Attitudes Surrounding a Dementia Diagnosis Among African American/Black Adults Age 40 and Older

2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis

ABOUT THIS SURVEY

The 2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis¹ was fielded March 12-24, 2021 and explored the stigma among adults age 40 and older related to a dementia diagnosis. This document showcases the results from the national survey for the African American/Black population (n=331) age 40 and older which represents a subset of the general population sample of adults of the same age (n=3,022).

In this fact sheet we will explore selected aspects related to dementia among the African American/Black adult population. This includes the perceptions of Alzheimer's disease and cognitive impairment, the acceptance of screening for dementia and a dementia diagnosis, the benefits of early-stage diagnosis, the fear and suffering associated with a diagnosis, and general knowledge of the risk associated with dementia and cognitive decline.

KEY FINDINGS

- African American/Black adults agree with adults age 40 and older overall that cognitive impairment and Alzheimer's disease are conditions that are judged negatively by society, at least to some degree.
- More African American/Black adults compared to white adults believe that an early-stage dementia diagnosis would give them more time to treat the disease better and it would motivate them to have a healthier lifestyle to potentially slow the progression of the disease.
- More African American/Black adults compared to white adults and adults overall want to be examined every year to know if they have developed dementia and want a doctor to evaluate their cognitive function to get a baseline measurement.
- Fewer African American/Black adults compared to white adults and adults overall would feel ashamed or embarrassed if they had dementia.
- Significantly fewer African American/Black adults compared to Hispanic/Latino adults, Asian American adults, white adults, and adults overall think they would no longer be taken seriously if they had dementia.
- African American/Black adults, if they had dementia, are less worried about losing their independence compared to adults from other races/ethnicities.
- Fewer African American/Black adults compared to adults from other races/ethnicities are worried that if they had dementia, they would suffer in certain ways (e.g., being a burden to others, being anxious or depressed).
- Knowledge and awareness about dementia, for example whether there is a cure, are low in general and among African American/Black adults.
- African American/Black adults are more willing than adults from other races/ethnicities to engage in brain-healthy behaviors to benefit their mental functioning.

¹ Mehegan, L. and Rainville, G. (2021). 2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults age 40-plus. doi: <https://doi.org/10.26419/res.00471.001>

DETAILED FINDINGS

Perceptions related to Alzheimer's disease and cognitive impairment.

According to African American/Black (AA/B) adults age 40 and older, the most-negatively judged conditions (at least to some degree) are addiction (85%), obesity (82%), and mental illness (78%). Most AA/B adults feel that Alzheimer's disease (58%) and cognitive impairment (61%) are also judged negatively by society. These beliefs are in line with the views of adults age 40 and older, overall. However, for some other conditions, significantly more AA/B adults compared to white adults and adults overall feel they are negatively judged by society (Figure 1).

Figure 1. Percent who feel each condition is judged negatively by society to at least some degree, by race/ethnicity

* Not statistically different from adults overall.

Benefit of early-stage diagnosis. There is widespread agreement among AA/B adults age 40 and older that diagnosing dementia at an early stage is beneficial, consistent with the opinions of adults overall (Figure 2).

Large majorities agree that being diagnosed at an early stage would allow them to: have more time to plan for future care, prepare an advanced directive or living-will, plan finances, have a healthier lifestyle to potentially slow the progression of the disease, increase the chance to treat the disease better, and be more willing to participate in research. Significantly more AA/B adults compared to white adults agree that an early-stage diagnosis would give them more time to treat the disease better (83% vs 73%) and agree that they would be motivated to have a healthier lifestyle (86% vs 79%).

Figure 2. Percent who agree that finding out they had dementia at an early-stage would be beneficial in the following ways (AA/B adults)

53% of African American/Black adults want a yearly exam for dementia; 62% want a baseline cognitive function evaluation

Acceptance of diagnosis and screening for dementia.

Very few AA/B adults, like adults overall, said if they had dementia they would not want to know (7%). But, significantly more AA/B adults (14%) compared to white (9%) and Hispanic/Latino (H/L) (8%) adults said they wouldn't want their family to know. Eight in 10 (82%) would want to know if they are at a higher risk for developing dementia and nine in 10 (92%) do not want a diagnosis withheld (Table 1 on the following page).

Table 1. Percent who agree with selected aspects of dementia screening and a dementia diagnosis.

Acceptance of dementia screening and a dementia diagnosis	All adults	Percent who agree by race/ethnicity			
		AA/B	White	H/L	Asian American
If my doctor diagnoses me with dementia, I want to be told	91%	92%**	91%	90%	84%
If I am at a high risk for developing dementia, I would like to know	78%	82%	77%	80%	82%
I would like to know if I have dementia	73%	74%	75%	67%	69%
I would like a doctor to examine me every year to know if I have dementia	46%	53%*	43%	56%	43%
I would like the doctor to evaluate my cognitive function to get a baseline measurement	54%	62%*	52%	55%	59%

*Significantly higher compared to white adults and adults overall.

