

Black and White Adult Family Members' Attitudes Toward a Dementia Diagnosis

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OBJECTIVES: To examine potential benefits of and barriers to diagnosis from the perspective of black and white adults directly affected by Alzheimer's disease (AD).

DESIGN: Telephone survey.

SETTING: Convenience sample recruited from two U.S. metropolitan areas.

PARTICIPANTS: One hundred seventy-eight family members of people with AD, including current and former AD caregivers and immediate blood relatives of someone with AD.

MEASUREMENTS: Respondents were asked to rate the importance of eight benefits of and 16 barriers to obtaining a diagnosis.

RESULTS: Family members strongly endorse several benefits of obtaining a diagnosis, including getting information, finding out what is wrong with their relative, and prompting future planning. A majority of survey respondents did not endorse any barriers examined. Lack of a cure for AD and the belief that little can be done for someone with AD were the most frequently endorsed barriers. Black respondents endorsed five of the eight benefits more frequently than white respondents.

CONCLUSION: Black and white adults with a family member who has received a diagnosis of AD perceive a range of benefits and few barriers to the diagnostic process examined in this study. Their positive experiences might be instructive to families considering pursuing a diagnosis and to physicians who may be reluctant to offer screening or referral because of the belief that families have little to gain. *J Am Geriatr Soc* 57:1562–1568, 2009.

Key words: Alzheimer's disease; primary care physicians; caregivers; dementia; diagnosis; disclosure

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With the aging of the population and the corresponding increase in prevalence of Alzheimer's disease (AD),¹ knowledge and awareness of the disease among the general public, family caregivers, and first-degree relatives have been reported to be high.^{2–6} However, diagnosis of AD is typically delayed until several years into the course of the disease,^{7,8} despite an increasing awareness of the benefits of more-timely recognition of and response to the early symptoms of the disease.^{9,10} Some of the reported benefits of obtaining a diagnosis include reducing uncertainty for the patient and family members, increasing access to and the efficacy of available medications, providing opportunities for patient involvement in planning for the future and making decisions about care and research participation, receiving referrals and access to supportive services and programs, and providing enhanced safety and security.¹¹

Despite growing attention to and debate about the identification of mild cognitive impairment and early-stage AD in the research community,^{12,13} little is known about how family members decide whether and when to seek help after first noticing symptoms of dementia in a loved one. In most of the handful of relevant studies, family members are asked to reflect on their past experiences with a dementia diagnosis. One such study¹⁴ reported that of spouse caregivers, most endorsed a number of benefits of obtaining a diagnosis, including finding out what is wrong with their spouse and excluding other causes of memory or behavior problems. Several obstacles to obtaining a diagnosis were also reported, including the belief that the process is time consuming and expensive, a diagnosis is unnecessary, because there is no cure or treatment for AD, and memory problems are part of normal aging.¹⁴ Based on focus group interviews, one study discovered that one of the major benefits of obtaining a diagnosis that caregivers reported was that it helped them to be more patient with and understanding of their ill family member and enabled them to make more-informed decisions on their behalf.¹⁵ In a sample of adults with early-stage dementia, a diagnosis provided a sense of relief, because it offered an explanation for their symptoms and marked the initiation of a treatment plan.¹⁶

Because family members are largely responsible for making decisions on behalf of those affected by AD, their knowledge, attitudes, and beliefs regarding assessment and treatment options are critical to an understanding of who gets diagnosed and the circumstances that prompt help-seeking. If, for example, family members believe that memory loss is an inevitable sign of aging, they may be unlikely to bring symptoms to the attention of a healthcare provider. Similarly, symptoms of dementia may be attributed to other causes, such as coexisting illnesses, a mental health condition, or stress. Although the general public is fairly knowledgeable about the disease,² notable differences in AD knowledge, beliefs, and experiences have been documented between groups defined according to race and ethnicity.¹⁷⁻¹⁹ In a nationwide study, for example, black and Hispanic respondents were significantly more likely than white adults to view memory loss as an expected part of aging while also being more optimistic about prospects for finding a cure through continued research.² These findings were consistent with those reported in a recent study that included family caregivers and first-degree relatives of people with AD.³ Specifically, blacks were significantly more likely than whites to believe that memory loss is an expected part of aging while being more optimistic about the current and future state of AD diagnosis, treatment, and research. Overall knowledge about AD and concern about the disease was lower in black than white respondents.³

