Attitudes Surrounding a Dementia Diagnosis Among Hispanic/Latino 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 Hispanic/Latino population (n=404) 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 Hispanic/Latino 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

- Hispanic/Latino 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 Hispanic/Latino adults compared to white adults believe that an early-stage dementia diagnosis would give them more time to treat the disease better.
- More Hispanic/Latino adults compared to white and Asian American adults and adults overall want to be examined every year to know if they have developed dementia.
- Few Hispanic/Latino adults are worried about being ashamed, embarrassed, or mistreated if they had dementia. Even fewer Hispanic/Latino adults compared to white adults and adults overall think they would feel ashamed or embarrassed if they had dementia.
- More Hispanic/Latino adults are worried about losing selected aspects of their independence than are adults from other races/ethnicities.
- More Hispanic/Latino adults are worried about financial suffering compared to other races/ethnicities. However, fewer H/L adults are worried about being a burden to others.
- More Hispanic/Latino adults than adults overall and adults from other races/ethnicities – except for Asian American adults – are worried their mental sharpness has already declined.
- Knowledge and awareness about dementia are low in general and among Hispanic/Latino adults.
- Hispanic/Latino 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 Hispanic/Latino (H/L) adults age 40 and older, the topmost-negatively judged conditions (at least to some degree) are addiction (81%), obesity (79%), and mental illness (76%). Most H/L adults feel that Alzheimer's disease (60%) and cognitive impairment (64%) are also judged negatively by society. These beliefs are in line with the views of adults age 40 and older, overall. However, a greater percentage of H/L adults (compared to white adults and adults overall), see some other medical conditions as judged negatively by society (Figure 1).

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

Benefit of early-stage diagnosis. There is widespread agreement among H/L 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 H/L adults agree that being diagnosed at an early stage would allow them to: have a healthier lifestyle to potentially slow the progression of the disease, have more time to plan for future care, plan their finances, have time to prepare an advanced directive or living-will, increase the chance to treat the disease better, and be more willing to participate in research. Significantly more H/L adults compared to white adults agree that an early-stage diagnosis would give them more time to treat the disease better (79% vs 73%).

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

56% of Hispanic/Latino adults want a yearly exam for dementia

Acceptance of diagnosis and screening for dementia. Very few H/L adults, like adults overall, said if they had dementia they would not want to know (6%) and they wouldn't want their family to know (8%). Eight in 10 (80%) said they would want to know if they are at a higher risk than others for developing dementia, but only two-thirds (67%) said they want to know if they

have dementia – significantly fewer than white adults (75%) and adults overall. However, if their doctor

formally diagnoses them with dementia, nine in 10 (90%) H/L adults want to know (Table 1).

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

*Significantly lower compared to white adults and adults overall.

**Significantly higher compared to white and Asian American adults and adults overall.

More than half (55%) of H/L adults said they would want their doctor to evaluate their cognitive function to get a baseline measure and a similar percentage (56%) said they would like to be examined every year to know if they have developed dementia. Significantly more H/L adults (56%) compared to white adults (43%), Asian American adults (43%) and adults overall (46%) want to be examined yearly for dementia.

Most commonly and like adults overall, H/L adults feel they should have their cognitive function assessed when their doctor feels it's necessary (31%). Significantly more H/L adults compared to white adults feel their cognitive function should be examined yearly starting at age 50 (28% vs 12%).

Half of H/L adults said they would be convinced to get their cognitive function evaluated if their doctor or another healthcare provider recommended it, and more than four in ten would be convinced if they felt they

were forgetting more than usual or if someone told them they were forgetting more than usual, in both cases significantly fewer compared to white adults and adults overall (see Figure 3 on the following page).

Perceptions of a dementia diagnosis. While relatively few H/L adults, like adults overall, agree with selected negative perceptions associated with a dementia diagnosis, three in 10 are concerned that their employer would find out and that they would be considered incompetent, if they had dementia (see Figure 4 on the following page). Fewer than one in 10 (8%) said they would give up on life. Significantly fewer H/L adults (14%) compared to white adults (20%) and adults overall (19%) said they would be ashamed or embarrassed if they had dementia.

