



AfricanAmerican Network**4**gainst Alzheimer's

The Costs of Alzheimer's and Other Dementia
for African Americans

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THE COSTS OF ALZHEIMER'S AND OTHER DEMENTIA FOR AFRICAN AMERICANS

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EXECUTIVE SUMMARY

While African Americans make up only 13.6% of the U.S. population, they bear a third of the costs of Alzheimer's disease and other dementias (AD). This is due to substantial, but underappreciated, racial disparities in the prevalence of AD. Older African Americans are two to three times more likely to have AD compared to non-Hispanic whites. More than 20% of Americans with AD are African Americans.

The economic burden of Alzheimer's and other dementias for African Americans was \$71.6 billion in 2012. Caregiving for African Americans with AD represents the bulk of these costs—more than 60%. More than 60% of the costs are borne by the families of African American women with AD, and close to half of the costs are concentrated in the southern states.

The estimated direct medical and long-term care costs of AD for African Americans were \$21.4 billion dollars. This includes \$5.5 billion in direct medical costs, \$1.3 billion in costs of adult day care in non-institutional settings, and \$14.6 billion in nursing home costs. Taxpayers pay for the majority of these health care-related costs through Medicare and Medicaid.

While the economic burden of AD is quite high, the full impact of AD cannot be expressed in dollars. The toll on patients with Alzheimer's disease and their loved ones is difficult to quantify. AD exacts an emotional burden on families and a physical and psychological burden on caregivers and

removes from society the memories, experiences and wisdom that its victims can no longer share. We have not attempted to quantify the economic costs associated with reduced quality of life for both patients and family caregivers. If we were able to compute these costs of AD, our estimates would be exceedingly higher.

Nationally, estimates show that the economic burden of AD is comparable to those of heart disease, cancer and diabetes. Yet, society does not devote proportionate resources to research, education, prevention, treatment and policy to address this leading cause of death. The prevention and treatment of AD are especially important to African Americans. We expect African Americans to bear an increasing share of the economic costs of AD. Based on the prevalence rate, the distribution of health care costs, and the growth and aging of the African American population, we expect the costs of AD for African Americans to more than double by 2050. Hence, society needs to develop prevention strategies as well as treatments and therapies able to slow the progress or significantly modify the disease and, ultimately, stop it outright and restore functional status to its victims. There is also a great need for policies, programs and interventions that assist caregivers and reduce the impact of AD on caregivers' earnings, savings, health and overall quality of life.

KEY FINDINGS

While African Americans make up 13.6% of the U.S. population, they bear one-third (33%) of the nation's total costs of Alzheimer's and other dementia.

The estimated annual cost to African Americans for Alzheimer's and other dementia in 2012 was \$71.6 billion. More than 60% of these costs are borne by the families of African American women with Alzheimer's and other dementia, and close to half of the costs are concentrated in the South.

African Americans provide \$43.6 billion annually — more than 17.4 billion hours — in unpaid caregiving for their loved ones with Alzheimer's.

The estimated direct medical and long-term care costs of Alzheimer's disease and other dementias for African Americans were \$21.4 billion dollars. This includes \$5.5 billion in direct medical costs, \$1.3 billion in adult day

care in non-institutional settings, and \$14.6 billion in nursing home costs.

While Medicare is the primary payer for the medical care costs, paying 59%, African Americans pay \$554 million out-of-pocket.

African Americans between the ages of 40 and 64 lost \$6.1 billion in labor market productivity due to Alzheimer's — mostly from lost wages.

The prevalence of cognitive impairment is two to three times higher for African Americans. Based on the prevalence rate and the distribution of health care costs, we expect that the costs of Alzheimer's care for African Americans will rise substantially in the future as the African American population ages. The prospects of 1 in 3 and then 1 in 2 older African Americans with cognitive impairment presents a significant challenge to African American families and society at large.

INTRODUCTION

It is well known that Alzheimer's and other dementias (AD) can place a tremendous burden on families. The emotional impact also can be devastating (AA 2012). But, while AD's physical and emotional toll is well-documented, its economic impact is substantial, too.

The economic burden of AD is comparable to other leading causes of death. For example, studies have estimated the annual costs of heart disease to be \$309 billion, cancer to be \$243 billion, and diabetes, \$188 billion (NHLBI 2011; ADA

2008). Hurd and colleagues (2013) estimate the costs of AD in 2010 were \$215 billion. This total includes the costs of both formal care purchased from health care providers and informal care provided by loved ones. The authors point out that the annual costs of formal care for dementia (\$109 billion) exceed the costs of such care for heart disease (\$102 billion) and cancer (\$77 billion) (Hurd et al 2013).

Hurd and colleagues (2013) also predicted that the societal costs of AD will more than double by 2040 because of the growth in the elderly population, if the prevalence rate and costs are constant. The

magnitude of the economic, medical, emotional and societal impact of AD should create a sense of urgency among policymakers to deal with this growing problem. However, while the economic burden of AD is comparable to other leading causes of death, comparable resources are not allocated for research, education, treatment and prevention of AD.

AD is an underappreciated disparities issue. Neither Alzheimer's disease nor dementia is listed among targeted conditions in the national plan to reduce racial and ethnic health disparities issued by the Department of Health and Human Services (HHS 2013). However, the prevalence of this disease for African Americans and its disproportionate emotional and economic burden for African Americans warrant its inclusion.