Finally, one of the few studies that examined cross-ethnic differences in dementia caregivers' retrospective accounts of their experience with obtaining a diagnosis found that black families were less likely than white families to take a "smooth pathway" to diagnosis.⁷ A smooth pathway was defined as starting with recognition of symptoms, followed by active help-seeking from a physician, and completed by diagnosis in primary care or by a referred specialist. Instead of this smooth pathway, black dementia caregivers were more likely than whites to have initiated help-seeking in response to a crisis, often when an ongoing behavioral problem became severe.

These and other racial and cultural differences in AD knowledge and beliefs and in issues related to caregiving and help-seeking probably affect attitudes toward obtaining a dementia diagnosis.²⁰⁻²⁴ Combined with estimates that AD prevalence may be higher for blacks than whites²⁵ and evidence that delays in diagnosis are particularly common in blacks, who may face unique barriers to care and seek care at a later point in the disease process than whites,^{7,26,27} further examination of racial differences in attitudes toward diagnosis is warranted. The primary purpose of the present study was to examine potential benefits of and barriers to diagnosis from the perspective of black and white adults directly affected by AD; a secondary purpose was to explore black-white differences in these perceptions.

METHODS

The Treatment and Illness Perceptions Survey

The Treatment and Illness Perceptions Survey (TIPS) was originally developed to examine attitudes, beliefs, and experiences regarding AD in a sample of first-degree relatives.²⁸ Scales assessing domains such as perceived threat of

AD, perceived causes of AD, and treatment beliefs all performed with very good to excellent reliability.²⁹ The current version of the survey was designed to examine knowledge about AD and symptoms, information sources about AD, perceptions of the effectiveness of various AD treatments, risk perceptions about AD, and attitudes about genetic testing for AD. Results pertaining to knowledge and beliefs about AD have been published separately.³

The survey was administered to a sample of adults with varying exposure to AD, including first-degree relatives (adult children and siblings) of people with AD (living or deceased), current and former primary caregivers of people with AD, and those with neither an affected first-degree relative nor an AD caregiving history. Presence of AD in the affected family member was assessed according to self-report. Potential participants who demonstrated an inability to understand and respond to the survey items because of cognitive impairment or lack of fluency in English were excluded from this study.

Using multiple strategies (e.g., newspaper advertisements, physician referral) and sources (e.g., community health fairs, university-affiliated AD research center), 301 adults (141 black; 160 white) residing in the Boston and Atlanta metropolitan areas were recruited for participation. Eleven individuals who reported "other" race or ethnicity were excluded because of their small subsample size. Participants were contacted by telephone; interviews averaged 30 minutes in length.

Measures

A subsample of the larger group of TIPS respondents who indicated that they have or had a family member with AD were asked about potential benefits of and barriers to obtaining a diagnosis of AD using the same items described in previous work.¹⁴ Specifically, participants were asked to rate the importance (1 = not important, 2 = somewhat important, 3 = moderately important, 4 = very important, 5 = extremely important) of eight possible benefits of obtaining a diagnosis: let me know what was wrong with my relative, allowed me to plan for the future, allowed me to involve my relative in important decisions (e.g., making a will), allowed me to obtain information about AD, may qualify my relative for drug treatment, was helpful to my family in case AD is hereditary, allowed me to exclude other causes of memory or behavior problems, and allowed me to use appropriate community services.

