# District of Columbia: 2020 Brain Health Needs Assessment

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# Executive Summary

In April 2020, DC Health partnered with the GW Institute for Brain Health and Dementia to conduct a Brain Health Needs Assessment for the District of Columbia (DC). The specific objectives of this work were to:

1. Estimate the prevalence of dementia in DC
2. Estimate the prevalence of modifiable risk factors for cognitive decline and dementia in DC
3. Identify challenges and unmet needs of caregivers for persons living with dementia in DC
4. Develop a guide identifying services and resources available to DC residents related to the needs of persons living with dementia and their caregivers

## *Objective #1: Estimate the prevalence of dementia in DC.*

We estimate the overall prevalence of dementia among adults 65 and older in Washington, DC to be 13%. In absolute numbers, this translates to over 10,000 DC residents with dementia. The prevalence of dementia is higher for older age groups, women, and minority racial/ethnic groups. The estimated prevalence of dementia among those over age 65 varies by DC ward. Generally, DC wards with higher estimated dementia prevalence also have higher estimated numbers of persons living with dementia.

Estimated number of persons with dementia and dementia prevalence among those age 65 and older in Washington, DC, based on ACS 2018, 5-year demographic data for DC

| | DC | Ward 1 | Ward 2 | Ward 3 | Ward 4 | Ward 5 | Ward 6 | Ward 7 | Ward 8 |
|---|---|---|---|---|---|---|---|---|---|
| Estimated Dementia Prevalence | 13.0% | 12.1% | 8.8% | 9.1% | 16.0% | 16.8% | 12.1% | 15.0% | 12.3% |
| Estimated Number of Persons with Dementia | 10,603 | 753 | 687 | 1,301 | 2,124 | 2,061 | 1,188 | 1,547 | 971 |

As there have been no substantial advances in treatment or prevention of dementia, it is reasonable to assume the prevalence of dementia in DC was similar in 2019. However, it is unclear whether these estimates will be a reasonable estimate of dementia prevalence in DC during or after the COVID-19 pandemic.

## *Objective #2: Estimate the prevalence of modifiable risk factors for cognitive decline and dementia in DC*

Scientists have identified numerous potential risk factors for cognitive decline and dementia, many of which are modifiable. However, the strength of evidence supporting the claim that a certain factor influences risk of cognitive decline and dementia varies across factors. Whether efforts to improve brain health through risk factor reduction will be effective depends on how common these risk factors are, in addition to the extent to which they increase or decrease risk.

Overall, there is moderate to strong evidence to suggest vascular risk factors and related lifestyle factors contribute to increased risk of cognitive decline and dementia. Diabetes, midlife hypertension, high cholesterol in midlife, midlife obesity, smoking, and lack of physical activity may increase risk of cognitive decline and dementia in later life. Each of these risk factors are also established risk factors for stroke, which can lead to vascular cognitive impairment and dementia. Many vascular risk factors are common in the adult DC population. In 2017, 7% of adult DC residents had diabetes. Among DC residents in midlife (ages 45-65), 39% had a diagnosis of hypertension and 32% had a diagnosis of high cholesterol. Over 50% of the adult DC population, and over 60% of DC residents in midlife (ages 45-65) were overweight or obese. Only 14% of adult DC residents were smokers, and 23% had no leisure time physical activity or exercise in the last month. Generally, non-Hispanic Black residents were more likely to have vascular risk factors than those of other racial/ethnic groups.

| Modifiable risk and protective factors for cognitive decline and dementia by strength of evidence | |
|---|---|
| Moderate to Strong Evidence | |
| Alcohol Intake | Midlife High Cholesterol |
| Diabetes | Midlife Hypertension |
| Depression | Midlife Obesity |
| Education | Physical Activity |
| Healthy diet | Severe head injury |
| | Smoking |
| Weak or Emerging Evidence | |
| Air pollution | Sleep |
| Cognitive activities | Social engagement |
| Cognitive training | Mild head injury |

Other modifiable risk and protective factors for cognitive decline and dementia supported by moderate evidence include healthy diet, alcohol intake, education, and depression. Healthy diet and higher education are associated with reduced risk of cognitive decline and dementia, while heavy alcohol intake and depression are associated with increased risk. In 2017, 62% of adult DC residents consumed fruit at least once per day, while 77% consumed vegetables at least once per day. 30% of adult DC residents did not drink alcohol, while 9% reported heavy alcohol consumption. Non-Hispanic White residents were more likely to be heavy drinkers than those of other racial/ethnic group, and non-Hispanic Black residents were most likely to abstain from alcohol use. In 2017, over 50% adult residents were graduates of a college or technical college. However, there were significant racial/ethnic and geographic disparities in educational attainment. Educational attainment was lowest in non-Hispanic Black residents and residents of Wards 7 and 8.

Emerging evidence suggests poor sleep and greater exposure to air pollution may also increase risk of cognitive decline and dementia, while the evidence linking social engagement, cognitive activities, cognitive training, and hearing loss to dementia risk is currently weak. Finally, while there is strong evidence linking severe head injury (e.g., requiring hospitalization) to increased risk of cognitive decline and dementia, there is limited evidence to suggest less severe head injury promotes later development of cognitive decline and dementia.

Many identified risk factors for cognitive decline and dementia are common in the DC population, providing an opportunity to improve brain health on a wide scale. Moreover, while the COVID-19 pandemic has disrupted many aspects of our lives, we expect many identified risk factors to remain highly prevalent in the DC community.

Establishing causal relationships between risk factors and risk of cognitive decline and dementia is difficult. However, even if the relationships between these risk factors and dementia are not causal, there are other benefits to public health or medical interventions to reduce risk factor burden. Many risk factors that have been linked to cognitive decline and dementia are also established risk factors for other diseases (e.g., cardiovascular disease) and interventions on these risk factors would be expected to improve overall health.

## *Objective #3: Identify challenges and unmet needs of caregivers for persons living with dementia in DC*

We identified challenges and unmet needs related to resource and service use for caregivers for persons living with dementia in two ways: (i) through focus groups with primary, unpaid caregivers of persons living with dementia and (ii) through discussions with representatives of organizations that serve caregivers and persons living with dementia.

### *Primary Caregivers*

Several key themes emerged in our focus groups with primary caregivers:

1. Need for help in navigating, identifying, and applying for resources and services.
2. Need for reconsideration of service eligibility criteria, including lowering of income thresholds, and exclusion of caregiver income from consideration.
3. Need for increased recognition of unique resource and service needs of persons with cognitive impairment across all stages of the disease.
4. Need for increased access to qualified home health aides to provide regular caregiving support and caregiver relief.
5. Need to address resource-specific challenges and unmet needs, especially around education of the community and home health aides about dementia, transportation, meal services, specific legal services, and the availability/quality of nursing homes.
6. Need to address disruption of centrally-provided services due to the COVID-19 pandemic.

### *Organizational Stakeholders*

Through our discussions with representatives of organizations that serve caregivers and persons living with dementia, we identified the following areas of unmet need related to resource and service use:

1. Need for increased messaging and awareness of available services.
2. Need for greater service availability and greater consistency of services across DC.
3. Need for increased training for those who interact with persons who have dementia, including law enforcement, emergency personnel, and home health aides.
4. Need for community messaging and caregiver education about dementia.
5. Need for dedicated services to protect the safety and autonomy of persons living with dementia.

*Common themes*

There was substantial overlap in the challenges and unmet needs identified by caregivers and organizational stakeholders. Both primary caregivers and organizational stakeholders recognized that caregivers of persons living with dementia need help in identifying and accessing resources and services. Primary caregivers expressed a preference for help from a care navigator (e.g. a case manager, social worker, or case worker) who can understand the circumstances and values of the caregiver and care recipient, and act as a guide throughout their time as a caregiver. Concerns about eligibility requirements were highlighted by both groups, although primary caregivers were concerned about financial eligibility requirements, while organizational stakeholders were concerned that the actions of first responders can impact future eligibility for benefits. Both groups highlighted a clear need for additional training of home health aides around dementia and how to best interact with and care for a person living with dementia. Similarly, both groups also suggested a need for increased education about dementia in the community. Finally, both groups highlighted a need for legal assistance to help to ensure their care, safety, and finances are managed according to the wishes of the person living with dementia.

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## *Objective #4: Develop a guide identifying services and resources available to DC residents related to the needs of persons living with dementia and their caregivers*

To fulfill Objective #4, we created a stand-alone guide, titled *Services and Resources for Memory Loss and Dementia Care: A Guide for the District of Columbia*. The guide identifies services and resources in DC that are available to persons living with dementia and their caregivers. This guide focuses exclusively on services and resources that are designed for individuals with dementia, or are dementia inclusive.

This information was gathered from online searches and phone calls to service providers, existing handbooks and guides, and interviews with community partners. It is important to note that this guide was prepared during the initial wave of the COVID-19 pandemic, during which service availability was fluid and evolving. Whenever possible, we confirmed accuracy of provided information directly with each resource or service provider. In situations where it was known that these services were operating prior to the onset of the pandemic in early 2020, these services were included in the guide for completeness. However, ongoing service may not have been confirmed in all cases.

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## *Recommendations*

Within this larger context, we make the following recommendations:

1. Efforts to promote brain health should focus on vascular risk factors and associated lifestyle factors (physical activity, smoking).
2. The District should engage in public health messaging in the community to increase dementia literacy.
3. Caregivers for persons living with dementia should have equal ability to access a care navigator through the District who can assist with identifying, navigating, and applying for resources and services that are appropriate to the circumstances of a caregiver or care recipient, independent of income.
4. Access to qualified home health aides or other services that allow caregiver relief and increased social and physical activity for care recipients should be prioritized when considering resources and services to provide to caregivers of persons living with dementia.
5. Un-befriended and isolated older adults living with dementia should be supported by an independent agency that will advocate for their needs, ensure and facilitate guardianship, protect property, prioritize autonomy, and enable trusts to allow for asset protection.
6. The District should develop a certificate or training program for home health aides around caring for a person living with dementia and recognize individuals or organizations who have undergone this training.
7. The District should develop a certificate or training program with dementia-specific education for first responders.
8. Persons living with dementia and their caregivers should have greater awareness of and access to legal services around establishing wills, living trusts and advance directives, and powers of attorney for health and financial matters.
9. If the COVID-19 pandemic continues to disrupt routines and access to resources and services, efforts to help caregivers compensate for lost support, particularly loss of access to adult day care programs, should be prioritized.

# Objectives

In April 2020, DC Health partnered with the GW Institute for Brain Health and Dementia to conduct a Brain Health Needs Assessment for the District of Columbia (DC). The specific objectives of this work were to:

1. Estimate the prevalence of dementia in DC
2. Estimate the prevalence of modifiable risk factors for cognitive decline and dementia in DC
3. Identify challenges and unmet needs of caregivers for persons living with dementia in DC
4. Develop a guide identifying assets and resources available to DC residents related to the needs of persons living with dementia and their caregivers

We begin this report with an introduction, providing background information on dementia and highlighting the motivation behind each objective. Next, we present the findings for Objectives #1 to #3 along with brief descriptions of the methodology, and strengths and limitations of our approach. To fulfill Objective #4, we created a stand-alone guide, titled *Services and Resources for Memory Loss and Dementia Care: A Guide for the District of Columbia* and submitted to DC Health along with this report. While we provide a brief description of the guide here, we refer the reader to that document. We close with recommendations and suggestions for future research.

Please note that this work was conducted from April 2020 through September 2020, during the initial wave of the COVID-19 pandemic. Dementia statistics and risk factor burden reflect status prior to the onset of the pandemic. Whether prevalence of dementia or associated risk factors in DC will remain similar after the pandemic is unknown. Similarly, caregiver needs changed in the face of the pandemic, and many resources and services were unavailable or available only in alternate forms. How the pandemic influences caregiver needs and the needs of persons living with dementia, as well as the availability of resources, continues to evolve.

# What Is Dementia?

Dementia is not a normal part of aging - it is caused by changes to the brain. Scientists have identified many different types of brain changes that lead to cognitive impairment.[1-3] As such, dementia is a term that encompasses many different types of cognitive impairment. The most common form of dementia is Alzheimer's disease dementia. However, there are many other types of dementia, including vascular dementia, Lewy body dementia, frontotemporal dementia (FTD), alcohol-related dementia, and dementia that results from a traumatic brain injury. There are even some rare, reversible forms of dementia (e.g. due to vitamin deficiency). However, most dementia in older adults is Alzheimer's disease dementia, vascular dementia, or a combination of the two.[4] Dementia is typically diagnosed based on clinical symptoms. Persons with dementia have difficulties with memory, attention, language, planning, or execution of complex tasks. To be diagnosed with dementia, these difficulties must be severe enough to interfere with activities of daily life.[5]

# Motivation for the Objectives of this Report

Dementia is common in older adults. Information on the prevalence of dementia is crucial to public health planning and resource allocation. In **Objective #1** we estimate the prevalence of dementia in DC, with the goal of providing information on how many DC residents have dementia, as well as groups and areas of DC with the greatest burden of dementia.

Unfortunately, there is no cure for the most common forms of dementia. However, scientists have identified many potential, modifiable risk factors for cognitive decline and dementia. Therefore, it may be possible to slow cognitive decline and to prevent or delay dementia through risk factor reduction. In **Objective #2**, we reviewed scientific evidence to identify potential, modifiable risk factors for dementia. The population-level benefits of risk factor modification rely on the prevalence of the risk factor and the extent to which it impacts dementia risk. Therefore, we also provide an assessment of risk factor prevalence in DC.

