



## *Alzheimer's, Dementia & Mental Health*

### African-American, Hispanic Caregivers Too Often Dismiss Alzheimer's as 'Old Age'

*Survey finds misperceptions, late diagnosis among these minorities*

March 14, 2007 - African-American and Hispanic, who care for a “loved one” with Alzheimer's disease are significantly more likely than caregivers of other races to consider the disease a normal part of the aging process and dismiss its symptoms as part of getting older, according to the Alzheimer's Foundation of America's (AFA) second ICAN: Investigating Caregivers' Attitudes and Needs survey. “This gap in understanding sheds light on the reasons for delay in diagnosis and treatment, which is an unnecessary setback for caregivers and individuals with the disease alike,” says AFA.

“Facing Alzheimer's disease is never easy, but getting a diagnosis and taking advantage of support services are crucial steps to treating and managing the disease,” said Eric J. Hall, Chief Executive Officer of the Alzheimer's Foundation of America. “We encourage everyone touched by Alzheimer's disease to reach out for assistance - help is out there.”

The survey was conducted by Harris Interactive(R) on behalf of AFA, a national nonprofit organization providing care and services to individuals with Alzheimer's disease and related dementias, and their families.

According to the survey released today, African-American and Hispanic caregivers surveyed were significantly more likely (37% versus 33%) than caregivers of other races (23%) to believe that Alzheimer's disease is a normal part of the aging process. In fact, Alzheimer's disease is a progressive, neurodegenerative illness.

Compounding the problem, African-American (70%) and Hispanic (67%) caregivers were also significantly more likely to dismiss the symptoms of Alzheimer's disease as old age than other respondents of other races (53%).

Additionally, African-American (67%) and Hispanic (63%) caregivers were significantly more likely to report that they did not know enough about the disease to recognize the symptoms compared to caregivers of other races (49%).

The survey also found that African-American (33%) and Hispanic (26%) caregivers were also more likely than caregivers of other races (12%) to recognize that they are at a higher risk for Alzheimer's disease.

"Alzheimer's disease is a devastating illness that is by no means a normal part of aging," explained Warachal E. Faison, M.D., Assistant Director of the Institute for Research Minority Training on Mental Health and Aging, and Clinical Director of the Alzheimer's Research and Clinical Programs at the Medical University of South Carolina.

"My deep concern is that caregivers who consider the disease normal and don't know how to recognize its symptoms are not going to be able to make the best healthcare decisions for their loved ones with the disease and themselves as caregivers. The fact is, it's crucial for caregivers to be able to identify symptoms and bring their loved one to a doctor without delay for proper diagnosis and treatment."

### Stigma Can Delay Diagnosis, While Ethnic Barriers May Not

Based on caregivers' responses, on average those they cared for with Alzheimer's typically experienced symptoms for 31 months before receiving a diagnosis.

While not associating symptoms with Alzheimer's disease can be a cause for a delay in diagnosis, concern about stigma associated with the disease can also play a role. About one-third (33%) of overall respondents reported that their loved one's concern about stigma delayed diagnosis, while about a quarter (26%) indicated that their own concern about stigma was a reason for the delay, the survey found.

African-American caregivers were significantly more concerned about stigma (36%) than Hispanic (22%) and other race (18%) caregivers.

Other reasons for the delay in diagnosis included not wanting to face the possibility of something being wrong, fear of the responsibility of caregiving, not being offered a memory screening, and resistance in visiting a doctor.

The survey indicated that respondents, regardless of their ethnic background, did not blame the delay in diagnosis on ethnic barriers.

## Attitudes Differ On Placing A Loved One In A Skilled Nursing Facility

Despite the role that assisted living facilities and nursing homes play in the continuum of care for people with Alzheimer's disease, the survey also revealed that significant proportions of African-American and Hispanic caregivers don't consider them an option.

Among caregivers surveyed whose loved one is not currently living in an assisted living facility or nursing home, other race caregivers (32%) were nearly twice as likely to think that placing their loved one in a facility is an option in the future compared to African-American (19%) and Hispanic (21%) caregivers.

Overall, caregivers who will not place their loved one in a facility felt that it is their responsibility to take care of their loved one (85%) or said they would feel guilty (60%).