As a transition to the next section of the survey, the interviewer read the following statement: "Some family members have identified obstacles to getting a diagnosis of AD. I will now ask you to indicate the extent to which you agree with the following statements." Respondents were asked to rate the degree to which they agreed (1 = strongly disagree, 2 = somewhat disagree, 3 = neutral, 4 = somewhat agree, 5 = strongly agree) with each of 16 potential barriers to obtaining a diagnosis of dementia: my family physician did not make a referral to a specialist, there are so few physicians trained to diagnose dementia in my local area, the process was so time consuming, the process was so expensive, the process was not covered by our health insurance, my family members did not agree that it was important, my relative was not willing to be tested, it is very

demanding for the patient, it is very demanding for the family, so little can be done for people with AD, memory problems are part of the normal aging process, there is no cure for AD, there is no effective treatment for AD, there is a stigma against people with AD, it is easier not to know what the diagnosis is, and it would require seeing a specialist instead of a family physician.

Data Analysis

Of the 301 respondents, 222 reported having a living or deceased family member with AD. Forty of the 222 respondents were missing key outcome data, and four participants were excluded from this analysis because of data inconsistencies (e.g., first reporting having a family member with AD but later responding “0” when asked about the number of affected family members). Thus, the analytical sample consisted of 178 respondents. The 40 respondents with missing data were significantly more likely to be black and significantly less likely to have ever been a caregiver for someone with AD. No significant differences (related to missing data status) were evident according to age, sex, education, or marital status ($P > .05$).

For this investigation, the percentage of adults rating each benefit as very or extremely important and strongly agreeing with each barrier to diagnosis was examined overall and according to race. Response options were collapsed in this way (i.e., very/extremely important vs all others and strongly agree vs all others) to permit comparison between respondents who unambiguously endorsed the items and all others.

Racial differences in response were first examined using chi-square tests. To determine whether any observed differences were significant after adjusting for racial differences in caregiver status, education, marital status, and month-end financial status (all significant at $P < .10$), multivariate logistic regression analyses were conducted. In a series of regression models, responses to each benefit and barrier were regressed on caregiver status (1 = current or former caregiver to someone with AD; 0 = not a current or former caregiver), education (1 = high school or less, 0 = greater than high school), marital status (1 = married, 0 = not married), month-end financial status (1 = end up with money left over, 0 = no money left over), and race (1 = black, 0 = white).

RESULTS

Sample Characteristics

The median age of the sample was 57 (range 27–81). Women constituted 82.0% of the sample, 57.9% of respondents were white, 77.0% participants reported having more than a high school education, 57.9% of the sample was married, and 59.6% reported having money left over at the end of the month. A significantly lower percentage of black respondents than of white respondents reported being married (42.7% vs 68.9%) and having more than a high school education (61.3% vs 88.4%). A higher percentage of black than white respondents reported being a current or former caregiver to someone with AD (80.0% vs 55.3%). No significant racial differences were observed for age, sex, or financial status ($P < .05$) (Table 1).

Table 1. Sample Characteristics—Overall and According to Race

Characteristic	%			Chi-Square (1 Degree of Freedom)	P- Value
	Total Sample (N = 178)	Black (n = 75)	White (n = 103)		
Age*[†]					
<57	49.7	46.0	52.4	0.72	.39
≥57	50.3	54.1	47.6		
Current or former caregiver to someone with Alzheimer's disease					
Yes	65.7	80.0	55.3	11.72	<.001
No	34.3	20.0	44.7		
Education					
≤High school	23.0	38.7	11.7	17.87	<.001
>High school	77.0	61.3	88.4		
Sex					
Male	18.0	16.0	19.4	0.34	.56
Female	82.0	84.0	80.6		
Marital status					
Married	57.9	42.7	68.9	12.28	<.001
Not married	42.1	57.3	31.1		
Month-end financial status					
End up with some money left over	59.6	52.0	65.1	3.07	.08
No money left over	40.5	48.0	35.0		
Race					
Black	42.1	—	—	—	—
White	57.9				

Percentages may sum to slightly more than 100 due to rounding.