While efforts to promote brain health are clearly needed, changes to the brain that lead to dementia often begin years before the onset of symptoms.[6] Therefore, they are unlikely to substantially reduce the number of people living with dementia in DC in the near term. Most people living with dementia are supported by family caregivers. Although there are many services and resources to support caregivers and care recipients, caregiving for a person living with dementia can be challenging. In **Objective #3**, we provide information on challenges and unmet needs of DC caregivers for persons living with dementia around resource and service use. This information was obtained through discussions with primary caregivers and representatives of organizations providing services to persons living with dementia. Finally, in **Objective #4**, we developed a stand-alone resource guide that can be used to connect caregivers and persons living with dementia to the District's many available services and resources.

# Objective #1: Estimate the prevalence of dementia in DC

*Background and approach*

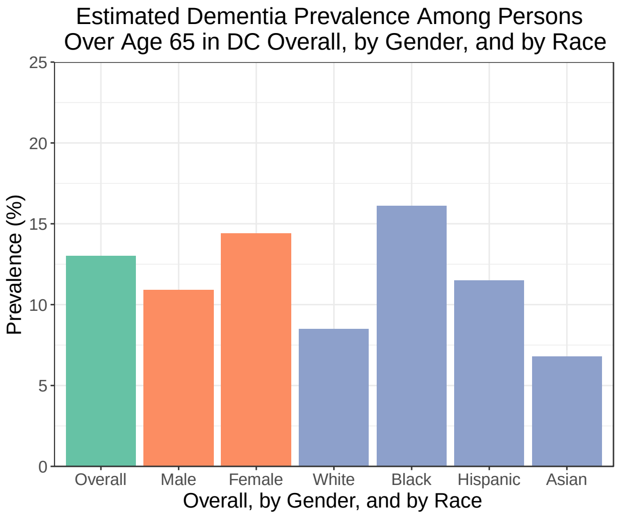
Estimating the prevalence of dementia in DC is challenging. We currently lack a national or local surveillance system for dementia, and there are no representative studies in DC with research-based dementia ascertainment. While it is possible to obtain estimates of dementia based on Medicare claims data, such statistics are not an accurate reflection of the prevalence of dementia in the community.[7,8] Most importantly, late or missed dementia diagnosis is common,[9] and claims data are often unavailable for persons who are enrolled in Medicare Advantage plans. Moreover, how well the presence or absence of a Medicare claim reflects the presence or absence of dementia varies by patient characteristics, including age and race.[10] This makes it less useful when interested in identifying geographic areas or subpopulations with a greater dementia burden. Current studies that provide estimates of the prevalence of dementia do so for the U.S. population rather than individual states or smaller geographic units.[11-13] Population demographics such as age, sex, and race vary widely by place and are themselves risk factors for dementia. Therefore, estimates for the entire country may not be applicable to smaller geographic areas and cannot provide insight into local variation in dementia prevalence.

To overcome these limitations, we used a risk-assessment approach to estimate the prevalence of dementia in Washington, DC. This approach uses a logical, scientific process to generate actionable information based on available, if imperfect, information, and is commonly used in other disciplines (e.g. risk assessment to understand potential impact of an environmental hazard).[14] Here we reviewed the published literature and cohort websites for reports of dementia prevalence, stratified by age, sex, and/or race-ethnicity. We then selected a subset of these reports, based on availability of risk estimates stratified by demographic characteristics, racial/ethnic diversity of the sample, and calendar period for the reported prevalence estimates to develop age-, sex-, and race/ethnicity specific dementia prevalence estimates. Finally, to create estimates for dementia prevalence in adults over age 65 in DC, we combined these age-, sex-, and race/ethnicity-specific dementia prevalence estimates with data from the 2018, 5-year American Communities Survey (ACS)[15] on the number of DC residents over age 65 in each age-, sex-, race/ethnicity category. This process was repeated to generate dementia prevalence estimates among persons over age 65 by demographic characteristics and by DC ward, as well as by key demographic subgroups within each ward. We validated this approach against existing estimates of dementia prevalence at the national level. Additional details of the methodology are presented in **Appendix A**.

*Findings*

We estimate the overall prevalence of dementia among adults 65 and older in Washington, DC to be 13.0% (**Table 1**). The prevalence of dementia increases with age, and women are more likely to have dementia than men. Persons who self-identify as non-Hispanic Black or Hispanic within the U.S. Census race/ethnicity categories also have higher prevalence of dementia than those who identify as non-Hispanic White or Asian.

The prevalence of dementia among those above age 65 varies by DC ward (**Table 1**). Across the eight DC wards, the prevalence of dementia among persons over age 65 is lowest for Ward 2 (8.8%) and Ward 3 (9.1%), and highest for Ward 4 (16.0%), Ward 5 (16.8 %), and Ward 7 (15.0%).



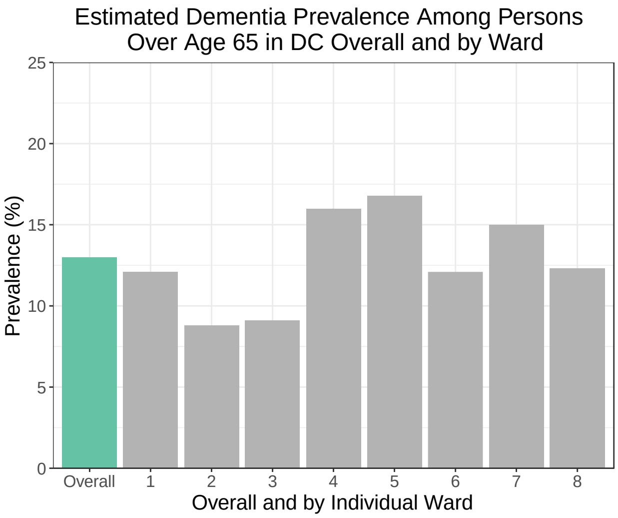


**Table 1.** Estimated dementia prevalence among persons age 65 and older in Washington, DC, based on ACS 2018, 5-year demographic data for DC

| | DC | Ward 1 | Ward 2 | Ward 3 | Ward 4 | Ward 5 | Ward 6 | Ward 7 | Ward 8 |
|---|---|---|---|---|---|---|---|---|---|
| Overall | 13.0% | 12.1% | 8.8% | 9.1% | 16.0% | 16.8% | 12.1% | 15.0% | 12.3% |
| Male | 10.9% | 9.1% | 8.2% | 8.7% | 13.0% | 14.3% | 10.1% | 12.3% | 10.7% |
| Female | 14.4% | 14.3% | 9.4% | 9.4% | 17.9% | 18.2% | 13.6% | 16.7% | 13.4% |
| Age 65-74 | 4.6% | 4.6% | 3.4% | 3.0% | 5.1% | 5.4% | 4.5% | 5.7% | 5.6% |
| Age 75-84 | 16.5% | 17.1% | 12.5% | 11.4% | 18.0% | 18.8% | 16.5% | 19.3% | 19.6% |
| Age 85+ | 41.3% | 43.3% | 33.7% | 34.3% | 42.3% | 43.4% | 42.2% | 45.1% | 44.1% |
| Non-Hispanic White | 8.5% | 6.0% | 7.9% | 8.5% | 11.1% | 11.3% | 7.2% | 11.4% | 7.7% |
| Non-Hispanic Black | 16.1% | 16.4% | 12.7% | 15.0% | 18.2% | 17.6% | 15.8% | 15.3% | 12.7% |
| Hispanic | 11.5% | 11.2% | 10.2% | 14.3% | 10.1% | 16.4% | 8.9% | 12.9% | 9.1% |
| Asian | 6.8% | 4.8% | 8.7% | 7.8% | 6.3% | 8.1% | 3.5% | 3.9% | 0.0% |

In absolute terms, we estimate over 10,000 persons living in DC had dementia in 2018. Generally, DC wards with higher estimated dementia prevalence also have higher estimated numbers of persons living with dementia.

**Table 2.** Estimated numbers of persons over age 65 with dementia in Washington, DC, based on ACS 2018, 5-year demographic data for DC

| | DC | Ward 1 | Ward 2 | Ward 3 | Ward 4 | Ward 5 | Ward 6 | Ward 7 | Ward 8 |
|---|---|---|---|---|---|---|---|---|---|
| Overall | 10,603 | 753 | 687 | 1,301 | 2,124 | 2,061 | 1,188 | 1,547 | 971 |

For context, we present demographic characteristics of persons age 65 or older in DC overall and by ward in **Table 3** to serve as a reference for interpreting fluctuations in dementia prevalence and counts across DC wards in **Table 1** and **Table 2**. DC wards with the highest dementia prevalence are also those with the greatest representation of older, black residents.

**Table 3.** Demographics of Washington, DC residents age 65 and older, based on ACS 2018, 5-year demographic data for DC

| Demographics | DC | Ward 1 | Ward 2 | Ward 3 | Ward 4 | Ward 5 | Ward 6 | Ward 7 | Ward 8 |
|---|---|---|---|---|---|---|---|---|---|
| N | 81,712 | 6,203 | 7,755 | 14,297 | 13,201 | 12,281 | 9,815 | 10,330 | 7,830 |
| Male | 40.8% | 42.3% | 49.9% | 40.9% | 39.7% | 36.8% | 42.4% | 39.1% | 39.6% |
| Female | 59.2% | 57.7% | 50.1% | 59.1% | 60.3% | 63.2% | 57.6% | 60.9% | 60.4% |
| Age 65-74 | 57.4% | 64% | 61.6% | 57.8% | 51.5% | 49.8% | 59.1% | 58.4% | 65.9% |
| Age 75-84 | 29.2% | 24.5% | 29.2% | 31.1% | 29.4% | 31.3% | 30.3% | 27.6% | 26.4% |
| Age 85+ | 13.4% | 11.5% | 9.3% | 11.2% | 19% | 18.9% | 10.6% | 14% | 7.7% |
| Non-Hispanic White | 34% | 28.2% | 72.3% | 84.7% | 20.2% | 10.8% | 37.7% | 2.8% | 4.2% |
| Non-Hispanic Black | 57.9% | 52% | 14.7% | 5.1% | 71.2% | 84.2% | 56.7% | 93.5% | 92.5% |
| Hispanic | 5.1% | 14.4% | 6.8% | 4.7% | 7.2% | 2.4% | 2.9% | 2.6% | 3.1% |
| Asian | 2.4% | 3.7% | 6.2% | 4% | 1.9% | 1.4% | 1.7% | 0.5% | 0.2% |

As there have been no substantial advances in treatment or prevention of dementia, it is reasonable to assume the prevalence of dementia in DC was similar in 2019. However, our estimates of dementia prevalence may not be a reasonable estimate of dementia prevalence in DC during or after the COVID-19 pandemic, which began in early 2020. Given COVID-19 is more likely to kill older adults, adults with chronic conditions, and adults of color,[16-20] the data upon which these estimates are based may no longer accurately represent variations in dementia prevalence by age, sex, and race/ethnicity groups or the current demographics of DC or its wards.

We used the best available data to inform our estimates, but recognize the limitations of this available data (see **Appendix A**). A large-scale surveillance study may be warranted if greater confidence in DC-specific estimates of dementia prevalence is desirable.

# Objective #2: Estimate the prevalence of modifiable risk factors for cognitive decline and dementia in DC

## *Background*

There are no disease-modifying treatments for cognitive decline and dementia. Therefore, efforts to promote brain health must rely on changing risk factor profiles. Scientists have identified numerous potential risk factors for dementia or cognitive decline, many of which are modifiable. However, the strength of evidence supporting the claim that a certain behavior, medical condition, or lifestyle factor increases or decreases risk of dementia varies. Whether efforts to improve brain health through risk factor reduction will be effective at reducing the prevalence of dementia in a community will depend on both how common these risk factors are, as well as the extent to which they increase or decrease risk of dementia. In this report, our goal was to identify risk and protective factors for cognitive decline and dementia and to quantify their prevalence in the DC population.

## *Approach*

We used data from several sources to identify modifiable risk factors for dementia and assess the strength of evidence linking them to cognitive decline and dementia. We searched for and reviewed reports obtained from PubMed, the Cochrane Library, the Agency for Healthcare Research and Quality (AHRQ) database, and the AlzRisk database (alzrisk.org). We also consulted the websites of the US Centers for Disease Control (CDC), National Institutes of Health (NIH), National Institute on Aging (NIA), and the World Health Organization (WHO) to identify evidence-based summaries and trusted public health messaging around risk factors for dementia. We also reviewed public health messaging and reports from expert panels convened by advocacy groups. We then considered the strength of the evidence, based on the availability of evidence from randomized controlled trials, systematic reviews, and original studies, as well as the consensus among scientists reflected in governmental reports or public health messaging (e.g. NIH, CDC, AHRQ, WHO). As such, this is not a comprehensive evaluation of all risk factors examined in relation to cognitive decline and dementia. Instead, we focus on risk factors with substantial evidence linking them to cognitive decline and dementia, as well as risk factors that have been previously highlighted in public health messaging.

To estimate the prevalence of modifiable risk factors for cognitive decline and dementia in Washington, DC, we used data for DC from the 2017 Behavioral Risk Factor Surveillance System (BRFSS) survey.[21] BRFSS data is collected in all 50 states through telephone surveys among individuals ages 18 and older. All estimates use the provided BRFSS weights, which allow calculation of DC-representative prevalence estimates. Additional details of our approach can be found in **Appendix B**.

## *Findings*

### *Overview of Risk Factors for Cognitive Decline and Dementia*

Both non-modifiable and modifiable risk factors contribute to dementia risk. Established non-modifiable risk factors for dementia include increased age and possession of specific genetic profiles, such as the APOE e4 allele which is associated with Alzheimer's disease dementia.[22-31] However, it should be noted that dementia is not inevitable for persons with the APOE e4 allele or with increasing age. While these risk factors are non-modifiable and are associated with greater risk of dementia, individuals with these risk factors will not necessarily develop dementia.