The Aging, Demographics, and Memory Study (ADAMS) reported that 21.3% of African Americans aged 71 and older had AD, compared to 11.2% of non-Hispanic whites (Potter et al 2009). The Washington Heights-Inwood Columbia Aging Project reported that African Americans were 2.4 times more likely to have AD than non-Hispanic whites (18.8% versus 7.8%) (Gurland et al 1999). Using data from the 2006 Health and Retirement Survey (HRS), the Alzheimer's Association reported that 23.6% of African Americans aged 65 and older have cognitive impairment, compared to 8.8% of non-Hispanic whites. The prevalence rate of cognitive impairment is two to three times higher among African Americans than in similar whites, and of course AD prevalence increases with age, as depicted below:

- 4.8% for African Americans vs. 1.2% for non-Hispanic whites aged 55-64,
- 12.4% for African Americans vs. 2.9% for non-Hispanic whites aged 65-74,

- 32.5% for African Americans vs. 9.8% for non-Hispanic whites aged 75-84, and
- 54.6% for African Americans vs. 26.9% for non-Hispanic whites aged 85 and older.

As the African American population becomes older, the prospects of one in three (by age 75) and then one in two (by age 85) older African Americans with cognitive impairment present a significant challenge not only to African American families but also society at large.

In this report we estimate the costs of AD for African Americans and forecast the economic impact of AD for African Americans through 2050, as a function of projections in the growth of the population of African American seniors over the next 40 years. As African American baby boomers progress into their senior years, and African American life expectancy continues to rise, it is predictable that AD will become an increasing concern for African Americans, and it is imperative that policymakers devote the attention and necessary resources to mitigating this very significant impact. It will be important to ensure that future updates to the HHS Disparities Action Plan contain references to the Alzheimer's and dementia crisis and include specific measurable actions to pursue.

WHY ARE AFRICAN AMERICANS AT GREATER RISK OF DEVELOPING AD?

AD has been linked to several risk factors that are more prevalent among African Americans, such as cardiovascular diseases, health behaviors, socioeconomic status and environmental factors (Griffith and Griffith 2008).

The nexus between race, cardiovascular diseases and AD risk is compelling. Hypertension, diabetes, stroke and coronary artery disease are risk factors for AD (Chin et al 2011). These chronic conditions are more prevalent in African Americans compared to other Americans.

Socioeconomic status and environmental factors may have a stronger influence on the race disparity as well (AA 2010). The risk of AD is inversely related to educational attainment and income. Hence because African Americans have lower average educational attainment and incomes compared to whites, they are at greater risk of having AD. Also, growing up in a rural area is a risk factor for AD. This is particularly relevant for older African Americans, many of whom grew up in the rural South and migrated to urban centers during adulthood. Air pollution, harmful metals and pesticides are environmental toxins that are also linked to Alzheimer's disease risk (Mattson 2004; Dosunmu et al 2007). These environmental hazards are associated with racial residential segregation, which has persisted over time. As with other health disparities, residential segregation facilitates race differences in exposure to environmental hazards and has become well-recognized as a primary driver of racial disparities in health (Williams and Collins 2001; Link and Phelan 1995).

STUDY METHODOLOGY

The economic impact of AD on patients and their families consists of several types of expenditures. People often live for many years with AD and therefore require health care and long-term care services. Because those with AD have difficulty with activities of daily living (i.e., dressing, bathing, grooming, using the bathroom, shopping, eating and managing money), they require intensive levels of informal care. These circumstances differ for other leading causes of death, for which the non-medical costs of the disease are mostly lost labor-market productivity and the cost of premature death. However, the incidence of AD is low for persons between ages 45-64, so its impact on labor-market productivity is low. Also, the onset of AD mostly occurs during retirement years, minimizing the cost of premature death, which is typically valued as foregone earnings. Consequently, most non-medical costs for AD are associated with its impact on caregivers, those persons who provide informal care. The costs of AD to society are thus very different from other chronic diseases because of the relative importance of informal care and the lack of medical interventions to prevent, slow or reverse AD. For example, informal care is not a major cost category for cancer and heart disease, yet direct medical costs for those conditions can be substantial.

The costs of AD can be divided into direct and indirect costs. Direct costs include expenditures for medical care, adult day care, nursing home care, assisted living and hospice care. Indirect costs include lost labor-market productivity for persons with AD as well as for their family members who leave the workforce to provide unpaid care. To compute the direct and indirect costs, we used findings from published studies

on dementias and health disparities, combined with data from the Medical Expenditure Panel Survey (MEPS), the National Health Interview Survey (NHIS), CDC's National Vital Statistics, and the U.S. Census.

We provide a more detailed description of the estimation methods in the appendix.

FINDINGS

AFRICAN AMERICAN ELDERLY POPULATION GROWTH

The 20th century witnessed a dramatic shift in the demographic landscape of America. At the midpoint of the century, U.S.-born whites comprised about 90% of the population. By century's end, the percentage of Americans who reported their race as non-Hispanic white in the decennial census declined to about 65%. The Census Bureau projects that by the middle of the 21st century non-Hispanic whites will comprise a numerical minority of the U.S. population. The nation will then be comprised of a majority of persons that we now refer to as racial and ethnic minorities.

Four states (California, Texas, New Mexico and Hawaii) and the District of Columbia are currently minority-majorities, and as many as four others could be majority-minority by 2020 (LaVeist 2012). This demographic shift is largely driven by increases in the Asian and Hispanic/Latino population. However, while the percentage of non-Hispanic whites has been declining as a result of a surge in the Asian and Hispanic/

Latino population, the percentage of African Americans has remained constant at around 13%.

In 1950 about 16.2 million of the 152 million Americans were African Americans (see Table 1). By the end of the century, the African American population more than doubled to 34.6 million. Today there are more than 41.2 million African Americans, according to the U.S. Census Bureau. The Census Bureau projects that by the middle of the 21st century the number of Americans who report their race as black/African American will increase by nearly 40%, to 57.5 million.