* Median age = 57 (range 27–81).

[†] Missing one data point.

The family member with AD was the mother of 53.4% of the survey respondents. Other affected family members were father (20.8%), spouse (15.7%), aunt or uncle (14.6%), grandparent (14.0%), sister (4.5), brother (3.9%), and some other relative (20.8%). Because respondents were able to report having or having had more than one family member with AD, the types of family members affected do not sum to 100%.

Benefits of Obtaining a Diagnosis

Respondents endorsed a median of six benefits (range = 0–8; data not shown). Three-quarters or more of the sample rated three of the eight potential benefits of obtaining a diagnosis as very or extremely important: learning what was wrong with their family member, the ability to make future plans, and obtaining information about the disease (Table 2). In addition, more than 60% of the sample reported that receiving a diagnosis might “qualify [their] relative for drug treatment” and allow them to use community services. Similar percentages endorsed that knowing the diagnosis was “helpful to [their] family in case AD is hereditary” and that it allowed them to eliminate other potential causes of their family members' symptoms. Just over

Table 2. Participants Rating Each Potential Benefit of Obtaining a Diagnosis of Alzheimer's Disease (AD) as Very or Extremely Important—Overall and According to Race

Benefit	%			Chi-Square (1 Degree of Freedom)	P-Value
	Total Sample (N = 178)	Black (n = 75)	White (n = 103)		
Let me know what was wrong with my relative	78.1	89.3	69.9	9.58	.002
Allowed me to plan for the future	75.3	80.0	71.8	1.55	.21
Allowed me to involve my relative in important decisions (making a will)	57.9	76.0	44.7	17.48	<.001
Allowed me to get information about AD	80.9	85.3	77.7	1.65	.20
May qualify my relative for drug treatment	63.5	74.7	55.3	6.99	.008
Was helpful to my family in case AD is hereditary	63.5	77.3	53.4	10.73	.001
Allowed me to rule out other causes of memory or behavior problems	67.4	68.0	67.0	.02	.89
Allowed me to use appropriate community services	67.4	78.7	59.2	7.47	.006

half the sample (57.9%) viewed “[involving their] relative in important decisions (making a will)” as an important benefit of obtaining a diagnosis.

In the unadjusted analysis, significant racial differences in perceived benefits were evident for five of the eight benefits: “let me know what was wrong with my relative,” “allowed me to involve my relative in important decisions (making a will),” “may qualify my relative for drug treatment,” “was helpful to my family in case AD is hereditary,” and “allowed me to use appropriate community services.” In all cases, a higher percentage of black than white respondents rated these benefits as very or extremely important (Table 2). After controlling for differences in caregiver status, education, finances, and marital status, racial differences remained significant, with black respondents having more than two times the odds of endorsing these benefits as very or extremely important as their white counterparts (Table 3).

Barriers to Obtaining a Diagnosis

Respondents endorsed a median of two barriers (range = 0–13; data not shown). As shown in Table 4, a majority of the

sample did not endorse any single barrier. The percentage of respondents strongly endorsing each of the 16 barriers ranged from 6.2%, for “it is easier not to know what the diagnosis is,” to 36.0%, for “there is no cure for AD.” Nevertheless, more than one-quarter of the sample endorsed three treatment-related barriers: the perception that “so little can be done for people with AD,” the lack of a cure for the disease, and the belief that “there is no effective treatment for AD.” Moreover, roughly one-quarter of the sample strongly agreed that obtaining a diagnosis of dementia is “very demanding for the family,” and 20.8% of the sample endorsed “there are so few physicians trained to diagnose dementia in my local area.”