Sex/gender and race/ethnicity are also considered to be non-modifiable risk factors for cognitive decline and dementia. More women develop dementia than men.[32] Potential explanations for the disparity in dementia prevalence between genders include longer life expectancy of women and sex-specific hereditary factors.[32,33] Compared to whites, Blacks/African Americans are about twice as likely to develop dementia, while the relative risk of dementia across Hispanic/Latinx and non-Hispanic white populations varies by location and heritage.[34-40] However, it should be noted that an increased risk associated with minority racial/ethnic status often reflects, at least in part, a higher burden of modifiable risk factors in these groups.[41]

Most modifiable risk factors for dementia can be classified as vascular risk factors, psychosocial factors, or lifestyle factors. Overall, there is moderate to strong evidence to suggest that vascular risk factors (diabetes, midlife hypertension, midlife high cholesterol, midlife obesity) and associated lifestyle risk factors (smoking, and physical activity) contribute to increased risk of cognitive decline and dementia (**Table 4**). Other modifiable risk and protective factors supported by moderate evidence include healthy diet, alcohol intake, education, and depression. Emerging evidence suggests poor sleep and exposure to air pollution may also increase risk of cognitive decline and dementia, while the evidence linking social engagement, cognitive activities, cognitive training, and hearing loss to risk of dementia is weak. Finally, while there is strong evidence linking severe head injury to increased risk of cognitive decline and dementia, there is limited evidence to suggest less severe head injury promotes later development of cognitive decline and dementia.

**Table 4.** Modifiable risk and protective factors for cognitive decline and dementia by strength of evidence

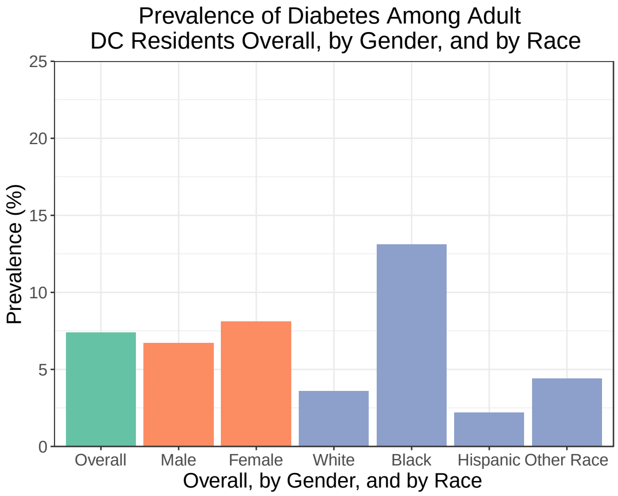
| Moderate to Strong Evidence | |
|---|---|
| Alcohol Intake | Midlife High Cholesterol |
| Diabetes | Midlife Hypertension |
| Depression | Midlife Obesity |
| Education | Physical Activity |
| Healthy diet | Severe head injury |
| | Smoking |
| Weak or Emerging Evidence | |
| Air pollution | Sleep |
| Cognitive activities | Social engagement |
| Cognitive training | Mild head injury |

Below we discuss each identified risk factor, grouped into four broad categories -- vascular, lifestyle, psychosocial, and other. Where possible, we also provide estimates of the prevalence of each risk factor in DC, overall and by sex, race/ethnicity, and DC ward. Tables summarizing the estimated prevalence of modifiable risk factors in DC residents are available in **Appendix C,** and larger versions of figures provided below are available in **Appendix D**.

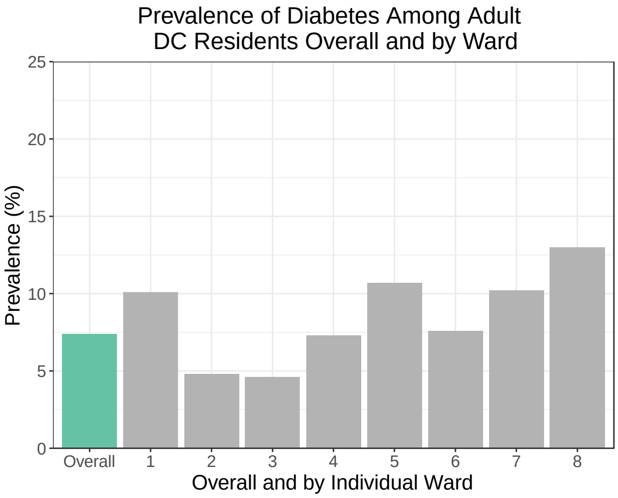
### *Vascular Risk Factors*

Diabetes. NIA recognizes Type II diabetes as a potential, modifiable risk factor for dementia.[42] Type II diabetes may lead to injury of brain vasculature and neurodegenerative changes which in turn may increase the risk of cognitive decline and dementia.[43] However, there is no strong evidence suggesting that control of Type II diabetes prevents or delays the onset of cognitive impairment.[44] This suggests that preventing the onset of diabetes may have a bigger impact on reducing dementia risk than managing the condition once it occurs. Diabetes is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia.[45-47]

The prevalence of physician-diagnosed diabetes in adult residents of DC in 2017 was 7%. The prevalence of diabetes was highest in non-Hispanic Black residents and in Wards 1, 5, 7, and 8. As people with diabetes may be unaware of their status, the prevalence of diagnosed and undiagnosed diabetes is likely higher.


Prevalence of Diabetes Among Adult DC Residents Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

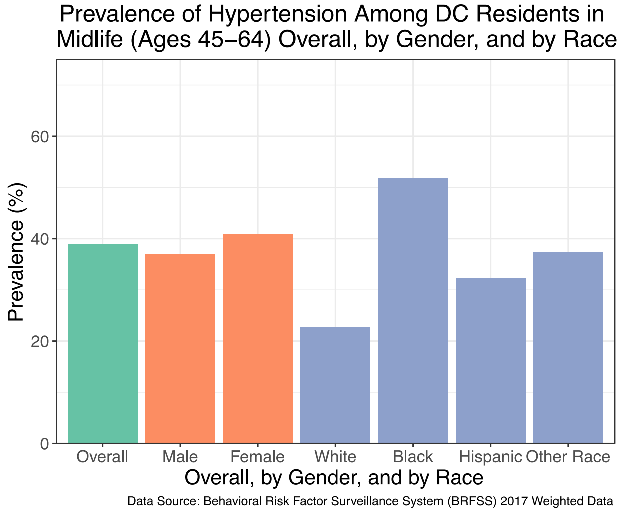

Prevalence of Diabetes Among Adult DC Residents Overall and by Ward

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

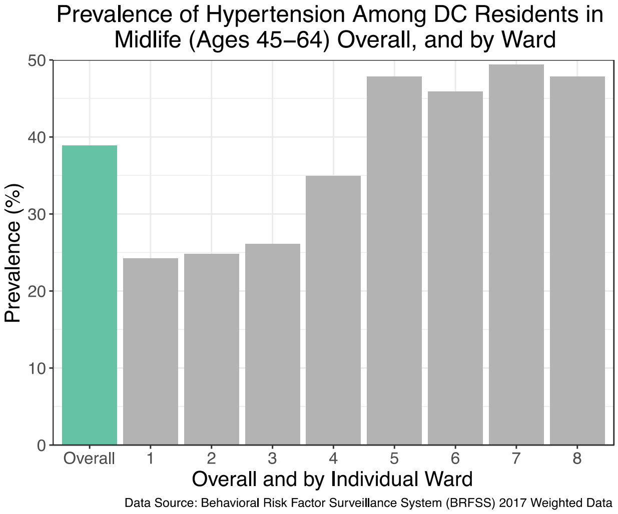
Hypertension. The CDC, NIA, WHO and a council of experts convened by the American Association of Retired Persons (AARP) recognize high blood pressure as a risk factor for cognitive impairment and dementia.[48] The association between high blood pressure and late-life cognition appears to be age-dependent.[49,50] Systematic reviews of randomized controlled trials (RCTs), observational studies, and meta-analyses suggest that mid-life hypertension (i.e. between the ages of 45 and 65) may be associated with an increased risk of developing cognitive decline and dementia.[49,51-55] To the contrary, hypertension in late life (i.e. after age 65) has been associated with decreased risk of dementia.[49,56] Hypertension is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia.[45-47]

Until recently, there was limited evidence to support the use of antihypertensive treatments to prevent cognitive decline and dementia despite several RCTs of blood pressure management examining dementia as a secondary outcome.[57,54] However, the recent SPRINT-MIND trial found that managing hypertension may reduce risk of late-life cognitive impairment.[58] SPRINT-MIND randomized participants with hypertension to a systolic blood pressure goal of either less than 120 mmHg (intensive treatment group) or less than 140 mmHg (standard treatment group). Persons in the intensive treatment group had a significantly reduced risk of cognitive impairment (i.e., mild cognitive impairment or dementia), although the reduction in risk of dementia was not significant.

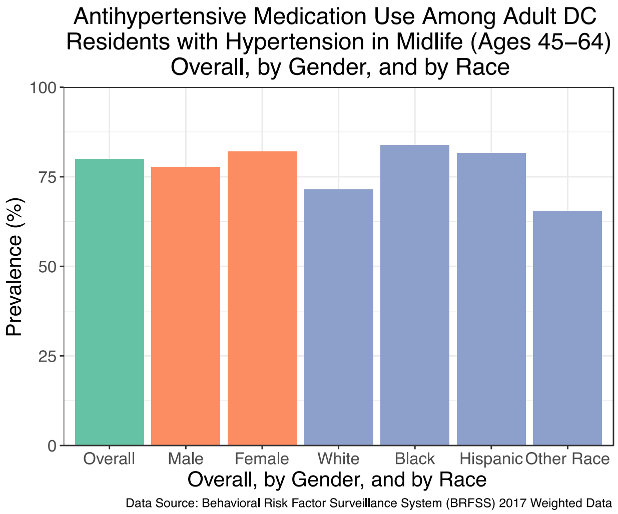
In 2017, the prevalence of diagnosed hypertension in all adult residents of DC was 26%. However, the prevalence of diagnosed hypertension among DC residents ages 45-65 (i.e., in midlife) was 39%. Similarly, the proportion of adults between ages 45 and 65 with diagnosed hypertension was higher in Wards 5, 6, 7, and 8 compared to Wards 1, 2, 3 and 4. Of all racial/ethnic groups, non-Hispanic Black residents were most likely to have a diagnosis of hypertension in midlife. These numbers reflect only people who have been diagnosed by a physician and are aware of this diagnosis. As not everyone with hypertension will be aware that they have hypertension, the true prevalence of hypertension is likely higher.



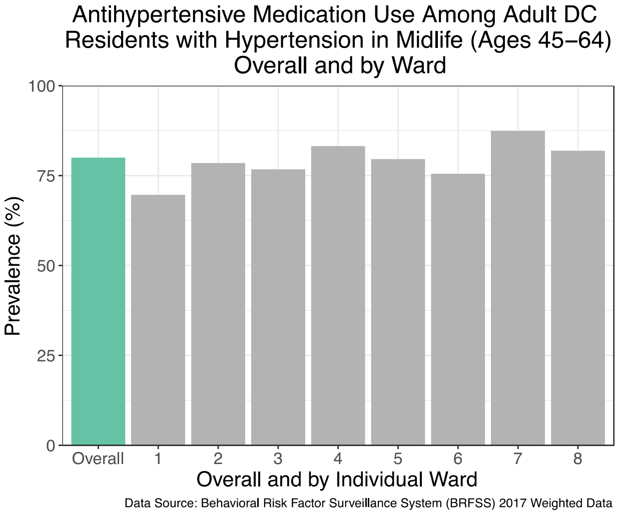
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



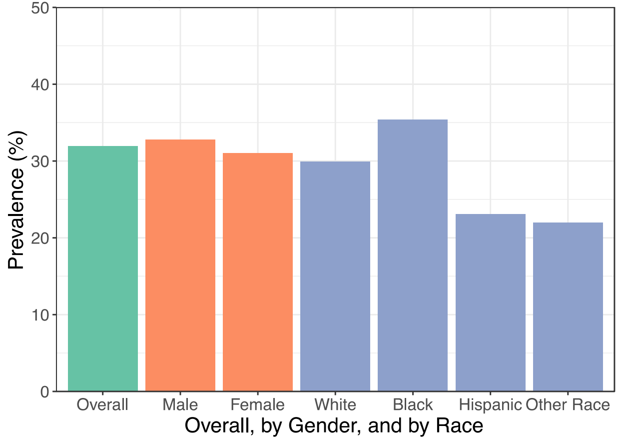
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

High Cholesterol. The CDC, NIH, and WHO recommend maintaining healthy cholesterol levels to potentially reduce the risk of developing dementia.[42,59,60] However, as with hypertension, the association between cholesterol levels and late-life cognition appears to be age-dependent. While high cholesterol in mid-life is associated with increased risk of dementia, high cholesterol in late-life is not consistently associated with increased risk.[61] It is also possible that preclinical dementia leads to declining cholesterol levels in late life.[62,63] High cholesterol in older adults is also associated with longevity and may be an indicator of better health status.[64] Finally, high cholesterol is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia.[45-47]

Medications – most commonly statins – are commonly prescribed to lower high cholesterol. A recent Cochrane Review of double-blind randomized placebo-controlled trials concluded that statins given to older individuals do not prevent cognitive decline or dementia over a 3 to 5 year period.[65] However, it remains possible that use of statins or other lipid-lowering therapies may reduce risk of cognitive decline and dementia if used to treat high cholesterol in midlife.[66]

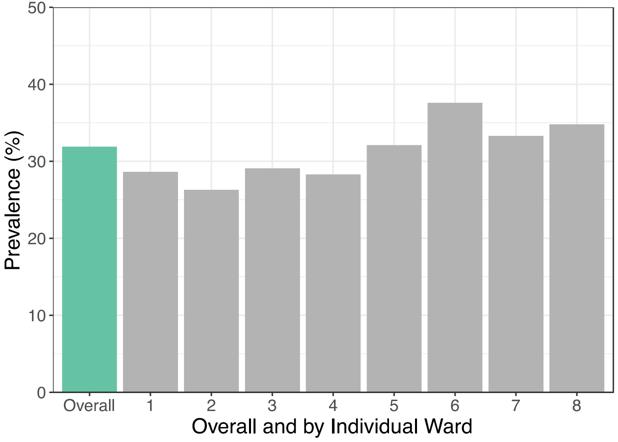
The prevalence of diagnosed high cholesterol was 23% in all adult residents of DC in 2017. However, 32% of DC residents ages 45-65 reported diagnosed high cholesterol, of whom just over half were taking medication to lower their cholesterol. The proportion of persons with high cholesterol in midlife did not vary substantially by DC ward. These numbers reflect only people who have been diagnosed by a physician and are aware of this diagnosis. As not everyone with high cholesterol will be aware that they have high cholesterol, the true prevalence of high cholesterol (regardless of diagnosis or awareness) is likely higher.