While the total number of African Americans represents a dramatic increase, Census Bureau projections show an even more striking pattern emerging as the 21st century unfolds. In 1950 African Americans age 40 and above comprised 28.4% of the total African American population, but by the year 2000 that percentage had increased to 34.5% (see Table 2). By 2050, Census Bureau projections indicate that almost one half (48.5%) of all African Americans will be age 40 or older. In other words, the African American population has been getting older, and the best available projections suggest that this pattern is accelerating.

Table 1. Total African American Population and Age Groups Over 40 (1950-2050)

Year	Black Population	Black Population 40-54	Black Population 55-64	Black Population 65-74	Black Population 75-84	Black Population 85 and Over	Total Black Population Over 40
1950	16,287,900	2,722,012	977,042	665,315	210,869	45,950	4,621,188
1960	19,006,281	2,968,365	1,286,539	821,619	300,812	66,642	5,443,977
1970	22,801,214	3,328,385	1,614,623	1,047,318	408,435	103,296	6,502,057
1980	26,890,093	3,554,304	1,920,950	1,349,251	593,752	161,801	7,580,058
1990	30,756,626	4,526,244	2,018,115	1,505,542	775,683	225,911	9,051,495
2000	34,658,190	6,781,066	2,370,110	1,613,172	896,489	313,289	11,974,126
2010	41,204,793	8,416,552	4,362,414	2,244,912	1,112,578	423,548	16,560,004
2020	44,809,572	8,099,264	5,235,998	3,407,093	1,460,214	538,998	18,741,567
2030	49,245,947	9,148,750	5,013,144	4,546,899	2,488,191	774,434	21,971,418
2040	53,411,745	10,750,420	5,454,521	4,446,854	3,387,037	1,356,190	25,395,022
2050	57,553,051	10,646,188	6,957,434	4,934,562	3,399,227	1,949,676	27,887,087

*Note: Figures for 2020-2050 are projections
Source: Census Population Estimates, Historical Data; Census Population Projection Data (Middle Series)

Table 2. Percent of the African American Population Over 40 (1950-2050)

Year	Black Population 40-54	Black Population 55-64	Black Population 65-74	Black Population 75-84	Black Population 85 and Over	Total Black Population Over 40
1950	16.7%	6.0%	4.1%	1.3%	0.3%	28.4%
1960	15.6%	6.8%	4.3%	1.6%	0.4%	28.6%
1970	14.6%	7.1%	4.6%	1.8%	0.5%	28.5%
1980	13.2%	7.1%	5.0%	2.2%	0.6%	28.2%
1990	14.7%	6.6%	4.9%	2.5%	0.7%	29.4%
2000	19.6%	6.8%	4.7%	2.6%	0.9%	34.5%
2010	20.4%	10.6%	5.4%	2.7%	1.0%	40.2%
2020	18.1%	11.7%	7.6%	3.3%	1.2%	41.8%
2030	18.6%	10.2%	9.2%	5.1%	1.6%	44.6%
2040	20.1%	10.2%	8.3%	6.3%	2.5%	47.5%
2050	18.5%	12.1%	8.6%	5.9%	3.4%	48.5%

*Note: Figures for 2020-2050 are projections
Source: Census Population Estimates, Historical Data; Census Population Projection Data (Middle Series)

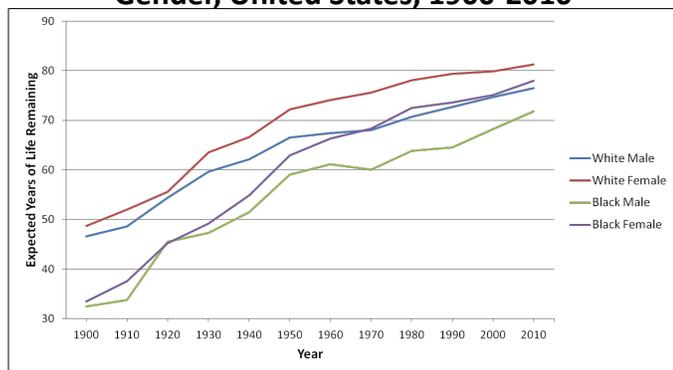
between African Americans and white Americans, as well as males and females.

At the beginning of the 20th century, life expectancy for African Americans was less than 35 years, while life expectancy for whites was nearly 50 years. White females consistently had the highest life expectancy throughout the century, from about 45 years to greater than 80 years by the year 2010. Early in the century white males had the second highest life expectancy;

The graying of the African American population can perhaps best be seen by examining patterns in life expectancy (see Figure 1). During the 20th century, life expectancy in the U.S. increased dramatically across the board. At the beginning of the century, it was relatively rare for Americans of any racial or ethnic group to live more than 60 years. By the end of the 20th century, however, it was not unusual for Americans to exceed 80 years of life. Yet, while life expectancy has increased for all groups, disparity in life expectancy has persisted

however, as the century progressed, gender disparity overtook the racial disparity in life expectancy, and by the 1960s life expectancy for black women equaled and then exceeded that for white males. While black male life expectancy also substantially increased during the 20th century, it did not improve as rapidly as for black females. White female life expectancy reached 65 years in the 1940s, white male life expectancy reached age 65 in the 1950s, and black females, in the 1960s. It was not until late in the 1990s that black male life expectancy reached age 65. However slowly, African American male life expectancy has continued to rise, and by 2010 black male life expectancy had exceeded 70 years.