Figure 3. Percent who said each would convince them to get a cognitive evaluation (top 3), for adults overall, H/L adults and white adults

Fear of loss of independence due to dementia. If they had dementia, H/L adults would worry about losing their independence like adults of other races/ethnicities (Table 2). But, H/L adults are significantly more worried about their loss of independence compared to other races/ethnicities. For example, half of H/L adults are worried they would lose their home if they had dementia compared to three in 10 white adults (30%) and AA/B adults (29%), and four in 10 (38%) Asian American adults. Fewer H/L adults are worried about losing their driver's license and other privileges compared to white adults (65% vs 71%) but it is their biggest fear.

Figure 4. Percent who agree with feelings and worries about dementia and how they would be treated by other people. (H/L adults)

If I had dementia, I would be...

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

*Significantly higher than white adults and African American/Black (AA/B) adults.

****Significantly higher than African American/Black adults.**

^Significantly higher than white adults, AA/B adults, and Asian American adults.

^*Not significant.

^^Significantly lower than white adults.

Perceived suffering due to dementia. Four in 10 or more H/L 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 higher fraction of H/L adults (46%) compared to white adults (36%) and AA/B adults (25%) feel their family would suffer financially. Additionally, more H/L adults (41%) feel they could not afford the cost of care compared to white adults (30%) and AA/B adults (25%).

When it comes to suffering in general, while over half of H/L adults (56%) feel they would be a burden to others if they had dementia, this represents significantly fewer than white adults (65%) and Asian American adults (72%). H/L adults are less likely to think they would be depressed or anxious (36%, each) compared to 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			
		H/L	White	AA/B	Asian American
Financial suffering					
If I had dementia, my family will suffer financially	36%	46%*	36%	25%	46%
If I had dementia, I could not afford the cost of care	31%	41%*	30%	25%	38%
Suffering, non-financial					
If I had dementia, my family will suffer emotionally	66%	71%**	67%	52%	72%
If I had dementia, I would be a burden to others	62%	56%***	65%	52%	72%
I worry if I lose memories of my past, I will lose my sense of self	51%	51%^	51%	42%	59%
If I had dementia, I would be anxious	43%	36%^ ^	45%	32%	54%
If I had dementia, I would be depressed	41%	36%^*	42%	35%	48%

*Significantly higher than white adults and African American/Black (AA/B) adults.

**Significantly higher than AA/B adults.

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

^Significantly higher than AA/B adults.

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

^*Significantly lower than Asian American adults.

Adults' perceptions of dementia risk and cognitive decline.

Six in 10 (62%) H/L adults believe that cognitive decline is inevitable as people get older and feel it is likely they will experience a cognitive decline when they get older (63%). Four in 10 (38%) are at least somewhat worried that their mental sharpness has already declined – like Asian American adults (40%) and significantly more than adults overall (28%), AA/B (24%), and white (26%) adults (Figure 5).

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

Nearly half (49%) feel it is at least somewhat likely they will get dementia in the future, a figure that is much 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.

General Knowledge and awareness. Significant lack of awareness exists about dementia. Significantly more H/L adults (57%) said they "don't know" if treatments are

available compared to AA/B (48%), white (44%), and Asian American (43%) adults (Figure 6).

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

One in five (21%) H/L adults are aware there is no cure for dementia – significantly fewer than white (47%), Asian American (35%), and AA/B adults (29%). Nearly two-thirds (64%) of H/L adults feel that a diagnosis of Alzheimer's disease is about the same as a dementia diagnosis, nearly the same as adults age 40 and older overall (63%). Significantly fewer H/L adults (27%) compared to white adults (34%) feel Alzheimer's disease is worse than dementia. Nearly six in 10 (58%) H/L adults feel that a dementia diagnosis is the same as a cognitive decline – significantly more than adults overall (50%) and white adults (48%). Significantly fewer H/L adults (31%) compared to white adults (48%) and adults overall (44%) feel that dementia is worse than a cognitive decline.

Calls to action. Significantly more H/L 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).

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

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

Table 4. Percent who are extremely or very likely to incorporate more healthy behaviors into their daily lives if they knew if 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 them maintain thinking skills by race/ethnicity			
		Hispanic/Latino	White	African American/Black	Asian American
Getting regular exercise	60%	64%*	58%	65%*	69%*
Engaging socially	62%	71%**	61%	58%	61%
Managing stress effectively	68%	74%***	66%	74%***	63%
Getting enough restful sleep	69%	77%**	67%	71%	66%
Eating nutritious and well-balanced meals	69%	75%*	67%	73%	72%
Engaging in mentally-stimulating activities	71%	74%	72%	75%^	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 the Hispanic/Latino population was 404.

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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>