregivers in the current study were interviewed soon after the patient was diagnosed, as recommended,[17] but recall bias is likely when people estimate previous events. The current study, like the previous one, used caregivers' reports of physician diagnoses if patients had seen a physician before coming to the clinic. It is possible that some physicians communicate a diagnosis of AD but qualify their comments in ways that lead caregivers to misperceive the diagnosis.[12] Alternatively, denial of a devastating illness may play a powerful role on the part of both the family and patients in not seeking additional evaluation.

Black community-dwelling patients with moderate to severe dementia have been found to demonstrate more dementia-related behaviors than white patients, including wandering and unreasonable anger, that pose dangers to the patients and their caregivers.[18] Increasing the awareness of AD in African Americans and providing treatments and services to affected families are priorities of the Alzheimer's Association. This study indicates that these are challenging goals. Almost half of the caregivers said that they found it

difficult to face the possibility that their family member might have dementia or AD. It may be especially true in African Americans that "for family members, there are powerful emotional barriers to affirming the existence of a memory problem, even after making the differentiation between ordinary and pathological forgetting."[12] Patients had scores that indicated severe cognitive impairment; therefore, there is an urgent need for these caregivers to receive education about safety needs of the individual.

Screening for dementia in primary care settings as part of the routine assessment of older persons may be a cost-effective public health intervention but is not routinely implemented.[19] Current guidelines do not recommend routine screening,[20,21] but from a clinical perspective, the importance of a timely diagnosis to benefit the family in understanding AD, keeping the patient safe, and planning for the future cannot be overstated. In addition, available screening and assessment tools may not adequately address the unique presentation of AD in African Americans,[1,3,22] and effective screening may be a more difficult aspect of an already challenging healthcare issue. As in the previous study[12] and this one, most patients who saw a physician first received a primary diagnosis of another condition or no diagnosis rather than a diagnosis of AD. The reader is referred to a comprehensive review of the complexities associated with cultural influences on dementia recognition and management.[23]

With adequate representation of African Americans in clinical trials, biomarkers of AD may be identified that can be used in screening, but all screening efforts require the ability to reach patients.[24] In primary care settings, physicians report that dementia screening is most often triggered when the family brings concerns about symptoms or behavioral signs to their attention.[25] The current study indicates that African-American caregivers were often reluctant to acknowledge the potential significance of the symptoms and signs they observed in a family member.

The high rate of no-shows (about 40%) in patients with scheduled appointments was found to seriously compromise recruitment of participants at the inner city clinic. Caregivers were predominantly adult children who were themselves at risk for major health problems; more than half reported having one or more major health problems (e.g., heart disease, hypertension). Lower socioeconomic status in families scheduled to be seen at an inner city clinic may be associated with transportation difficulties or caregivers' difficulty arranging time off from a job to accompany the patient to the clinic. Referral of a family member to a memory assessment clinic may be viewed as just "one more medical appointment," without perceived benefits. Families who believe that it is their responsibility to care for an impaired relative using their own coping resources, which has been shown to shape African-American families' responses to dementia caregiving,[14,26,27] may expect to gain little from attending a memory clinic or seeking physician consultation. Making practical information such as home safety measures and behavior management skills available to families and transmitting this information through accepted agencies (e.g., churches) may be a useful strategy. Additional efforts may include computerized short screening instruments for patients waiting to see their primary care provider, programs in work settings that teach potential caregivers about normal aging changes versus illness and how to discuss these topics with their family, and public health campaigns with prominent African-American role models to promote community awareness. Achieving more timely diagnosis of AD in African-American communities is likely to require a variety of perceptive, creative efforts from healthcare and community leaders.[24]

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