Prevalence of High Cholesterol Among DC Residents in Midlife (Ages 45–64) Overall, by Gender, and by Race



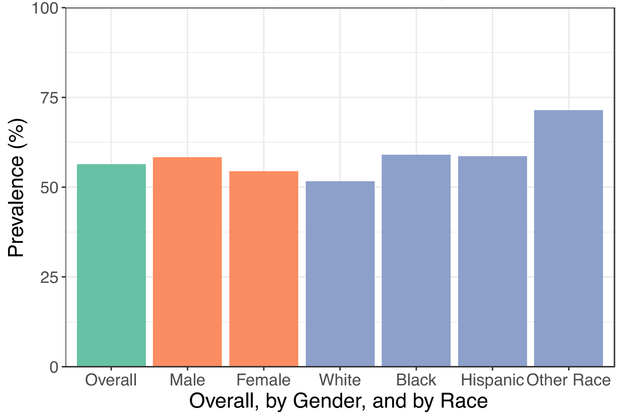
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Prevalence of High Cholesterol Among DC Residents in Midlife (Ages 45–64) Overall and by Ward



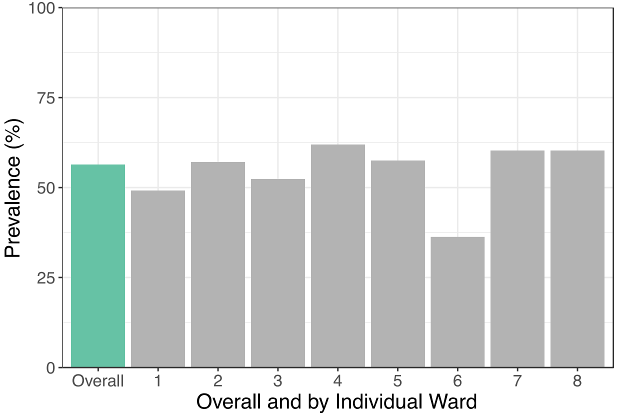
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Medication Use Among Adult DC Residents with High Cholesterol in Midlife (Ages 45–64) Overall, by Gender, and by Race



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Medication Use Among Adult DC Residents with High Cholesterol in Midlife (Ages 45–64) Overall and by Ward

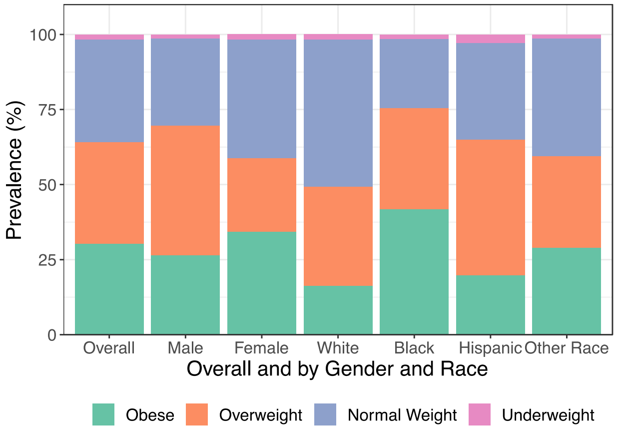


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Obesity. NIH recognizes a growing interest in the potential link between obesity and increased risk of dementia.[42] Consistent observational evidence suggests that obesity and weight gain in midlife increases risk of dementia and cognitive decline.[51,53,67-69] This association may be explained by increases in central adiposity, which is associated with white matter changes, disturbances of blood-brain barrier integrity, brain atrophy, inflammation, hormonal changes, and co-morbidities associated with obesity.[70,71] Conversely, being underweight or having substantial weight loss in late life is associated with increased risk of dementia.[69,72] However, while weight loss or being underweight in late life may directly contribute to dementia risk, it is also possible that it is a sign of preclinical dementia.[73] Obesity is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia. [45-47]

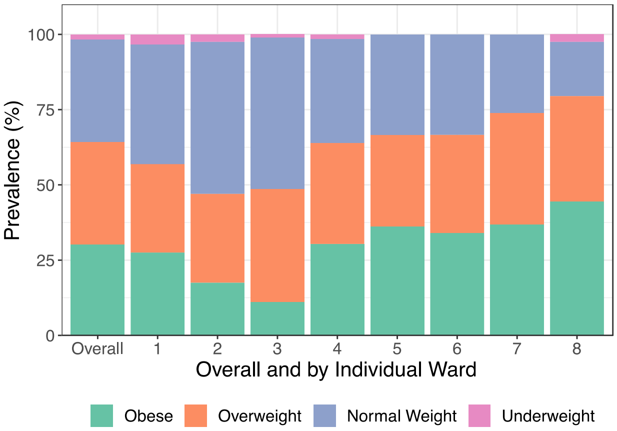
In 2017, 54% of the adult DC population and 68% of the non-Hispanic Black DC adult population was overweight or obese. After restricting to adults in midlife (ages 45-65), 64% of DC residents and 75% of non-Hispanic Black DC residents were overweight or obese.

Body Mass Index Categories Among DC Residents in Midlife (Ages 45–64) Overall, by Gender, and by Race



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Body Mass Index Categories Among DC Residents in Midlife (Ages 45–64) Overall and by Ward

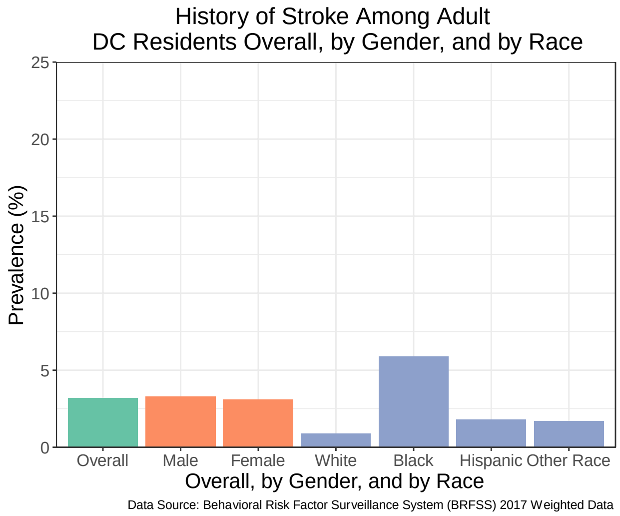


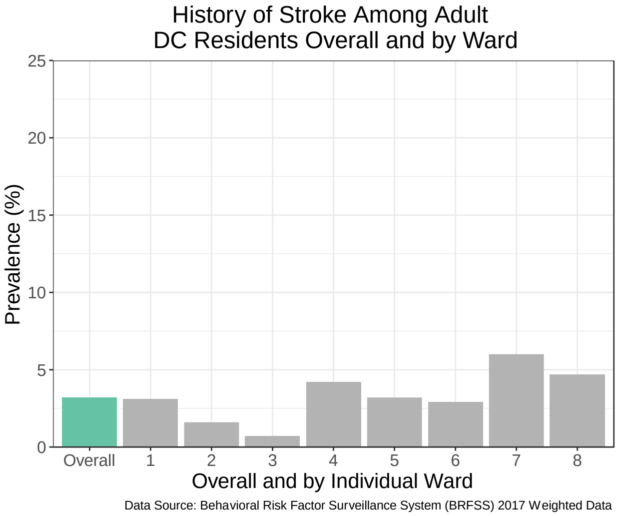
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Stroke. NIH and a council of experts convened by the AARP acknowledge that stroke may increase the risk of developing dementia.[48,74] It is well established that stroke may directly lead to cognitive impairment and dementia.[46] However, it is uncertain whether stroke is a risk factor for developing other types of dementia that are not a direct result of the stroke, including Alzheimer's disease dementia or Lewy Body dementia. The American Stroke Association recognizes that key risk factors for stroke are also risk factors for dementia.[75] Therefore, past stroke may be an independent risk factor for future dementia, or it may be associated with increased risk of dementia due to shared risk factors.

Please note that although we discuss it here, we omit stroke from our list of modifiable risk factors. Stroke prevention and management largely focuses on vascular risk factor prevention or management as well as non-elective surgical procedures. As such, we do not present it as a distinct, modifiable risk factor.

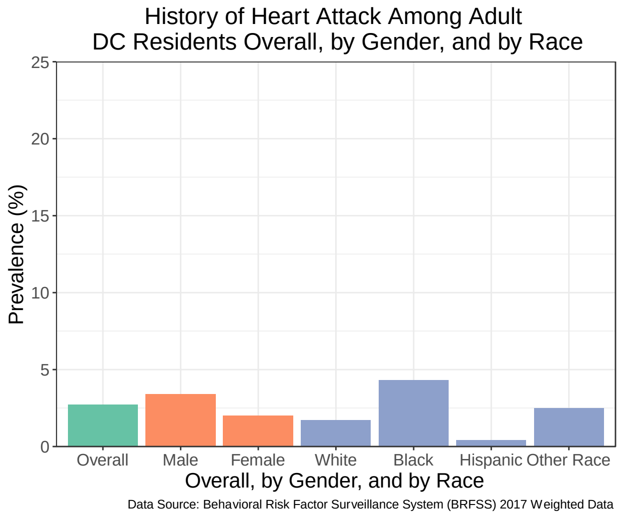
Among adult DC residents, 3% were stroke survivors in 2017. Non-Hispanic Black residents are more likely to be stroke survivors than Hispanic or non-Hispanic white residents. Wards 7 and 8 have the highest prevalence of stroke survivors.

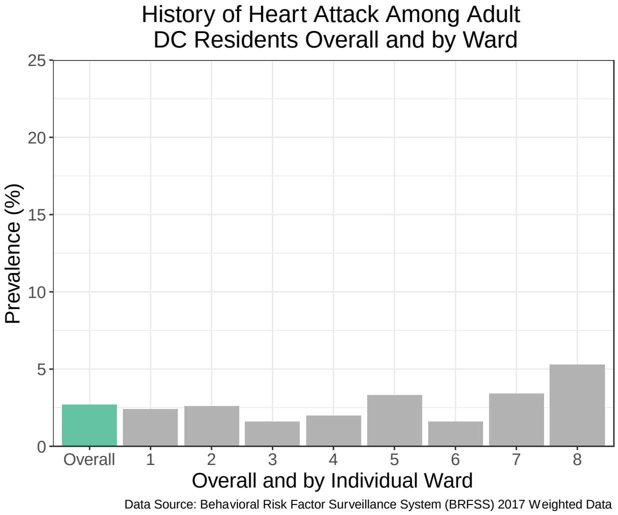


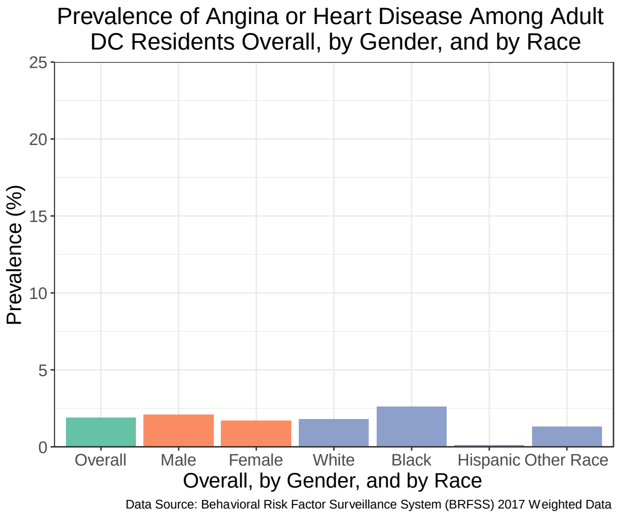


Heart Disease. The NIH recognizes that heart disease may be a risk factor for dementia.[74] However, analogous to stroke, there is considerable overlap between the risk factors for heart disease and dementia.[75] As with stroke, we omit heart disease from our list of modifiable risk factors. Heart disease prevention and management largely focuses on vascular risk factor prevention and management, or non-elective surgical procedures. As such we do not present it as a distinct, modifiable risk factor.

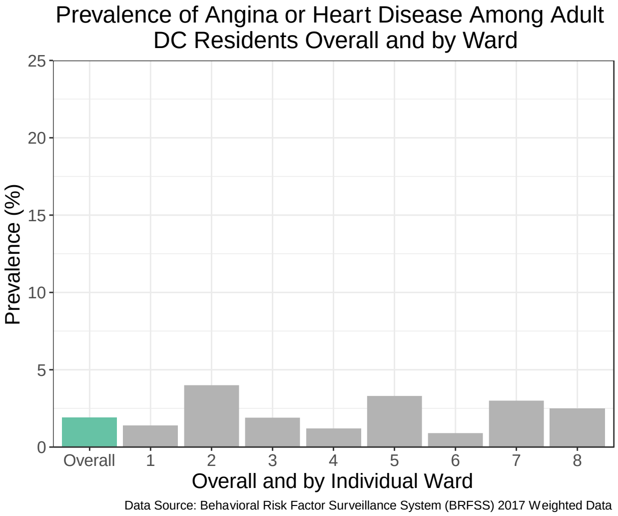
Heart disease most commonly refers to coronary artery disease, but also includes other heart conditions.[76,77] A person may not know they have heart disease until they experience a heart attack, heart failure, or arrhythmia, which produce noticeable symptoms. Among adult DC residents surveyed in 2017, 3% reported prior heart attack, while 2% reported physician-diagnosed angina (chest pain) or coronary heart disease.







Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

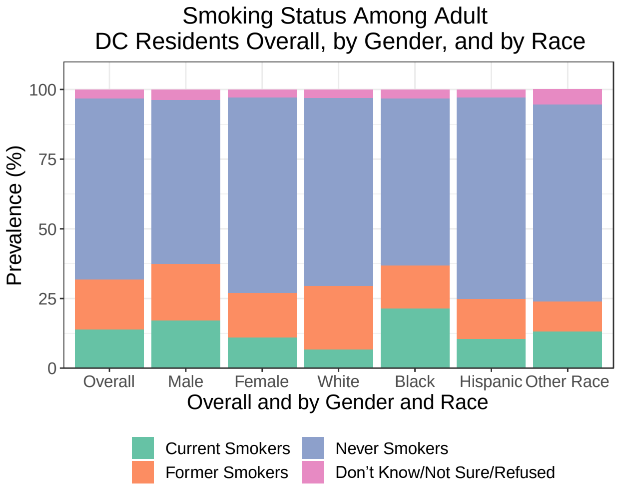


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

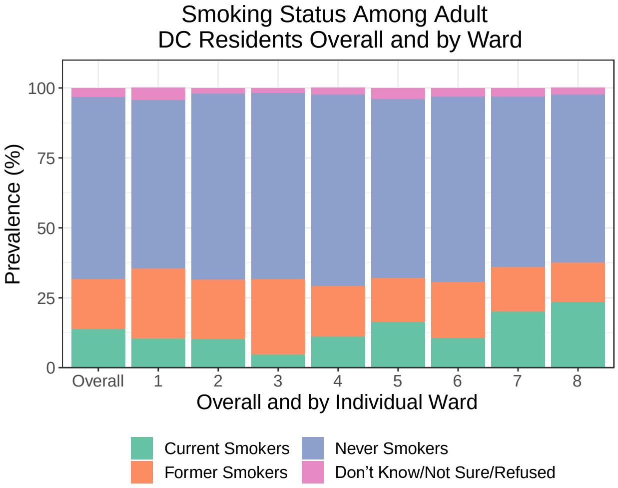
### *Lifestyle Factors*

Smoking. The CDC and NIH recognize smoking as a potential, modifiable risk factor for cognitive decline and dementia.[42,59] Smoking-related cerebral oxidative stress and increased risk of comorbidities may explain the association between smoking and increased risk of dementia.[78] Smoking is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia.[45-47]

Overall, 14% of DC residents in 2017 were current smokers. Men, non-Hispanic Black DC residents, and residents of Wards 7 and 8 were more likely to be current smokers than women, persons of other race/ethnicity, or residents of other DC Wards.



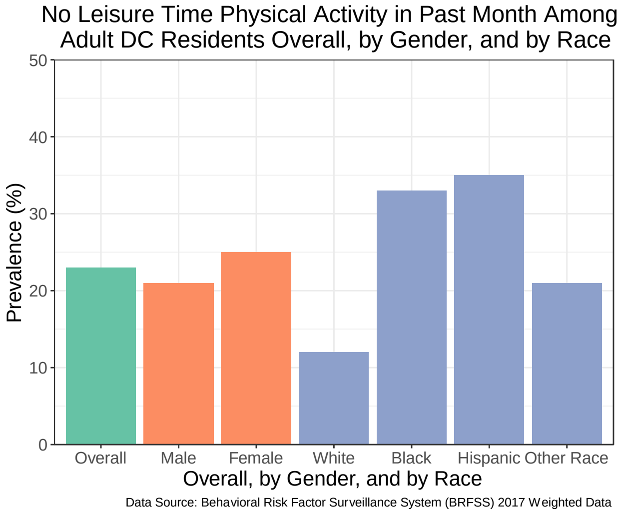
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



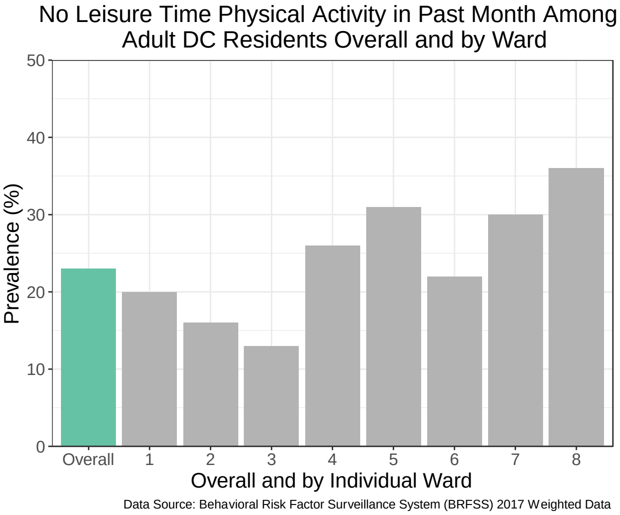
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Physical Activity. The NIH, WHO, and a council of experts convened by the AARP recommend physical activity for healthy older adults to potentially improve cognitive function and reduce the risk of developing dementia.[42,60,48] Observational studies generally suggest a link between physical activity and dementia.[79] However, a recent review of randomized trials concluded that aerobic physical activity did not lead to cognitive benefits for persons without known cognitive impairment.[80] It may be that the type of physical activity and/or the length of the intervention period matters.[57] Mechanisms underlying the association between more physical activity and better cognitive performance may include improved cardiac and immune function, changes to neuronal function, up-regulation of brain-derived neurotrophic factor (BDNF), and reduction in obesity, vascular risk factors, and comorbidities. [81-83] Lack of physical activity is also an established risk factor for stroke, which can lead to vascular cognitive impairment and dementia. [45-47] Physical activity is also important for controlling other vascular risk factors.[84]

In 2017, 23% of DC residents reported no leisure time physical activity or exercise in the last month, while 49% reported meeting the physical activity guidelines for at least 150 minutes of aerobic physical activity per week. Non-Hispanic Black and Hispanic residents were least likely to meet the physical activity guidelines and most likely to be inactive. Residents of Wards 2 and 3 were most likely to be physically active, while residents of Wards 5, 7, and 8 were the least likely to be physically active.



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



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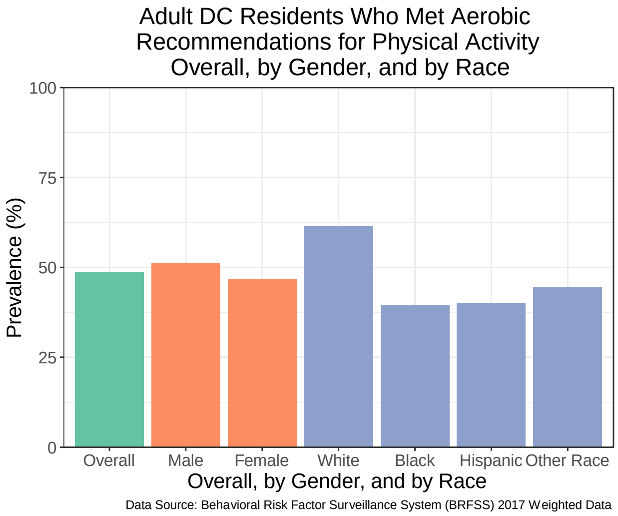
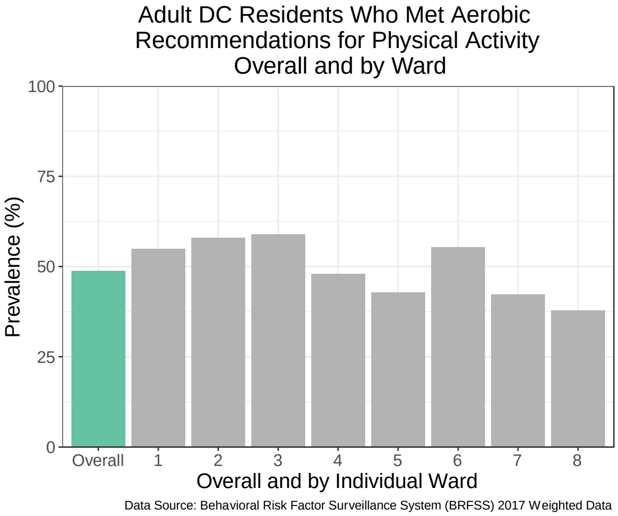

Adult DC Residents Who Met Aerobic Recommendations for Physical Activity Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


Adult DC Residents Who Met Aerobic Recommendations for Physical Activity Overall and by Ward

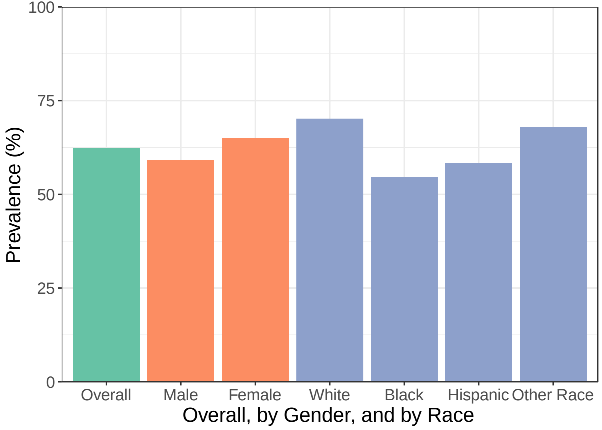
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Healthy Diet. The NIH and WHO recommend that older adults eat a healthy diet to stay healthy as they age, and recognize that this may also reduce the risk of developing cognitive impairment or dementia.[42,60] The Mediterranean diet is the most studied diet in relation to brain health. It is characterized by high intake of fruits, vegetables, whole grains, and healthy fats; moderate intake of protein from fish, eggs, beans, and poultry; low intake of dairy or red meat; and moderate alcohol consumption, typically wine. Systematic reviews of observational studies have concluded that greater adherence to a Mediterranean diet is associated with slower rates of cognitive decline and decreased risk of Alzheimer's disease, despite differences in findings across individual studies.[85,86] Findings from a recent clinical trial support this conclusion, showing that the participants randomized to a Mediterranean diet supplemented with extra virgin olive oil or nuts had improved cognitive function compared to participants on a control diet (advised to reduce fat).[87] The most common explanation for this association is that adherence to a Mediterranean diet is associated with a lower risk of vascular risk factors and associated comorbidities,[88] although other mechanisms, including decreased oxidative stress, are also plausible.[89] There is less consensus on the benefits or harms of other diets or the benefits and harms of specific foods or nutrients. Most observational studies suggest "healthy" diets (i.e. diets generally high in fruits and vegetables, and low in meat or dairy) to be associated with reduced risk of Alzheimer's disease dementia.[90] However, there are few randomized trials of dietary interventions for cognitive benefit, which experts agree are needed to confirm the observational evidence and establish diet as having a clinically meaningful and causal impact on cognitive decline and dementia risk.[91,92]

There is limited evidence to suggest that vitamins and supplements reduce the risk of dementia. There are observational studies to suggest that omega-3 fatty acids, soy, ginkgo biloba, folic acid alone or with other B vitamins, beta-carotene, vitamin C, vitamin D plus calcium, and multivitamins or multi-ingredient supplements may protect against cognitive decline and dementia. [93,94] However, RCTs have found little to no benefit of vitamins and supplements containing these micronutrients in reducing the risk of cognitive decline, mild cognitive impairment (MCI), or Alzheimer's disease dementia.[93,94] One common critique of these trials is the short length of follow-up.[94] Whether longer-term use of vitamins and supplements is beneficial remains unclear.

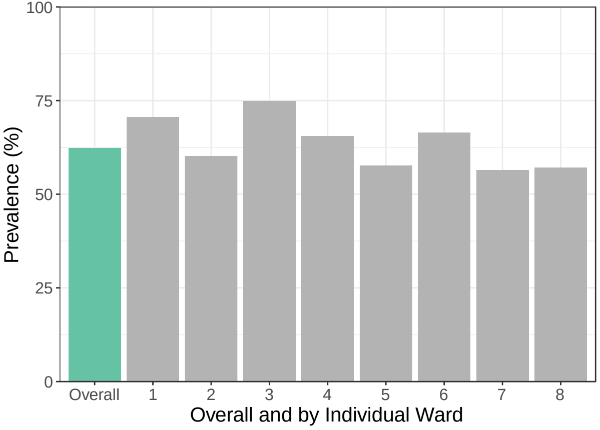
Measures of diet in the 2017 BRFSS data were limited. 62% of adult DC residents consumed fruit at least once per day, while 77% consumed vegetables at least once per day. Non-Hispanic white DC residents were most likely to consume fruit or vegetables at least once per day, while non-Hispanic black DC residents were least likely. The proportion of persons with regular fruit consumption was highest in Wards 1 and 3, and lowest in Wards 7 and 8. The proportion of persons with regular vegetable consumption was lowest in Wards 7 and 8.