In the unadjusted analysis, significant racial differences were evident for five of the 16 barriers (Table 4). A lower percentage of black than white respondents endorsed two of the aforementioned treatment-related barriers (no cure and no effective AD treatment). In contrast, blacks endorsed three access-related barriers more frequently than whites: “there are so few physicians trained to diagnose dementia in my local area,” “the process was so expensive,” and “our health insurance did not cover the process.” After adjustment for covariates, only the treatment-related barriers remained significantly different for blacks and whites. The odds of black respondents strongly agreeing that these factors made obtaining a diagnosis of dementia difficult were approximately 50% to 75% lower than for white respondents (Table 5).

Table 3. Benefits of a Diagnosis of Alzheimer's Disease (AD) According to Race (Reference = White)

Benefit	Adjusted Odds Ratio (95% Confidence Interval)		P-Value
Let me know what was wrong with my relative	3.47	(1.32–9.17)	.01
Allowed me to plan for the future	1.90	(0.81–4.45)	.14
Allowed me to involve my relative in important decisions (making a will)	4.48	(2.02–9.93)	<.001
Allowed me to get information about AD	1.38	(0.57–3.32)	.48
May qualify my relative for drug treatment	2.60	(1.24–5.46)	.01
Was helpful to my family in case AD is hereditary	3.36	(1.57–7.18)	.002
Allowed me to rule out other causes of memory or behavior problems	0.97	(0.47–2.00)	.93
Allowed me to use appropriate community services	2.15	(1.01–4.58)	.048

Adjusted for caregiver status, education, finances, and marital status.

DISCUSSION

Understanding how families decide whether and when to obtain a dementia diagnosis is timely, given the growing awareness of the benefits of early diagnosis and the availability and efficacy of new treatments. Results suggest that, on the whole, family members affected by AD endorsed a wide range of the benefits but few of the barriers to obtaining a diagnosis examined in this study. The most frequently endorsed benefits pertained to obtaining information, finding out what was wrong, and prompting future plans. In addition to the lack of a cure for AD, the beliefs that little can be done for someone with AD, that there is a lack of effective treatment, and that obtaining a diagnosis was a demanding process for families were the barriers most frequently endorsed.

Table 4. Percentage of Participants Strongly Agreeing that Each Factor Served as a Barrier to Obtaining a Diagnosis of Alzheimer's Disease (AD)

Barrier	%			Chi-Square (1 Degree of Freedom)	P- Value
	Total Sample (N = 178)	Black (n = 75)	White (n = 103)		
My family physician did not make a referral to a specialist.	19.1	22.7	16.5	1.07	.30
There are so few physicians trained to diagnose dementia in my local area.	20.8	28.0	15.5	4.10	.04
The process was so time consuming.	12.4	17.3	8.7	2.96	.08
The process was so expensive.	10.7	16.0	6.8	3.86	.05
Health insurance did not cover the process.	12.4	18.7	7.8	4.76	.03
My family members did not agree that it was important.	6.7	6.7	6.8	.00	.97
My relative was not willing to be tested.	12.9	8.0	16.5	2.79	.09
It is very demanding for the patient.	17.4	20.0	15.5	0.60	.44
It is very demanding for the family.	24.7	24.0	25.2	0.04	.85
So little can be done for people with AD.	29.8	22.7	35.0	3.13	.08
Memory problems are part of the normal aging process.	8.4	12.0	5.8	2.14	.14
There is no cure for AD.	36.0	24.0	44.7	8.04	.005
There is no effective treatment for AD.	25.8	14.7	34.0	8.45	.004
There is a stigma against people with AD.	17.4	18.7	16.5	0.14	.71
It is easier not to know what the diagnosis is.	6.2	6.7	5.8	—*	1.00
It would require seeing a specialist instead of a family physician.	6.7	8.0	5.8	0.33	.57

* Fisher exact test.