Figure 1. Life Expectancy at Birth by Race and Gender, United States, 1900-2010



Source: 1900-1969: National Center for Health Statistics, National Vital Statistics, "United States Life Tables, 2008", Vol. 61, No. 3, Sept 12, 2012, tab 46; 1970-2010: National Center for Health Statistics, National Vital Statistics Reports, "Deaths: Final Data for 2010", Vol. 61, No. 4, May 8, 2013, tab 80
*Data for Black between 1900-1969 are shown as non-white

The increasing proportion of African Americans living to middle age and older has important social, economic and health implications for African Americans and the nation. Among the most important is a predictable increase in the number of African Americans with AD. In the 2012 edition of the CDC's National Center for Health Statistics report, *Health, United States*, for the first time, AD is one of the 10 leading causes

of death for African Americans (NCHS 2013). In the year 2010 the African American AD death rate was 20.6 per 100,000 persons (age-adjusted), which represented 5220 deaths. The overall AD death rate was 27.0 per 100,000 persons (age-adjusted), which represented 83,494 deaths. This made Alzheimer's disease the 6th leading cause of death for all Americans and the 4th leading cause of death among African Americans ages 85 and older—811.5 per 100,000 persons (NVS 2012).

GROWTH IN ALZHEIMER'S DEATHS

In table 3, we forecast African American deaths from Alzheimer's using two projection methods. In the first method we assume that the Alzheimer's death rate of 12.67 per 100,000 African Americans will remain constant through the year 2050. In the second set, we assume that the 1.94% increase in the African American Alzheimer's death rate between 2008 and 2010 will continue through 2050. The most conservative estimation method, constant death rate, projects that the number of African American Alzheimer's deaths will increase by 39.7%, from 5220 deaths in the year 2010 to 7292 deaths in the year 2050. The alternate method of estimation, which assumes the African American Alzheimer's death rate will continue to rise, projects a 46.8% increase in AD deaths

between the years 2010 and 2050. By either method, we predict a substantial increase the number of African American AD deaths by 2050.

TOTAL COSTS OF ALZHEIMER'S AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

We estimate that the total direct and indirect costs of AD for African Americans were almost \$71.6 billion in 2012 (see table 4). About 60.9% of these costs (\$43.6 billion) are the value of caregiving hours for African Americans suffering with AD. Nursing home care is the second-highest category of costs (\$14.6 billion), followed by lost productivity for adults aged 40-64 with AD (\$6.1 billion), and the cost of medical care (\$5.5 billion).

Table 3. Projected Alzheimer's Death Rates and Deaths for African Americans (2010-2050)

Year	Total Black Population	Constant Black Alzheimer's Death Rate Projection	Projected Black Alzheimer's Deaths Assuming Constant Death Rate	Projected Black Alzheimer's Death Rate Projection	Projected Black Alzheimer's Deaths Assuming Projected Death Rate
2010	41,204,793	12.67	5220	12.67	5220
2020	44,809,572	12.67	5677	13.95	5746
2030	49,245,947	12.67	6239	15.35	6325
2040	53,411,745	12.67	6767	16.9	6962
2050	57,553,051	12.67	7292	18.6	7663

Note: All rates and numbers for 2010 are actual statistics, see source below; all rates and numbers for 2020-2050 are projections

Source: CDC/NCHS, Health, United States, 2012, Table 20; Data from the National Vital Statistics System (NVSS)

Table 4. Total Health Care, Productivity and Caregiving Costs for African Americans Over Age 40 with Alzheimer's Disease and Other Dementias in Institutional and Non-Institutional Settings (2012 US \$ Million)

Type of Costs	2012 US \$ Millions	Percent
Medical Care	5,538	7.7
Adult Day Health Care	1,300	1.8
Nursing Home Care	14,637	20.4
Hospice Care	11	0.0
Assisted Living	398	0.6
Lost Productivity	6,125	8.6
Value of Caregiving	43,567	60.9
Total Costs	71,576	100.00

Source: Authors' calculations based on the 2010 MEPS, the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

DIRECT COSTS OF ALZHEIMER'S AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

The estimated direct medical and care costs of AD for African Americans were \$21.4 billion dollars. This estimate includes \$5.5 billion in direct medical costs, \$1.3 billion in costs of adult day care services in non-institutional settings, and \$14.6 billion in nursing home costs. The direct medical care costs were the additional cost that having Alzheimer's disease or another dementia imposes on adults over the age of 40. These medical costs rise with age. We estimated that these costs were:

- \$2777 for adults aged 40 to 54,
- \$4091 for adults aged 55 to 64,
- \$5464 for adults aged 65 to 74,
- \$5405 for adults aged 75 to 84, and
- \$5005 for adults age 85 and older.

The nursing home care estimate is based on costs of \$233 per day and assumes that 40% of adults with Alzheimer's and other dementias require some nursing home care (see Table 5). These results were subsequently adjusted by the proportion of nursing home stays per individuals with AD.

Medicare is the primary payer for the medical care costs, paying 59% of the costs (\$3.3 billion). African Americans pay \$554 million out of pocket (see Table 6).

Medicaid is the primary payer for care from nursing homes, adult day care centers and assisted living facilities, paying 54% of the costs (\$8.8 billion). Medicare pays 18% of these costs, primarily nursing home care (\$2.9 billion). African American families pay 18% of these costs out-of-pocket (\$2.9 billion).

Certainly, older African Americans incur the greatest share of the health care costs of AD. Figure 2 illustrates this point by comparing the distribution of African Americans ages 55 and older to the age distribution of African Americans with Alzheimer's disease and other dementias, and the distribution of selected health care costs.