Fruit Consumption at Least 1x Day Among Adult DC Residents Overall, by Gender, and by Race



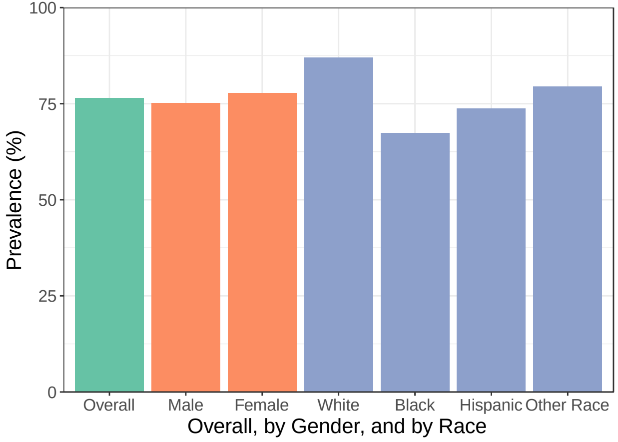
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Fruit Consumption at Least 1x Day Among Adult DC Residents Overall and by Ward



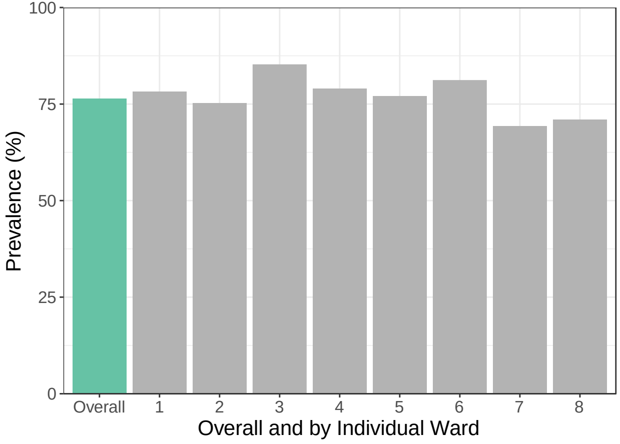
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Vegetable Consumption at Least 1x Day Among Adult DC Residents Overall, by Gender, and by Race



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Vegetable Consumption at Least 1x Day Among Adult DC Residents Overall, by Gender, and by Race

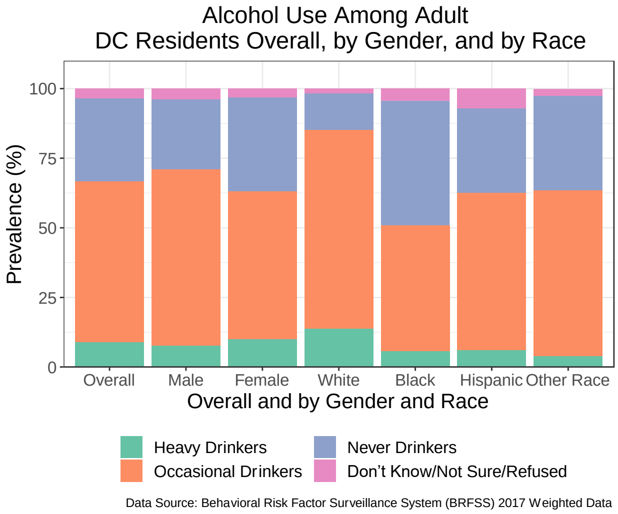


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

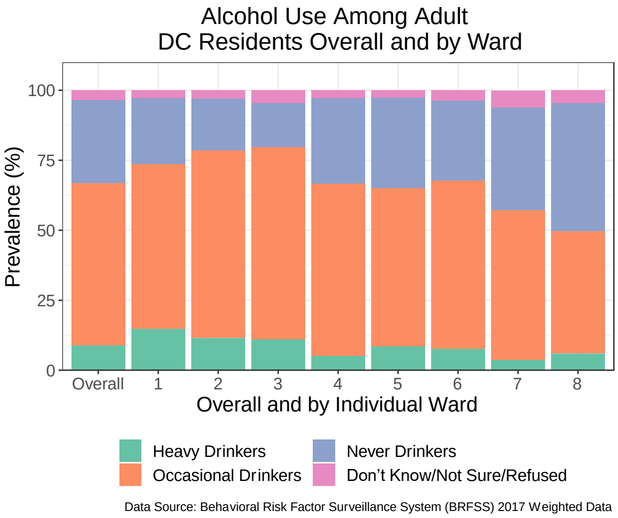
<u>Alcohol Intake.</u> The, WHO and a council of experts convened by AARP suggest that avoiding excessive alcohol use may reduce the risk of developing ADRD.[60,48] Observational studies suggest that heavy use may increase risk, while light to moderate use may decrease risk.[95-98] As this pattern mirrors that observed for cardiovascular disease, alcohol use may influence

dementia risk through effects on cardiovascular disease or associated risk factors.[99] Nevertheless, older adults should not increase their consumption of alcohol to lower the risk of developing dementia, as the line between moderate and heavy alcohol use is unclear. As with stroke, long-term, excessive use of alcohol is an established cause of cognitive impairment and dementia, though alcohol-related dementia is relatively rare.[100]

In 2017, 30% of adult DC residents reported that they do not consume alcohol, and 9% were heavy drinkers, defined as adult men who have more than 14 drinks per week and adult women who have more than 7 drinks per week. Non-Hispanic White residents were less likely to abstain from alcohol and more likely to be heavy drinkers than those of other racial/ethnic groups. Non-Hispanic Black residents were most likely to abstain. Residents of Wards 1, 2 and 3 were most likely to be heavy drinkers.



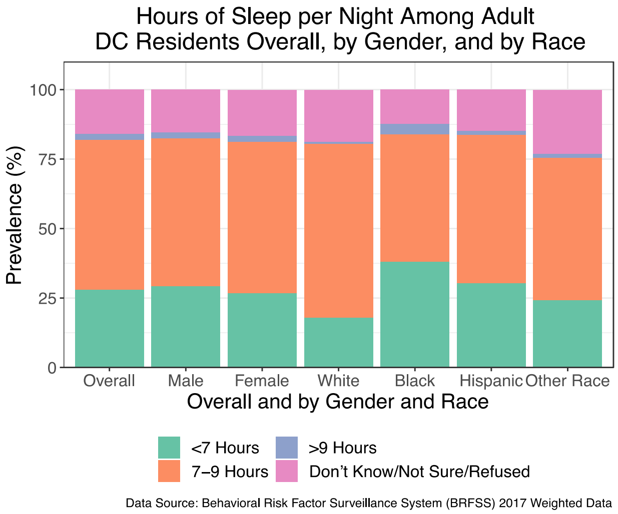
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Sleep. A council of experts convened by AARP to share the best advice on maintaining and improving brain health for older adults suggested that poor sleep quality and insufficient quantity, as well as sleep disorders, including sleep apnea, can lead to memory and thinking issues.[48] However, the body of evidence supporting this conclusion is relatively small, and further work is necessary.[101,102]

In 2017, 54% of adult DC residents reported 7-9 hours of sleep per night. However, 28% reported less than 7 hours. Of all racial/ethnic groups, Non-Hispanic Black participants were most likely to sleep for less than 7 hours per night.



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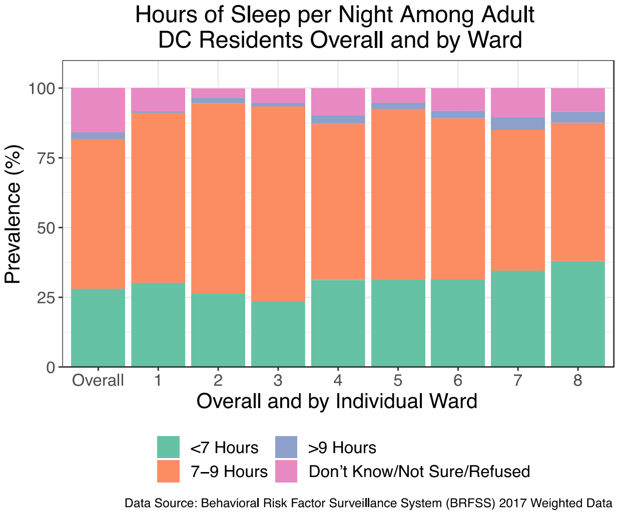
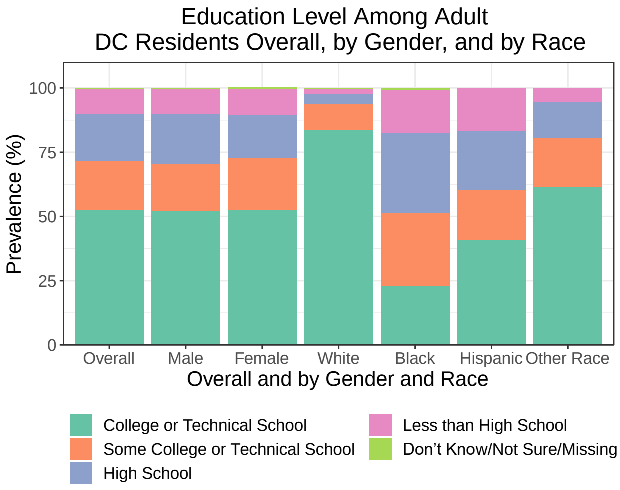


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

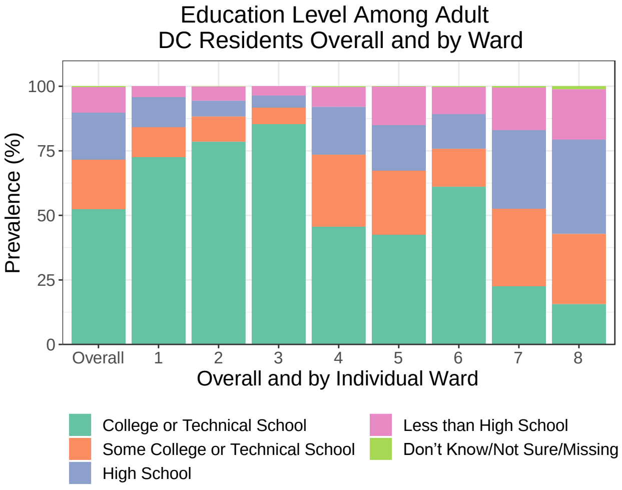
### *Psychosocial Factors*

Education. There is considerable evidence suggesting an association between low educational attainment and worse late life cognition or increased risk of dementia.[51,103-106] Although education may impact risk of dementia through impact on the likelihood of having other risk factors (e.g. hypertension), it appears more likely that it reduces risk of cognitive decline or dementia by increasing cognitive reserve.[107-109] Specifically, cognitive reserve allows individuals to use compensatory approaches or strategies to perform cognitive tasks and avoid cognitive disability despite dementia-related changes to the brain.[107,110]

The DC population is highly educated. In 2017, over 50% adult residents were graduates of a college or technical college. However, there were significant racial/ethnic and geographic disparities in educational attainment. While 84% of non-Hispanic White residents have graduated from a school of higher education, this is true for only 23% of non-Hispanic Black and 41% of Hispanic residents. Similarly, over 70% of DC residents in Wards 1, 2 and 3 have graduated from college or technical college, compared to 23% of residents in Ward 7 and 16% of residents in Ward 8.


Education Level Among Adult
DC Residents Overall, by Gender, and by Race

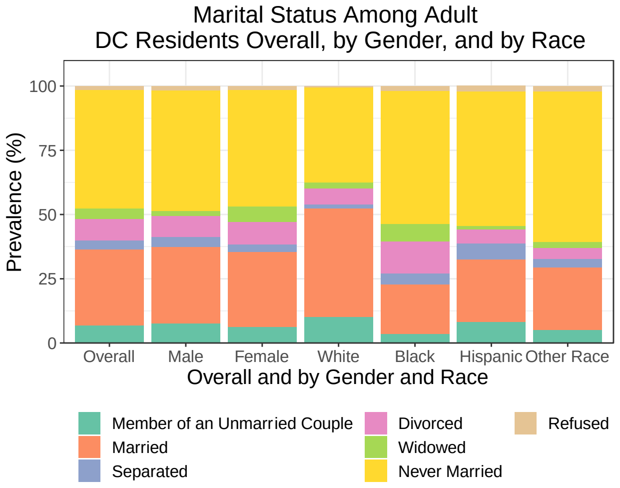
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


Education Level Among Adult
DC Residents Overall and by Ward

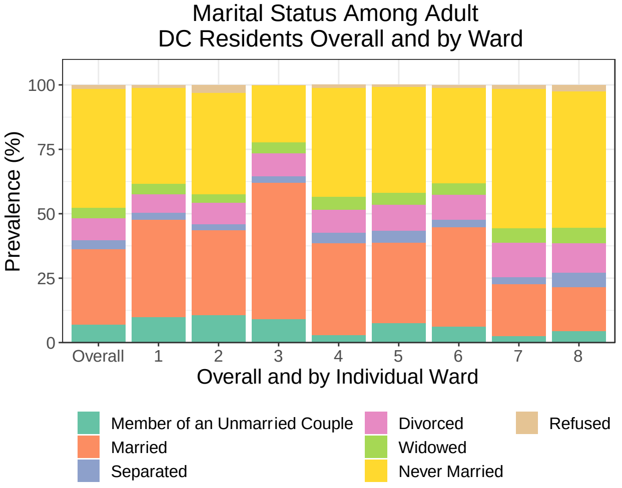
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Social Engagement. NIH recommends social engagement for older adults as a part of a healthy lifestyle, and recognizes that spending time with family or friends may reduce the risk of cognitive impairment and dementia.[42] Older adults with socially integrated lifestyles appear to have a lower risk of cognitive decline and dementia.[111-115] However, whether this reduced risk is a cause or an effect of social engagement remains unclear. As persons experience greater cognitive impairment, they may also reduce their scope of activities.[116-118]

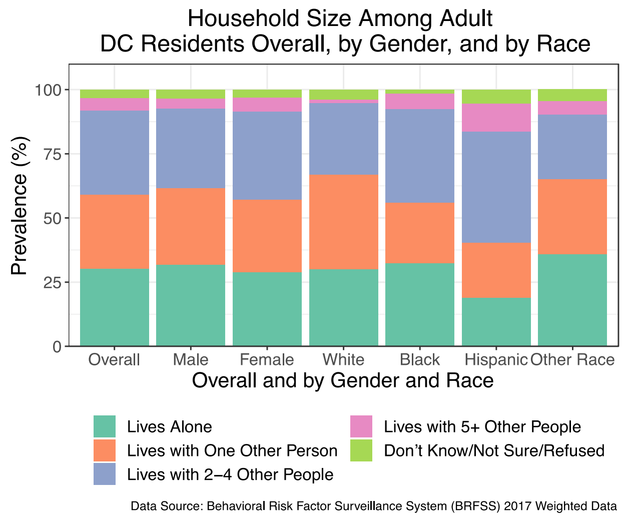
Data on social engagement in DC is limited. However, spouses or other partners often provide substantial social support. In DC in 2017, 30% of residents were married, and 7% classified themselves as part of an unmarried couple. Non-Hispanic White residents are most likely to be in a committed partnership, while non-Hispanic Black residents are least likely to be in a committed partnership. There is significant variation in the proportion of persons in a committed partnership by DC Ward, ranging from just over 20% in Wards 7 and 8 to 62% of adult residents in Ward 3. Household size may also be an indirect indicator of social engagement. Overall, 30% of DC residents live alone, and 29% live with 1 other person.