This pattern of results is consistent with that reported in a previous survey of spouse caregivers that addressed the same benefits of and barriers to diagnosis.¹⁴ However, in

Table 5. Barriers to Diagnosis of Alzheimer's Disease (AD) According to Race (Reference = White)

Barrier	Adjusted Odds Ratio (95% Confidence Interval)	P- Value
My family physician did not make a referral to a specialist.	1.29 (0.55–3.03)	.57
There are so few physicians trained to diagnose dementia in my local area.	1.86 (0.80–4.29)	.15
The process was so time consuming.	2.45 (0.87–6.88)	.09
The process was so expensive.	2.53 (0.75–8.54)	.13
The process was not covered by our health insurance.	1.52 (0.50–4.59)	.46
My family members did not agree that it was important.	0.89 (0.23–3.49)	.87
My relative was not willing to be tested.	0.52 (0.17–1.60)	.26
It is very demanding for the patient.	1.37 (0.56–3.38)	.49
It is very demanding for the family.	1.00 (0.44–2.27)	1.00
So little can be done for people with AD.	0.50 (0.23–1.10)	.08
Memory problems are part of the normal aging process.	2.66 (0.70–10.08)	.15
There is no cure for AD.	0.46 (0.22–0.98)	.04
There is no effective treatment for AD.	0.23 (0.09–0.57)	.002
There is a stigma against people with AD.	1.43 (0.58–3.55)	.44
It is easier not to know what the diagnosis is.	0.94 (0.23–3.84)	.93
It would require seeing a specialist instead of a family physician.	0.90 (0.21–3.83)	.89

Adjusted for caregiver status, education, finances, and marital status.

that study, the benefits of and barriers to diagnosis were more frequently endorsed than in the present sample. These differences may be related to differences in sample composition (e.g., spouse caregivers currently living with the care recipient in the case of the earlier study; family members of a current or deceased family member with AD in the present study).

To address the second objective of this study, racial differences in perceived barriers and benefits to diagnosis were examined for two primary reasons; specifically, recent research suggests that knowledge and attitudes about AD and the timing of help-seeking once symptoms are recognized varies according to race. In the current study, racial differences in perceived benefits of diagnosis were notable. Black respondents endorsed five of the eight benefits more frequently than white respondents after controlling for demographic variables. Three of these benefits involved obtaining information for the family (finding out what was wrong, involving their family member in decision-making, letting the family know in case AD is hereditary); the other two benefits pertained to access to treatment and community services.

Roughly one-quarter or more of the sample unambiguously endorsed only four of the 16 barriers examined; three were treatment-related barriers (no cure, no effective treatment, little can be done for someone with AD) and the fourth pertained to the demand that the diagnostic process places on the family of the affected individual. In adjusted analyses, black respondents were significantly less likely to endorse two of the three treatment-related barriers than their white counterparts: “there is no effective treatment for AD” and “there is no cure for AD.” This finding is consistent with the high level of optimism about future advances in research shown by blacks in another recent study.²

To summarize the racial differences in findings, it is notable and encouraging that black respondents expressed more-positive views of obtaining a diagnosis than their white counterparts, especially in light of the consistent health disparities that have been identified in awareness of and response to illness. Not only were black respondents more likely to strongly endorse a number of benefits, but they were also less likely to view the fact that there is currently no cure or effective treatment as a barrier to diagnosis. Although it is difficult to interpret these findings, it could be that black respondents held lower expectations for their help-seeking experience than white respondents. Their positive views, then, may reflect the fact that their experience in obtaining a diagnosis (and possibly receiving follow-up care and referrals) was more worthwhile than they expected it to be, leading to a stronger endorsement of benefits than by their white counterparts. Another possible explanation for the particularly positive views about diagnosis expressed by black respondents in this study might be related to their perceptions of AD. For example, to the extent that blacks view AD as part of normal aging and as “God’s will,”²³ obtaining a diagnosis could be viewed as a necessary step in the process of accepting the illness, as opposed to a dreaded and definitive event. As described previously,³⁰ future work should move beyond simply quantifying racial differences and begin to explore the cultural dynamics behind observed differences by taking into account region, language, religion, quality of education, literacy, acculturation, and wealth.