**Significantly higher compared to Asian American adults.

More than six in 10 (62%) AA/B adults said they would want their doctor to evaluate their cognitive function to get a baseline measure and more than half (53%) said they would like to be examined every year to know if they have developed dementia. Significantly more AA/B adults compared to white adults and adults overall want a baseline measurement of their cognitive function (62% vs 52%, 54% overall) and to be examined yearly for dementia (53% vs 43%, 46% overall).

Most commonly and like adults overall, AA/B adults feel they should have their cognitive function assessed when their doctor feels it's necessary (26%). Nearly six in 10 (58%) AA/B adults said they would be convinced to get a cognitive evaluation if their doctor or another healthcare provider recommended it. Half (51%) of AA/B adults said they would be convinced to get an evaluation if they felt they were forgetting more than usual or if someone told them they were forgetting more than usual (48%) (Figure 3).

Figure 3. Percent who said each factor would convince them to get a cognitive evaluation (top 3) -- AA/B adults

Perceptions of a dementia diagnosis. While relatively few AA/B adults, like adults overall, agree with selected negative perceptions associated with a dementia diagnosis, the most frequently cited concern is that an employer would find out (29%) followed by the possibility that they would be considered incompetent (23%). Fewer than one in 10 (6%) said they would give up on life if they had dementia. Significantly fewer AA/B adults (14%) – but the same fraction as H/L adults – compared to white adults (20%) and adults overall (19%)

said they would be ashamed or embarrassed if they had dementia.

(H/L: 24%, white: 25%, and Asian American: 42%) think they would no longer be taken seriously (Figure 4).

Significantly fewer AA/B adults (16%) compared to adults overall (25%) and adults from other races/ethnicities

Fear of loss of independence due to dementia. If they had dementia, AA/B adults would worry about losing their independence like adults of other races/ethnicities (Table 2). AA/B adults, however, are significantly less afraid about losing their independence compared to other races/ethnicities. For example, four in 10 (39%) of AA/B adults are worried they would not be able to get

long-term care insurance if they had dementia compared to half (51%) of H/L adults and Asian American adults and nearly half (48%) of white adults and adults overall. Fewer AA/B adults (62%) are worried about losing their driver’s license and other privileges compared to white adults (71%) and adults overall (70%) but it is their biggest fear.

Table 2. Percent who agree with statements representing the fear of loss of independence.

Fear of loss of independence	All adults	Percent who agree by race/ethnicity			
		AA/B	White	H/L	Asian American
If I had dementia, I would be afraid I would lose my driver’s license and other privileges	70%	62%*	71%	65%	68%
If I had dementia, I would be afraid I would have to live in a nursing home	55%	51%^*	55%	53%	59%
If I had dementia, I would be afraid I could not get long-term care insurance	48%	39%**	48%	51%	51%
If I had dementia, I would be afraid I could not get life insurance	41%	37%***	40%	48%	48%
If I had dementia, I would be afraid I could not afford health insurance	39%	33%***	36%	52%	55%
If I had dementia, I would be afraid I would lose my home	33%	29%^ ^	30%	50%	38%

*Significantly lower than white adults and adults overall.

^*Not significant.

**Significantly lower than all other races/ethnicities and adults overall.

***Significantly lower than Asian American adult and H/L adults.

^^Significantly lower than H/L adults.

Perceived suffering due to dementia. One-quarter of AA/B adults feel that if they had dementia their family would suffer financially, and they may not be able to afford the cost of care (Table 3). A lower fraction of AA/B adults (25%) compared to white adults (36%), H/L adults (46%), Asian American adults (46%) and adults overall (36%) feel their family would suffer financially. Additionally, fewer AA/B adults (25%) feel they could not afford the cost of care compared to H/L adults (41%) and Asian American adults (38%).

When it comes to suffering in general, while over half of AA/B adults (52%) feel they would be a burden to others if they had dementia, a significantly smaller percentage than white adults (65%) and Asian American adults (72%). AA/B adults are less likely to think they would be depressed or anxious compared to white and Asian American adults.

Table 3. Percent who agree with statements representing suffering because of a dementia diagnosis.

Suffering	All adults	Percent who agree by race/ethnicity			
		AA/B	White	H/L	Asian American
Financial suffering					
If I had dementia, my family will suffer financially	36%	25%*	36%	46%	46%
If I had dementia, I could not afford the cost of care	31%	25%**	30%	41%	38%
Suffering, non-financial					
If I had dementia, my family will suffer emotionally	66%	52%*	67%	71%	72%
If I had dementia, I would be a burden to others	62%	52%***	65%	56%	72%
I worry if I lose memories of my past, I will lose my sense of self	51%	42%*	51%	51%	59%
If I had dementia, I would be anxious	43%	32%***	45%	36%	54%
If I had dementia, I would be depressed	41%	35%^	42%	36%	48%

*Significantly lower than all other races/ethnicities and adults overall.