Marital Status Among Adult
DC Residents Overall, by Gender, and by Race

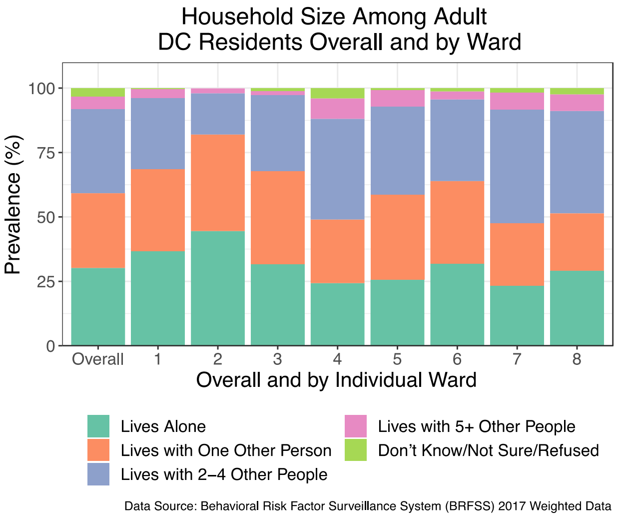
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


Marital Status Among Adult
DC Residents Overall and by Ward

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


Household Size Among Adult DC Residents Overall, by Gender, and by Race

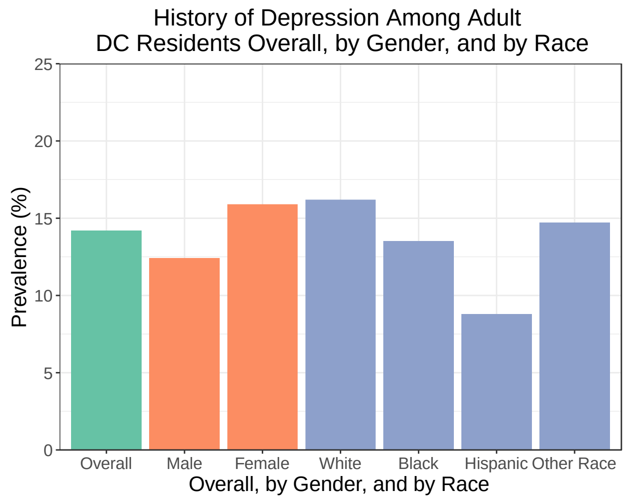
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


Household Size Among Adult DC Residents Overall and by Ward

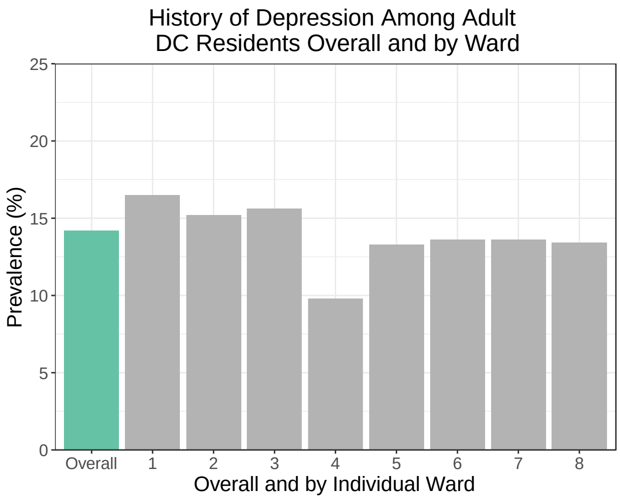
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

<u>Depression</u>. There is considerable evidence to suggest that persons with a history of depression may be more likely to develop dementia.[119] However, depression may also be an early symptom of brain changes associated with dementia.[120,121]

In 2017, 14% of DC residents reported having a history of depression. Women were more likely than men to report a history of depression. Among all racial/ethnic groups, Hispanic individuals were least likely to report a history of depression.


History of Depression Among Adult DC Residents Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


History of Depression Among Adult DC Residents Overall and by Ward

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

### *Other Risk Factors*

<u>Head Injury</u>. The CDC recognizes severe head injury as a potential, modifiable risk factor for dementia.[59] Severe head injury (e.g. requiring hospitalization) can directly lead to cognitive impairment immediately after the event, and this cognitive impairment may or may not abate over time. There is also evidence to suggest that severe head injury may increase risk of later

cognitive decline and dementia, after the initial recovery period is complete.[122-124] To the contrary, there is limited evidence linking less severe head injury to later life cognitive decline and dementia. Although early case-control studies suggested those with prior head injury are more likely to develop cognitive decline and dementia as they age, longitudinal cohort studies generally do not support a link.[122,124-131]

Hearing Loss. The *Lancet* Commission recognizes hearing loss as a potential, modifiable risk factor for dementia.[132] While observational evidence linking hearing loss to cognitive decline or dementia suggests a link, it is unclear whether this represents an effect of hearing loss on cognition or the presence of underlying brain changes that lead to both cognitive decline and hearing loss.[133-135] Hypothesized mechanisms for a direct effect include challenges with communication and interpersonal relationships, which can contribute to social isolation, or diversion of brain resources from cognitive activities to auditory perception.[136] Several randomized trials of hearing interventions for the preservation of cognitive function are underway.[137]

Air Pollution. The *Lancet* Commission also recently recognized air pollution as a potentially modifiable risk factor for cognitive decline and dementia.[132] Multiple observational studies have linked exposure to particulate matter and oxides of nitrogen with cognition and dementia, although there remains significant heterogeneity of specific findings across studies.[138,139] Hypothesized mechanisms include an promotion of oxidative stress and inflammation or an effect of air pollution on vascular health, which in turn impacts brain health.[140,141]

Cognitive Activities. As with education, cognitive activities are hypothesized to reduce risk of cognitive decline and dementia by increasing cognitive reserve. Observational studies generally report a link between greater participation in cognitive activities (e.g., solitary, cognitively engaging activities, like reading, playing games, watching TV, or listening to the radio) and reduced risk of cognitive impairment or dementia.[141,142] However, as with social engagement, it may be that as persons experience greater cognitive symptoms, they may also reduce their cognitive activities, even before progressing to the point where they meet criteria for dementia.[143]

Cognitive Training. As with education and cognitive activities, cognitive training is hypothesized to reduce risk of cognitive decline and dementia by increasing cognitive reserve. Cognitive training typically consists of guided practice on tasks targeting a specific domain (e.g. memory-related tasks). Randomized trials have demonstrated that persons who received cognitive training to improve memory improved in immediate and delayed verbal recall. [144] However, this effect was also observed in the active control groups, and therefore could not be attributed directly to cognitive training.[144] Similarly, few trials that demonstrated improvements in cognitive test performance in those who receive cognitive training have been able to show that this translates into improvement in global cognition or daily function.[145] For example, the largest trial of cognitive training to date, the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) trial, showed that cognitive training in a specific cognitive domain improves performance in that domain, but generally has little impact on performance in other domains, functional outcomes, or dementia risk.[143,146-149]

### *Causality and Risk Factor Modification*

Establishing causal relationships between risk factors and risk of cognitive decline and dementia is difficult. It is often infeasible to conduct randomized controlled trials (RCTs) to establish a link between a potential risk factor and cognitive outcomes due to ethical or practical considerations. For example, it would now be unethical to randomize people to antihypertensive medication or placebo, as we know that medical management of hypertension reduces risk of heart attack, stroke, and mortality. Similarly, because dementia-related brain changes may begin decades before clinical symptoms, it is possible that early and sustained risk factor modification is necessary to reduce risk of cognitive decline and dementia. An RCT with a 10 or 20-year follow-up would be extremely costly and potentially infeasible. However, even if we are not certain whether the relationship between these risk factors and cognitive decline or dementia is causal, there are benefits to risk factor reduction. Many of these risk factors are also established risk factors for other diseases, particularly cardiovascular disease. Even if they do not directly impact dementia risk, interventions on these risk factors would be expected to improve overall health.

# Objective #3: Identify challenges and unmet needs of caregivers for persons living with dementia in DC

*Background and Approach*

Caring for a person living with dementia can be challenging. This type of caregiving also differs from caregiving for a person with other conditions, both in terms of the activities involved and the impact on caregivers.[150,151] Persons living with dementia often require supervision in moderate and advanced stages of disease, as it may be unsafe for them to be alone. Similarly, dementia is often accompanied by behavioral symptoms, personality changes, and communication difficulties.

Given limited resources, communities, governments, and organizations must make choices on how best to support caregivers for persons living with dementia. In this context, it is critical to understand which services and resources caregivers rely upon, challenges with access to needed services, and areas of unmet service and resource needs. Therefore, our goal here was to identify challenges and unmet needs related to resource and service use by caregivers of persons living with dementia in DC.

To accomplish this goal, we held a series of focus groups with unpaid caregivers of persons living with dementia focused on identifying challenges and unmet needs related to resource and service use of caregivers of persons living with dementia in DC. We recruited participants with the help of community partners. Eligibility criteria for focus group participation required participants to be: 1) a self-reported, unpaid primary caregiver for an older adult with dementia, 2) 18 to 85 years of age, 3) a resident of Washington, DC, and 4) able to provide meaningful dialogue for a focus group. We conducted a series of 5 moderated, 90-minute focus groups, enrolling a total of 24 participants (our pre-specified target enrollment). Prior to focus group participation, study staff completed intake forms to record information on participant characteristics. Due to the COVID-19 pandemic, focus groups were held virtually via video conference. The focus groups were recorded, transcribed, and systematically coded and analyzed. This study was approved by the George Washington University (GW) Institutional Review Board. Further methodological details on recruitment, focus groups, and data analysis are available in **Appendix E**.

In response to the goals of this project, we focused on the broad types of challenges and unmet needs around service and resource use experienced by DC caregivers. Thus, in-depth understanding of the various challenges identified, as well as other areas of unmet caregiver need, remain to be explored.

Additionally, many organizational stakeholders also commented on areas of unmet need during conversations held to support creation of the guide identifying resources and services available to DC residents living with dementia for Objective #4. Although not a systematic investigation, we summarize these comments as well. As these two groups – unpaid primary caregivers and organizational stakeholders – represent very different perspectives, we present findings and implications of each activity separately, and conclude with a discussion of common themes.

### *Challenges and Unmet Needs Identified by Primary Caregivers of Persons with Dementia*

#### *Participant Characteristics*

A total of 24 participants were recruited across five focus groups. Compared to the general DC population, our sample was more likely to be female, older, and Black/African American (**Table 5**). All participants had at least a high school degree. Despite the age profile of the participants, approximately two thirds were caring for a parent and only one fifth were caring for a spouse. Half of the participants reported that their loved ones were exhibiting symptoms of advanced dementia. Participants came from 10 zip codes across DC, spanning all wards except Wards 2 and 6. Almost all participants reported living with the care recipient.

**Table 5.** Focus group participant characteristics

| Characteristic | N (%) |
|---|---|
| *Caregiver's gender* | |
| Male | 6 (25%) |
| Female | 18 (75%) |
| *Caregiver's age* | |
| 45-60 | 4 (17%) |
| 61-65 | 9 (38%) |
| 66-70 | 6 (25%) |
| 70+ | 3 (13%) |
| Unknown | 2 (8%) |
| *Caregiver's race/ethnicity* | |
| Non-Hispanic white | 3 (13%) |
| Non-Hispanic Black | 18 (75%) |
| Hispanic | 2 (8%) |
| Unknown | 1 (4%) |
| *Caregiver's education* | |
| High school or some college | 10 (42%) |
| Associate's or Bachelor's | 7 (29%) |
| Graduate degree | 5 (21%) |
| Unknown | 2 (8%) |
| *Ward* | |
| Ward 1 | 3 (13%) |
| Ward 2 | 0 (0%) |
| Ward 3 | 1 (4%) |
| Ward 4 | 4 (17%) |
| Ward 5 | 7 (30%) |
| Ward 6 | 0 (0%) |
| Ward 7 | 3 (13%) |
| Ward 7 or 8[b] | 4 (17%) |
| Ward 8 | 1 (4%) |
| Unknown | 1 (4%) |
| *Care recipient's relationship to caregiver* [a] | |
| Parent | 17 (71%) |
| Spouse | 5 (21%) |
| Grandparent | 2 (8%) |
| Sibling | 1 (4%) |
| *Care recipient's dementia severity as reported by caregiver* | |
| Mild | 4 (17%) |
| Moderate | 7 (29%) |
| Advanced | 12 (50%) |
| Unknown | 1 (4%) |
| *Whether care recipient lives with caregiver* | |
| Yes | 22 (92%) |
| No | 1 (4%) |
| Unknown | 1 (4%) |

[a] Total N exceeds 24 as two participants took care of two family members
[b] Data on ward was derived based on zip codes, and zip code 20020 spans Wards 7 and 8

#### *Resources Used by Focus Group Members*

Focus group participants discussed use of multiple resources and services, including DC agencies, senior centers and adult daycare centers, in-home support, caseworkers/social workers/ counselors, nursing homes, home modification and renovation, meals and food services, transportation services, education services, and legal services. A narrative summary of the focus group discussion around use of each type of resource is provided in **Appendix F**. This summary includes both positive experiences and challenges, as well as supporting quotes from participants.