Table 5. Total Direct Medical Care Costs for African-Americans with Alzheimer's Disease and Other Dementias in Institutional and Non-Institutional Settings, by Age Group (2012 US \$ Million)

Age Groups (Years)	Medical Care Cost	Adult Day Care	Nursing Homes	Total Cost
40-54	47	20	224	291
55-64	857	248	2,793	3,898
65-74	1,521	330	3,713	5,564
75-84	1,955	428	4,823	7,206
85+	1,158	274	3,084	4,516
Total	5,538	1,300	14,637	21,475

Source: Authors' calculations based on the 2010 MEPS, the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

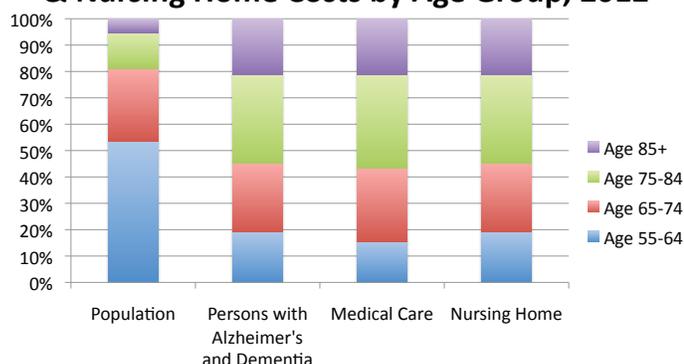
Table 6. Distribution of Medical Care Costs for African Americans with Alzheimer's Disease and Other Dementias in Non-Institutional Settings, by Payer (2012 US \$ Million)

Source of Payment	Medical Care		Adult Day Care, Hospice, Assisted Living, Nursing Homes	
	\$ Million	Percent	\$ Millions	Percent
Out-of-Pocket	554	10	2,942	18
Medicaid	554	10	8,827	54
Medicare	3,267	59	2,942	18
Private Insurance	332	6		
Other	831	15	1,635*	10*
Total	5,538	100	16,346	100

Source: Authors' calculations based on the 2010 MEPS, the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

*We were unable to separate private insurance and other sources of payment for adult day care, hospice, assisted living and nursing home care; the figures reported combine private insurance and other

Figure 2. Distributions of African American Older Adults Population, Those with Alzheimer's or Another Dementia, Medical Care & Nursing Home Costs by Age Group, 2012



Source: Authors' calculations based on the 2010 MEPS, the 2010 & 2012 Alzheimer's Disease Facts & Figures and the Census Bureau Data.

More than 80% of the costs were for African Americans aged 65 or older. African Americans over age 75 contributed to more than 50% of the costs. We did not include African Americans aged 40 to 54, because while they are 50% of the population, they account for less than 2% of the health care costs. Based on the relationship between the age distribution of the population, the disease prevalence rate and the distribution of health care costs, we expect that the costs of health care for Alzheimer's disease and other dementias for African Americans will rise substantially in the future as the African American population ages.

INDIRECT COSTS OF ALZHEIMER'S AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

We estimate lost productivity to be 8.6% of the total costs of Alzheimer's and dementia for African Americans (see Table 7). Adults aged 40 to 64 with Alzheimer's or dementia lost \$6.1 billion in labor market

productivity. Most these costs were due to lost wages as persons with AD become unable to work and can no longer earn the same salary or wages. Those who were able to continue working lost almost \$1.9 billion from dramatically reduced hours.

COSTS OF CAREGIVING TO AFRICAN AMERICANS

The most expensive indirect cost of AD to African American families is caregiving (see Table 8). Persons suffering with AD required more than 17.4 billion hours of unpaid caregiving in 2011 (AA 2012). We assumed African Americans received 20.2% of these caregiving hours, an amount in proportion to the share of African American AD patients. We valued these hours at \$12.12, the average hourly earning of a home health care services aide (AA 2012), to calculate the total costs of caregiving to African American families as \$43.6 billion.

Table 7. Productivity Loss for African Americans Aged 40-64 with Alzheimer's Disease and Other Dementias by Age Group (2012 US \$ Millions)

Age Group (Years)	Days	Hours	Wages	Total
40-54	0.2	151	319	470
55-64	2	1,708	3,945	5,655
Total	2.2	1,859	4,264	6,125

Source: Authors' calculations based on the 2010 MEPS, the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

Table 8. Value of Caregiving for African Americans with Alzheimer's Disease and Other Dementias, 2012

Caregiving Hours	17,365,265,478
Percent of African Americans with Alzheimer's and Dementia	20.7%
Hourly Value of Caregiving	\$12.12
Total Cost (2012 US \$ Millions)	\$43,567

Source: Authors' calculations based on the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

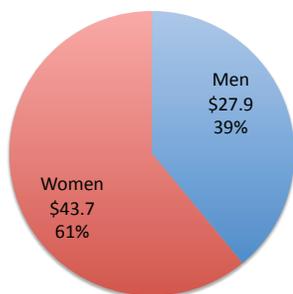
DISTRIBUTION OF COSTS OF ALZHEIMER'S AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

Figures 3 and 4 show the distribution of the costs of AD for African Americans by gender and census region. More than 60% of the costs (\$43.7 billion) are borne by the families of women with AD. Almost half of the costs (\$35.1 billion) are concentrated in the South. The next highest region is the East with \$14.3 billion.

FORECAST OF FUTURE COSTS OF ALZHEIMER'S AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

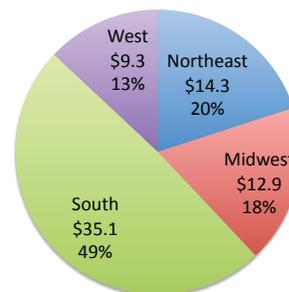
As stated earlier, the African American population will age significantly by 2050. From 2012 to 2050, the population of African Americans age 40 and older will grow by 68%. However, the population of African Americans with AD will grow by 186%, based on our estimate that 2.16 million African Americans age 75 and older will have AD in 2050 (see Table 9). Because of the growth in AD patients in the African American community, the costs will more than double by 2050, from \$71.5 billion to \$146.0 billion, measured in constant 2012 U.S. dollars (see Figure 5).