Although this study expands understanding of attitudes toward diagnosis, several study limitations should be noted. First, the sample was primarily female and reported a higher than average educational level. Second, these results should be viewed as preliminary because they are based on small subgroup sample sizes. In addition, all study participants had a living or deceased family member who had received a diagnosis of AD; beliefs of those who chose not (or could not) obtain a diagnosis were not assessed. Nevertheless, this study reflects the views of those who have received a diagnosis, and as such, results may be useful to family members who are considering what to do next once symptoms of dementia are recognized in a family member.

Furthermore, although a wide array of benefits and barriers that have been identified in previous research were assessed, there are probably additional factors that were omitted, some of which may be particularly influential in decision-making of minority families. For example, a diverse sample of older adults mentioned two barriers to seeking memory screening that were not included in this study: the fear that a diagnosis might result in healthcare discrimination or in losing a driver’s license.³¹ The perception of covert racism or cultural insensitivity on the part of some healthcare professionals may also serve as a barrier for families considering seeking needed services, including a diagnosis.³² Finally, black families may be less likely to seek help because of the strong belief that it is their sole responsibility to care for a relative with dementia with only limited outside help.^{20,26,32} These broader and possibly culturally specific factors should be included in future research on family decision-making about help-seeking related to pursuing a diagnosis.

It is also important to acknowledge that perceptions about the benefits and barriers of a diagnosis were gathered retrospectively. With time, family members may forget details about the experience, and their views about obtaining a diagnosis may change with the progression of the disease. Because time since diagnosis was not assessed, the effect of time on attitudes as measured in this study could not be examined.

Future research in this area should involve a larger and more diverse and representative sample. Inclusion of two groups—families who are yet undecided about pursuing a diagnosis and those who have chosen not to do so—would provide an important compliment to the present study. Learning more from these groups might also help to identify unique benefits and barriers to diagnosis that may differ according to race and help to explain why blacks may experience longer delays between symptom recognition and diagnosis than whites. It would also be informative to ask those who are currently experiencing mild cognitive impairment to reflect on their views about further testing and diagnosis, because the perspective of the individual affected by AD is often lost in dementia research.³³ Finally, to determine whether educational outreach efforts designed to increase public awareness of AD and the benefits of early diagnosis are having the desired effect, longitudinal research is needed to assess change over time in attitudes and beliefs.

Touting the benefits of obtaining a diagnosis, particularly one viewed as “early,” may be an easy task for advocacy organizations, the research community, and healthcare providers. Convincing an adult child or spouse to undergo the steps necessary to obtain a comprehensive diagnosis for a family member is quite another.³⁴ Results of this study suggest that black and white family members who have received a diagnosis perceive a number of benefits of having done so while endorsing few of the barriers examined in this study. These results are encouraging and suggest that efforts to raise disease awareness and improve access to dementia care and treatment may prove fruitful, because family members are not inherently averse to the diagnostic process itself. To the extent that the positive experiences of those who have been through the process can be directly shared through educational outreach, more families may consider pursuing a diagnosis and participating in research if the option is presented in a tailored and culturally appropriate manner. For example, findings from the current study suggest that family-related benefits might be especially salient for black families. An educational campaign from a trusted source, such as the National Alzheimer’s Association, that incorporates personal testimonials from family members who have experienced the diagnostic process may be particularly likely to inspire help-seeking. Results might also be informative to primary care physicians who may be reluctant to offer screening and referral for a comprehensive diagnosis because of concerns that families may not realize significant benefits or encounter negative consequences.^{33,35,36} Knowing that family members are generally relieved to have the information that a diagnosis provides might also discourage physicians from dismissing memory complaints and increase the likelihood that they would intervene.^{9,37,38}

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