**Significantly lower than Asian American and H/L adults.

***Significantly lower than white and Asian American adults and adults overall.

[^]Significantly lower than white and Asian American adults.

Adults’ perceptions of dementia risk and cognitive decline. Nearly six in 10 (57%) AA/B adults believe that cognitive decline is inevitable as people get older and nearly the same fraction feel it is likely they will experience a cognitive decline when they get older (55%) – significantly fewer than white adults (68%). One-quarter (24%) are at least somewhat worried that their mental sharpness has already declined –significantly fewer than among Hispanic/Latino (40%) and Asian American (38%) adults (Figure 5).

Figure 5. Percent who are at least somewhat worried their mental sharpness has already declined, by race/ethnicity

About one-third (36%) feel it is at least somewhat likely they will get dementia in the future, a figure that is significantly lower than among adults overall (48%) as well as among white and H/L adults (49%) and Asian American adults (50%). But it is also higher than the actual prevalence of dementia. According to the Alzheimer’s Association, the prevalence of Alzheimer’s disease among adults age 65 and older is 11%². The prevalence of dementia among adults over age 65 with previously-diagnosed mild cognitive impairment is 15%³.

²Alzheimer’s Association. 2021 Alzheimer’s Disease Facts and Figures. *Alzheimer’s Dementia* 2021;17(3)

General Knowledge and awareness. Significant lack of awareness exists about dementia. Nearly half (48%) of AA/B adults said they “don’t know” if treatments are available for dementia. Similar percentages of adults overall, white adults, and Asian American adults also do not know if dementia can be treated which is significantly lower than among H/L adults (Figure 6).

Figure 6. Percent who don’t know if there are treatments available for dementia, by race/ethnicity

Only one in three (29%) AA/B adults are aware there is no cure for dementia – significantly fewer than white adults (47%) and adults overall (41%). Seven in 10 (70%) AA/B adults feel that a diagnosis of Alzheimer’s disease is about the same as a dementia diagnosis, significantly more than white adults (62%). Significantly fewer AA/B adults (26%) compared to white adults (34%) feel Alzheimer’s disease is worse than dementia. Over half (56%) of AA/B adults feel that a dementia diagnosis is the same as a cognitive decline – significantly more than white adults (47%). Additionally, significantly fewer AA/B adults (36%) compared to white adults (48%) and adults overall (44%) feel that dementia is worse than a cognitive decline.

³ Petersen, R. C., Lopez, O., Armstrong, M. J., Getchius, T. S. D., Ganuli, M., Gloss, D.,...Rae-Grant, A. (2018). Practice guideline update summary: cognitive impairment. *Neurology*, 90, 126-135. doi: 10.1212/WNL.0000000000004826

Calls to action. Significantly more AA/B adults compared to adults from other races/ethnicities are likely to incorporate selected behaviors into their daily lives if they know that each behavior may help them maintain their mental functioning/thinking skills (Table 4). Significantly more AA/B adults compared to white adults said they would incorporate more regular exercise into

their daily lives. Additionally, more AA/B adults compared to white and Asian American adults, and adults overall said they would manage stress effectively. Finally, more AA/B adults compared to Asian American adults said they would add more mentally-stimulating activities into their daily lives.

Table 4. Percent who are extremely or very likely to incorporate more healthy behaviors into their daily lives if they knew it may help them maintain their thinking skills.

Brain-healthy activities	All Adults	Percent extremely or very likely to incorporate more of each selected activity into their daily lives if they knew it may help maintain thinking skills by race/ethnicity			
		African American/ Black	White	Hispanic/ Latino	Asian American
Getting regular exercise	60%	65%*	58%	64%*	69%*
Engaging socially	62%	58%	61%	71%**	61%
Managing stress effectively	68%	74%***	66%	74%***	63%
Getting enough restful sleep	69%	71%	67%	77%**	66%
Eating nutritious and well-balanced meals	69%	73%	67%	75%*	72%
Engaging in mentally-stimulating activities	71%	75%^	72%	74%	63%

*Significantly higher than white adults.

**Significantly higher than adults overall, white and AA/B adults.

***Significantly higher than adults overall, white and Asian American adults.

^Significantly higher than Asian American adults.

METHODOLOGY

This survey was conducted online between March 12-24, 2021, via the Ipsos KnowledgePanel®. This nationally representative survey targeted panel members age 40 and older (n=3,022). All data are weighted by age, gender, and race according to the most recent Census population statistics. The margin of error for the national survey is ± 1.89 percentage points. The sample size for African American/Black adults was 331.

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The entire final report for the general population survey is entitled [2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults age 40-plus](https://doi.org/10.26419/res.00471.001), <https://doi.org/10.26419/res.00471.001>