Figure 3. Distribution of Economic Burden for African Americans with Alzheimer's and Other Dementias by Region, 2012



Source: Authors' calculations based on the 2010 MEPS, the 2010 & 2012 Alzheimer's Disease Facts & Figures and the Census Bureau Data.

Figure 4. Distribution of Economic Burden for African Americans with Alzheimer's and Other Dementias by Region, 2012



Source: Authors' calculations based on the 2010 MEPS, the 2010 & 2012 Alzheimer's Disease Facts & Figures and the Census Bureau Data.

THE IMPLICATIONS OF COSTS OF ALZHEIMER'S ON AFRICAN AMERICAN FAMILIES

The estimated economic burden of Alzheimer's disease and other dementias to African Americans was \$71.6 billion in 2012. We expect this cost will more than double by 2050. While African Americans make up only 13.6% of the U.S. population, they bear almost 33% of the total national costs of AD (Hurd 2013). More than 5.2 million Americans have AD; 1.1 million are African American. As noted above, families of African American women with AD and those who live in the South bear most of these costs. The value of informal care for African Americans with AD is a substantial portion of the cost.

The full burden of Alzheimer's disease cannot be expressed in dollars. The toll of the disease on its patients and their loved ones cannot be easily quantified. Alzheimer's disease exacts an emotional burden on families and a physical and psychological burden on caregivers and removes from society the memories, experiences and wisdom that its victims can no longer share. We have not attempted to quantify the loss of quality

Table 9. Total Population of African Americans and Those with Alzheimer's and Other Dementias (in Thousands), by Age Group

Age Group (Years)	Prevalence Rate - Alzheimer's and Other Dementias	2012		2030		2050	
		Population	Persons with Alzheimer's and Other Dementias	Population	Persons with Alzheimer's and Other Dementias	Population	Persons with Alzheimer's and Other Dementias
40-54	0.002	8,416.5	16.8	9,148.8	18.3	10,646.1	21.3
55-64	0.048	4,362.4	209.4	5,013.1	240.6	6,957.4	334.0
65-74	0.124	2,244.9	278.4	4,546.9	563.8	4,934.6	611.9
75-84	0.325	1,112.6	361.6	2,488.2	808.7	3,399.2	1,104.7
85+	0.546	423.5	231.2	774.4	422.8	1,949.7	1,064.5
Total		16,560.0	1,097.4	21,971.4	2,054.2	27,887.1	3,136.4

Source: Authors' calculations based on the 2010 MEPS, the 2010 and 2012 Alzheimer's Disease Facts & Figures and Census Bureau Data

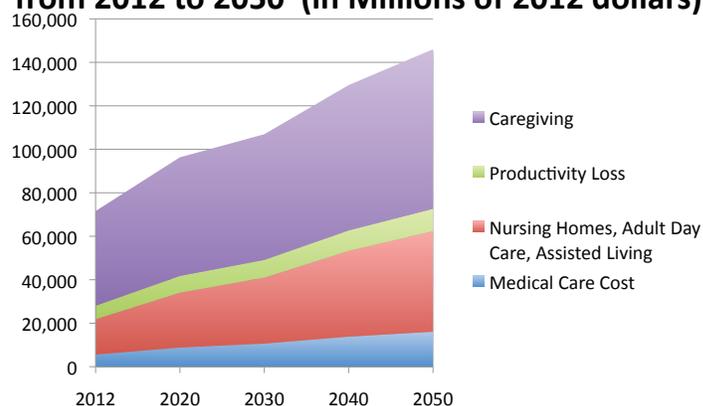
loved ones with AD. Hence for caregivers who earn high wages or salaries, their caregiving hours are valued at a higher price. Conversely, for persons who make lower wages, their caregiving hours are valued at a lower price. This method would tend to lower the value of the caregiving by African Americans and women compared to whites and men, even for the same assistance.

of life of patients and their families. How do you value lost memories or experiences never shared? How do you value broken relationships? We also have not attempted to quantify long-term effects of AD, especially on caregivers. Caregivers, who are predominately women, give up not only unpaid time, but they also sacrifice their own health and hopes, dreams and aspirations that could have resulted in a higher-paying job, more satisfying career, greater community service or a more enjoyable family life. If we were able to compute these costs of AD, our estimates would be exceedingly higher.

Caregiving and lost productivity associated with AD have a significant inter-generational impact on African Americans, creating a substantial shift of resources from working-age adults and their children to retirees. AARP estimates that caregiving costs the nation \$450 billion annually (Feinberg et al 2011). Caregivers sacrifice time, money and opportunities, which results in lower earnings and retirement investment. Thus, fewer resources remain for adult caregivers to invest in their children, depressing family wealth creation.

Our estimates of the costs of AD are relatively conservative. We used an incremental costs methodology to estimate the costs of formal care. This method adjusts for other chronic conditions that patients with AD may have. Our estimate of costs of informal care is also conservative. We used methodology developed by Arno and colleagues (1999). It values unpaid caregiving hours provided to AD patients at \$12.12, which is the average of the federal minimum wage and mean hourly wage for home health aides. Hurd and colleagues (2013) used an alternate method, an estimate of the wage of the caregiver, to value hours of unpaid caregiving. This results in a higher per-hour wage because it assumes that caregivers sacrifice hours of work to provide services to their

Figure 5. Projected Costs of Alzheimer's Disease and Other Dementias for African Americans from 2012 to 2050 (in Millions of 2012 dollars)



Source: Authors' calculations based on the 2010 MEPS, the 2010 & 2012 Alzheimer's Disease Facts & Figures and the Census Bureau Data.