## Religion/Spirituality Have Significant Impact on Decision-Making, Support

Religion and spirituality tend to play an important role in the lives of caregivers, from seeking support to making healthcare decisions. The survey found that respondents who are religious are more likely to turn to religious leaders for support and let their religion influence their healthcare decisions than non-religious respondents (73% versus 31%).

However, nearly two-thirds (63%) of non-religious respondents said that their spiritual beliefs have a significant impact on their healthcare decisions. The caregiving journey also made both religious and non-religious respondents feel more religious (36%), with African-American (48%) and Hispanic (35%) caregivers much more likely to feel this way than other race (26%) caregivers.

A majority of respondents overall did not feel they needed more or better support from their religious leaders, while about a third indicated they could have used more support from them.

African-American caregivers (46%) were more likely to express that they could have used more support from their religious leaders, compared to Hispanic (36%) and other (23%) caregivers.

## Support Groups are Most Popular among African-American and Hispanic Caregivers

African-American and Hispanic caregivers rely heavily on support groups. In fact, among those surveyed, African-American (47%) and Hispanic (50%) caregivers were significantly more likely to currently use a support group than other race caregivers (29%).

Yet only around half of African-American respondents and a little more than one-third of Hispanic respondents said that they felt the support groups they were able to access were appropriate to their specific religious or ethnic background. Interestingly, religious respondents overall were more likely to have access to a support group than non-religious respondents (47% versus 36%).

The survey also found that a majority of caregivers -- African Americans in particular -- wished they had more emotional support from friends and family as well as knowledge and direction from healthcare professionals.

At diagnosis, caregivers overall wished they had received more information about Alzheimer's disease (75%) and treatment options (75%); African-American caregivers (83%) surveyed were significantly more likely than Hispanic (73%) and other (68%) caregivers to wish they had received more information.

### Majority of Caregivers Unaware of Combination Therapy

When it comes to treatment, a majority of caregivers surveyed overall were not currently aware of combination therapy (67%). Combination therapy describes treatment combining medication from the two classes of Alzheimer's disease drugs currently approved by the FDA. African-American (26%) and Hispanic (32%) caregivers were less likely than other race (38%) caregivers to be aware of combination therapy.

Additional key survey findings can be found at [www.alzfdn.org](http://www.alzfdn.org).

### About Alzheimer's Disease

Alzheimer's disease is a progressive, degenerative disorder that attacks the brain's nerve cells, resulting in loss of memory, thinking and language skills, and behavioral changes. An estimated one in 10 persons over age 65 and nearly half of those 85 or older have Alzheimer's disease. Alzheimer's disease currently strikes approximately five million Americans; published reports project that by 2050 this number could more than triple to more than 16 million people in the United States.

Alzheimer's disease occurs significantly more frequently among African American (10.5%) and Hispanic (9.8%) individuals than among Caucasian (5.4%) individuals. Moreover, the proportion of African American and Hispanic individuals reaching ages 65+ in the U.S. is increasing more rapidly than the proportion of Caucasian individuals.(2)

Symptoms of moderate Alzheimer's disease can include difficulty identifying familiar people, places, or things, restlessness, sleep disturbances, poor judgment or difficulty with reasoning, aggression or agitation, inappropriate behavior, increased difficulty with everyday activities, losing touch with reality, suspiciousness or paranoia, and hallucinations.

### About The Survey

This second ICAN: Investigating Caregivers' Attitudes and Needs survey was conducted by telephone within the United States for the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc between January 9 and February 6, 2007 among 655 adults (aged 18 and over) who are caregivers currently caring for a loved one with Alzheimer's disease. Among those, there are Hispanic (150), African American (252) and other races (253) caregivers. The survey focused on three groups of caregivers: African Americans, Hispanics, and Other Races. The Other Race caregivers is comprised of Whites, Asian/Pacific Islanders, Native American or Alaskan natives, those of mixed racial backgrounds, and those identifying themselves as "other." Data were not weighted and therefore results can only be reflected to the samples surveyed.

### About The Alzheimer's Foundation of America

The Alzheimer's Foundation of America is a national nonprofit organization that focuses on providing optimal care to individuals with Alzheimer's disease and related illnesses, and their families. Based in New York, AFA unites hundreds of member organizations that provide hands-on support services. AFA's services include a toll-free hotline staffed by licensed social workers, educational materials, a free magazine for caregivers, a national memory screening initiative, and training for healthcare professionals. For more information, call (toll-free) 866-AFA-8484 or visit <http://www.alzfdn.org/>

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