The prevention and treatment of AD is as important to African Americans as that for heart disease, hypertension, diabetes, cancer and stroke. Because older African Americans are at greater risk of AD and the African American population is aging, the magnitude of this problem will only increase. Policymakers and community leaders must address this challenge through research, education, prevention, treatment and policy. We need to support research to help us better understand AD and to identify prevention strategies, treatments and ultimately cures. We also need more research on differential ways that this devastating disease distinctly impacts African Americans. In addition, we need policies, programs and practices that support caregivers of persons with AD. Caregivers need help that allows them to continue in their careers. Society needs to develop tools and other resources to help them cope with the economic, emotional and physical challenges associated with caring for a person with AD.

CONCLUSION: PUBLIC POLICY RECOMMENDATIONS

Despite the challenges reflected in this report, there are reasons for optimism about achieving the national goal of preventing and effectively treating Alzheimer's disease by 2025, if not sooner. In setting a bold and time-based goal for this pursuit, our nation has elevated Alzheimer's disease to a level of prioritization not previously seen. Now, the task before the entire nation—including both the public and private sectors—is to deliver meaningful actions and commit the resources necessary to achieve this and other goals of the plan. Just as the national plan focuses on research, patient care and

caregiver supports, so, too, do the following policy recommendations put forward by the AfricanAmericanNetworkAgainstAlzheimer's.

RESEARCH

The costs of Alzheimer's to the African American community are substantial and disparate, making the imperative for a means of prevention and treatment even more crucial to this community. Stopping Alzheimer's by 2020, 2025—or any other point in time—requires scientific and medical breakthroughs and discoveries that can be developed into safe and effective therapies, treatments and means of prevention. Such goals are impossible absent appropriate resources.

The AfricanAmericanNetworkAgainstAlzheimer's recognizes the challenging fiscal pressures the Administration and Congress are facing and applauds the Administration in particular for reallocating funding in recent fiscal years to further support research into Alzheimer's disease and dementia by the National Institutes of Health (NIH). While helpful, even these additional allocations are but a drop in the bucket of the \$2 billion of annual NIH funding for Alzheimer's research that leading researchers think is necessary to achieve the 2025 goal. As such, the Network strongly supports efforts to ramp up NIH funding for Alzheimer's research, to meet or exceed \$2 billion annually within five years. In addition, the Network supports investment in AD prevention research, such as examining the role of environmental and lifestyle risk factors.

CLINICAL TRIALS: MINORITY PARTICIPATION

In addition to funding, the Network is encouraged to see our national plan recognize the underrepresentation of minority populations in

Alzheimer's disease research trials and to set an objective of increased participation by these populations in research. Lives are saved every day due to discoveries made in clinical trials. Yet African Americans, who stand to benefit significantly from medical research, are often reluctant to participate and often underrepresented in important medical research to find treatments for the very diseases that most impact them. This low participation makes it difficult to assess how new drugs will affect African American patients, which in turn makes it harder to resolve disparities in health.

The Network recognizes that achieving the goal of increased minority participation in research will require the engagement of government, industry, patients, physicians, community and faith-based organizations, and other stakeholders. This is a major priority for the Network, which urges all parties to come together to develop clear, coordinated, community-based strategies to ensure robust minority population participation in forthcoming clinical trials.

PATIENT CARE

The lack of a timely and accurate Alzheimer's diagnosis is a major impediment to patients today. Current estimates indicate that only about half of all patients with Alzheimer's ever receive such a diagnosis, and the picture is even worse for African Americans, who tend to be diagnosed later if at all. The absence or significant delay of a diagnosis forces patients to travel a tortuous, expensive and emotionally draining journey as they seek to understand their condition and treatment options.

To rectify this situation, the Network strongly

supports and urges Congress to enact the Health Outcomes Planning and Education (HOPE) for Alzheimer's Act. This bipartisan and bicameral legislation will amend Medicare to establish a comprehensive Alzheimer's diagnosis and services benefit for Medicare beneficiaries whose physicians think an evaluation of Alzheimer's is warranted. If such a diagnosis is made, the beneficiary along with his/her personal representative or family caregivers would be eligible to receive valuable care planning and related guidance. This will help give the beneficiary access to the full array of appropriate medical and non-medical treatment options and will support families in caring for such patients.

CAREGIVER SUPPORTS

As noted above, the HOPE Act will benefit both patients and caregivers. While the patient would receive an accurate diagnosis and access to all necessary care and services, the caregiver would benefit from the enhanced care planning, which would include information on access to caregiver supports. Such planning and supports have been shown to help alleviate the immense stress that Alzheimer's places on family caregivers and to help caregivers to care for their loved ones in the home for a longer period of time.

In addition to governmental efforts to support family caregivers in navigating a diagnosis of Alzheimer's disease, the AfricanAmericanNetworkAgainstAlzheimer's calls upon employers, particularly those in the private sector, to recognize the enormous impact such a diagnosis has on caregivers and to enact family-friendly workplace policies that can provide a high degree of support. Such policies will allow employees serving as Alzheimer's family caregivers

to take care of their loved one without fearing loss of a job, reduced hours or other harmful economic ramifications that such changes often bring.

APPENDIX

ESTIMATING ALZHEIMER'S DEATHS

To estimate the number of Alzheimer's deaths among African Americans for 2050, we first computed the "crude" (non-age-adjusted) death rate. The crude Alzheimer's death rate for 2010 is computed by taking the total number of African American Alzheimer's deaths (5220), dividing that by the total population of African Americans (41,204,793) and multiplying the result by 100,000. This computation results in an African American non-age-adjusted Alzheimer's death rate of 12.67 deaths per 100,000 African Americans for the year 2010. Between the years 2008 and 2010, the Alzheimer's crude death rate increased by 1.94%.

We used data from the 2010 Medical Expenditure Panel Survey (MEPS) to estimate health care costs and lost labor-market productivity associated with Alzheimer's disease and other dementias for African Americans aged 40 years or older. We identified adults in the MEPS with cognitive disorders (i.e., dementia, delirium, amnesic and other cognitive disorders) using the Clinical Classification System (CCS) code 653 (Stagnitti 2011). Using a cost of illness (COI) approach, we estimated the impact of Alzheimer's disease and other dementias on annual health care expenditures, days and hours off work, and reduced hourly wages because of Alzheimer's disease and dementias. Specifically, we estimated a per-person incremental cost of Alzheimer's

disease and dementias for each category. We then multiplied the incremental costs by the estimated population of African Americans with Alzheimer's and dementia. To compute the population of African Americans with Alzheimer's and dementia, we used the age-specific prevalence rates for cognitive impairment published in the *2010 Alzheimer's Disease Facts and Figures* and multiplied them by the population estimates of African Americans reported by the U.S. Census.

DIRECT HEALTH CARE COSTS

Using the 2010 data from the MEPS, we developed a model to estimate total health care expenditures associated with Alzheimer's disease and other dementias. Total expenditures include inpatient, emergency room, outpatient (hospital, clinic and office-based visits), prescription drugs and other costs (e.g., home health services, vision care services, dental care, ambulance services and medical equipment). These expenditures include out-of-pocket and third-party payments to health care providers but do not include health insurance premiums. Expenditures for hospital-based services include those for facility and separately billed physician services. Prescription drug expenditures do not include over-the-counter purchases. We controlled for demographic, socioeconomic, location and health status measures. The demographic factors were age, race/ethnicity, gender and marital status. The socioeconomic factors were education, income and health insurance status. The location factors were census region and urban-rural residence.

Typically, we would estimate a two-part health care expenditure model (Manning et al, 1998; Mullahy 1998; Manning and Mullahy, 2001; Buntin and Zaslavsky 2004) to address issues of zero

expenditures for certain patients. However, this was not required as more than 97% of individuals in the subsample had positive expenditures. Hence, we only estimated generalized linear models to predict levels of expenditures for individuals with positive expenditures. We used a log link and gamma distribution to address the skewness in the expenditure data. We conducted the different diagnostic and specification tests recommended by Manning and Mullahy. We estimated the models using the survey regression procedures in STATA 12, which appropriately incorporate the design factors and sample weights. Finally, we computed the incremental costs associated with Alzheimer's disease and dementias for African Americans aged 40-54, 55-64, 65-74, 75-84 and 85 and older, compared to those without Alzheimer's disease and dementia. We also apportioned health care costs by source of payment (i.e., out-of-pocket, Medicare, Medicaid, private insurance and other third-party payers), by gender and different regions of the country.

VALUE OF LOSS PRODUCTIVITY

Similar to estimating direct medical expenditures, we used data from the 2010 MEPS to estimate two-part models of days and hours of work lost and reduced wages associated with Alzheimer's disease and other dementias for African Americans aged 40-54 and 55-64. The functional form of the models depended upon the dependent variables. For missed days or hours of work, we estimated the impact of Alzheimer's disease and other dementias on the probability of missing a work-day during the year. Second, we estimated generalized linear models to predict levels of days or hours of work missed for individuals with positive days or hours of work missed. We used a log link and gamma distribution to address the skewness in the data for missed days and an inverse Gaussian distribution for missed

hours of work. For reduced wages, the first part of the model consisted of a probit regression. The second equation estimated the impact of Alzheimer's disease and other dementias on hourly wages. Using a two-step estimator for labor supply to predict reduced wages due to Alzheimer's disease and other dementias, we adjusted the models by using an inverse Mills ratio to account potential selection bias (Greene 2005; Cameron and Trivedi 2008). Combining the results from these different parts of the models, we computed the productivity costs associated with Alzheimer's disease and other dementias for African Americans aged 40-54 and 55-64, compared to those without Alzheimer's disease and other dementias.

PROJECTING FUTURE COSTS OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS FOR AFRICAN AMERICANS

To compute projected costs of Alzheimer's disease and other dementias for African Americans for years 2020, 2030, 2040 and 2050, we used projected population data from the Census Bureau by single year of age, sex, race and Hispanic origin for African American populations aged 40 years or older. Using these data, we generated the projected number of African Americans in the United States by different age groups for 2020, 2030, 2040 and 2050. We computed both direct and indirect costs of Alzheimer's disease and other dementias for African Americans by multiplying the population for African Americans in each of the age categories mentioned above by the respective prevalence rates for African Americans with Alzheimer's disease and other dementias. Subsequently, we multiplied the results by the incremental costs of Alzheimer's disease and other dementias for African Americans for each of the age categories previously mentioned.

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African Americans are at least twice as likely to develop Alzheimer's as non-Hispanic White Americans. While Alzheimer's is the 6th leading cause of death for all Americans, it is the 4th leading cause of death for older African Americans. The AfricanAmericanNetworkAgainstAlzheimer's unites and mobilizes the powerful voice of the African American community to speed the pace of research and build real momentum to end Alzheimer's disease. The AfricanAmericanNetworkAgainstAlzheimer's is an initiative of USAgainstAlzheimer's.

To join or learn more, please visit: www.AfricanAmericansAgainstAlzheimers.org