### *Challenges and Unmet Needs of Primary, Unpaid DC Caregivers*

Participants discussed multiple challenges and unmet needs related to resource and service use when caring for a person living with dementia in DC. Key themes that emerged from this work include:

1. *Need for help in navigating, identifying, and applying for resources and services.*

   Participants reported the process of navigating the system to identify and apply for relevant resources and services to be challenging and overly complex. Some shared that they are overwhelmed by the amount of information and referrals that they receive from agencies such as the DACL, describing feeling that they are being given "the run around." Given the burdens of caregiving itself, the onus of processing and distilling this information to identify the resources that meet their individual needs was reported to be too time-consuming and stressful. Conversely, there were also participants who had challenges accessing sufficient information due to the lack of centralized information, lack of responsiveness of agencies, or lack of coordination between agencies. For some, the application process for receiving resources is also a barrier, which many characterized as overly burdensome and difficult to understand.

   Participants wished for greater guidance and a more streamlined process for navigating and accessing resource. Suggestions included (i) a system whereby the city automatically assigns each caregiver with a caseworker to guide them through the process of identifying and applying for resources and services, (ii) a system to proactively track and monitor community-dwelling seniors for dementia to ensure that they are receiving care, and (iii) greater coordination across DC agencies and organizations.

2. *Need for reconsideration of service eligibility criteria, including lowering of income thresholds, and exclusion of caregiver income from consideration.*

   Our focus group participants encountered a major challenge in qualifying for services, most notably home health aides and home modification services. Participants are frustrated by income-based eligibility requirements for services, and especially angered by the fact that some programs consider not just the care recipient's income, but also the caregiver's income. A number of participants also noted that the qualifying threshold for services is typically too low. They are frustrated by the fact that they are deemed to have too much income to qualify for certain services, while at the same time feeling that they are struggling financially, and unable to afford the needed services out-of-pocket. In response to these challenges, at least two participants suggested that providing some form of flexible caregiving subsidy or credit would be helpful in supporting caregiving efforts.

A handful of participants discussed grants that are available through the DC Caregivers Institute (DCCI) and Senior Centers that help cover some of the in-home support services and other caregiving-related expenses. However, they were unclear on the eligibility criteria for receiving these grants, and the availability of these grants was unknown to most. Participants also suggested that elderly residents should be entitled to and automatically enrolled in services that support their well-being based on need, without consideration for income. Although this was not a focus of our investigation, challenges related to qualification for services appeared to be less common among the few focus group participants with Medicaid or Veterans Affairs (VA) insurance coverage. However, this warrants further investigation.

3. *Need for increased recognition of unique resource and service needs of persons with cognitive impairment across all stages of the disease.*

   Of note, one participant observed that services such as in-home support are particularly limited for persons with cognitive impairments, but who are still relatively able physically. They explained that they are unable to qualify for a home health aide due to their care recipient's lack of physical limitations. However, they need an aide for social, language, and intellectual stimulation, as well as for supervising or guiding physical activity, all of which are beneficial to the well-being of those with dementia. They urged for a program similar to the DC Medicaid Elderly & Persons with Disabilities (EPD) Waiver that would provide this and other appropriate services to persons across stages of dementia in accordance with their varying needs. These sentiments were echoed by others, who discussed the need for services targeted for individuals across the disease progression continuum, including those in the earlier stages of dementia, and the importance of having DC Health recognize the diversity of needs across older adults. One solution proposed by focus group participants was for DC Health to provide general financial support for caregiving and allowing each caregiver or family to decide how to allocate funds in a way that best suits the needs of their particular case, in place of providing pre-determined categories of services (e.g. meal services vs. transportation vs. home health aides).

4. *Need for increased access to home health aides to provide regular caregiving support and caregiver relief.*

   The most crucial and consistently reported unmet need of focus group participants was the need for home health aides to provide regular caregiving support and caregiver relief. (Of note, participants commonly referred to this as "respite care", but desire regular and ongoing arrangements rather than intermittent, short-term relief). Given the time, effort, and mental/physical challenges associated with caregiving for a person living with dementia, participants emphasized the importance of in-home support to allow them to take regular breaks, attend to their own self-care, attend to other responsibilities, and if desired, to be able to continue employment. Additionally, some noted the need for home health aides for accompanying care recipients to attend adult daycare and other senior center programs, per senior center requirements. Most participants faced challenges with regard to qualifying for covered home health aide services, which is typically too costly to afford out-of-pocket. Pathways to access were varied and, in many cases, slow and burdensome. Among those with home health aide support, some reported having aides that were unreliable or unhelpful, improperly trained to care for persons with dementia, or who had language barriers with the care recipient. Additionally, the number of hours of home health aide support that our participants are able to receive was commonly reported to be insufficient. Finally, some participants use and are grateful for programs that help pay for family members or friends to provide in-home support and caregiver relief (through DC Caregiver Institute and Consumer Direct – Service My Way); however, knowledge of these programs did not appear to be common across all participants.

5. *Need to address resource-specific challenges and unmet needs.*

Participants highlighted a number of resource-specific challenges and needs as high priority areas, including need for increased education of the community and home health aides, improved transportation, higher quality meal services, legal support, and availability of high-quality nursing home options in the DC area (**Table 6**).

A number of participants noted a need for increased education on dementia for the general community, as well as for home health aides and healthcare professionals. Specifically, some participants are frustrated with other family members' and friends' lack of knowledge on the needs and behaviors of someone experiencing dementia. Lack of knowledge also appears to impact how prepared or willing family and friends are to provide caregiving support. Similarly, some participants described experiences with home health aides who were unhelpful or unreliable due to lack of training specific to the care of dementia patients. One participant also noted that lack of physician training around dementia delayed diagnosis and appropriate care.

Improved transportation services were identified as a priority need by a number of participants. Existing services were generally described as insufficient and/or unreliable. For some, the lack of transportation services was a barrier to using adult daycare programs. Participants also highlighted a need for higher quality meals services. Among the few who discussed use of meals delivery services, most appeared unsatisfied with the nutritional value and/or taste of the food. Participants also raised the need for legal assistance in establishing wills, living trusts and advance directives, as well as appointing powers of attorney for health and financial matter. Generally, participants were not aware of legal support services for these issues.

A few participants reported concerns about the quality and availability of nursing homes in DC, with at least one participant citing it as the reason they do not wish to enroll their loved ones in a nursing home. It is important to note, however, that use of nursing homes was not discussed at length as our discussions were focused on services and resources to support caregiving for loved ones at home. Furthermore, because the need for nursing homes is dependent on the state of health and limitations of the care recipient, as well as on the availability and capability of caregivers, those with greater need for nursing homes may not have been represented in our participant sample. Thus, the full scope of challenges and unmet needs related to nursing home use is likely not reflected here. Similarly, there was limited discussion of assisted living facilities and memory care residential facilities were not discussed.

6. *Need for options to compensate for disruption of centrally-provided services due to the COVID-19 pandemic.*

   Because our focus groups were conducted between May and July of 2020, our focus group participants also discussed a number of challenges caused specifically by the COVID-19 pandemic. Many organizations and services are temporarily closed or otherwise disrupted during the pandemic, and these disruptions are affecting caregivers and care recipients in a number of ways. Notably, the closing of adult daycares has disrupted routines, as well as care recipients' opportunities for socialization and exercise, all of which are crucial for the well-being of persons living with dementia. For example, one participant described that their loved one became more challenging to care for as a result of this loss of routine. The lack of adult daycare availability has also placed greater burden on caregivers, most of whom have been unable to find alternative care support services. Without adult daycare services, caregivers must now provide the stimulation that their loved ones were previously receiving at adult daycare. These challenges have been compounded by the disruption of family and friend support networks, as well as the restrictions to activities outside the home. Technological resources may be helpful alternatives for providing stimulation and engagement. However, these resources can be expensive, and technology can be challenging to learn, especially for the older and cognitively impaired population. Those with existing in-home support arrangements generally reported few disruptions beyond the need for precautions around the use of personal protective equipment. However, one participant lost health aide coverage for several weeks due to COVID-19 disruptions to health aide availability. Other disruptions and closures noted included nursing home enrollment and home modification services, which are delaying access to needed services.

**Table 6.** Summary of resources used by focus group participants, and associated challenges

| Resource | Challenges |
|---|---|
| Department of Aging & Community Living (DACL) and DC Caregivers Institute (DCCI) | • Need for care navigator (e.g. case worker or social worker) to help navigate the process of identifying and applying for resources<br>• Amount of information and referrals provided without guidance can be overwhelming<br>• Problems with receiving timely assistance due to high demand<br>• Lack of coordination with other agencies |
| Senior Centers and Adult Daycare Services | • Requirement for care recipients to be accompanied by someone while attending daycare or activities is challenging to those who do not have aide services<br>• Transportation challenges to and from senior centers<br>• COVID-19 closures have caused routine disruption and loss of activities |
| In-Home Support | • Difficult to obtain home health services<br>• Stringent eligibility requirements for home health aides, which are too expensive to afford out-of-pocket<br>• Challenging to receive sufficient hours<br>• Home health aides may be unreliable or unhelpful, may have language barriers, or may not be adequately trained to care for persons with dementia<br>• Lack of in-home support for assisting or supervising care recipients with physical activity or exercises<br>• Limited awareness of other in-home support services besides home health aides<br>• COVID-19 disruptions to services |
| Caseworker/ Social Worker/ Counselor | • May be unresponsive and slow to follow up on inquiries<br>• Some caseworkers/social workers only communicate with the care recipient rather than with the caregiver, which is ineffective due to the care recipients' cognitive issues |
| Nursing Homes | • Access limited due to inadequate number of beds in quality facilities in DC<br>• COVID-19 interruptions to enrollments |
| Home Modification/ Renovation | • Eligibility for services is a major challenge: it is often based on the total income of the household rather than the income of the care recipient. Many who are not eligible are also unable to afford the services out-of-pocket<br>• Rental regulations make home modification difficult<br>• COVID-19 closures of agencies |
| Meals and Food Services | • Quality of food (nutritional value and taste) from existing meal delivery services is poor |
| Transportation Services | • Concerns about reliability of existing transportation services<br>• Concerns about availability of needed transportation (e.g., scheduling, capacity, bus or van availability)<br>• General lack of high-quality and reliable transportation services for use by persons living with dementia |
| Education Services | • Lack of family/friend/community knowledge about dementia and how to provide support to those with dementia and their caregivers<br>• Lack of adequate home health aide training with regard to caring for persons with dementia<br>• Need for timely identification and diagnosis of dementia to help educate families about how to provide appropriate care and to refer families for services |
| Legal Services | • Need for legal services to assist with end-of-life related legal issues, including establishing wills, living trusts and advance directives, as well as appointing powers of attorney for health and financial matters. |

> Participants also spoke about a number of services, including the DC Caregivers Institute's needs evaluation, senior center meetings for caregivers, and caregiver education/training services, that have moved online or over the phone, which some are finding to be frustrating. Similarly, some participants discussed general difficulties with learning and using technology. Because our participants were restricted to those who were able to participate in our online focus groups, it is possible that changes to these services may be even more challenging to adapt to among those with less technological familiarity or capabilities. Though the shift to telehealth due to the COVID-19 pandemic was not discussed in our focus groups, it is possible it is posing challenges to more elderly caregivers and care recipients with dementia given the general technology-related challenges that our participants described.

In interpreting these findings, it is important to remember that this work focused on the broad types of challenges and unmet needs around service and resource use that is experienced by DC caregivers. Other challenges and areas of unmet need (e.g., psychosocial and financial needs, caregiver physical and mental well-being, caregiver employment issues, and long-term care needs), remain to be explored. Similarly, it may be beneficial to conduct targeted, in-depth examination of unmet needs related to specific resources, as well as examination of the role of modifying factors (e.g. insurance status, disease severity) on caregiver needs.

Our sample size was limited, and so it is possible that our findings are specific to the caregivers we enrolled, rather than representative of the broader DC population of caregivers for a person living with dementia. In addition, our results may to reflect the experience of under-represented groups (e.g., caregivers for a person living with mild cognitive impairment or mild dementia, caregivers without access or ability to participate in a video-conference, persons who were unconnected to the community partners who contributed to our recruitment efforts, and persons who do not speak English or for whom an English-language format would be a barrier to participation).

Finally, we focused on unmet needs of caregivers, not for persons living with dementia. Persons living with dementia may face distinct challenges or unmet needs, particularly if the person living with dementia does not have a trusted, primary caregiver.

### *Challenges and Unmet Needs Identified by Organizational Stakeholders*

In the process of identifying assets and resources available to DC residents living with dementia and their caregivers, we engaged multiple local stakeholders. While the objective of these conversations was to ensure that we accurately represented DC resources available to persons living with dementia, many of these stakeholders also commented on areas of unmet need for District residents with cognitive impairment or people who were caregivers for someone living with dementia. Broadly, these stakeholders identified the following areas, echoing many of the themes identified in our focus groups:

1. *Need for increased messaging and awareness of available services.*

   Organizational stakeholders felt that lack of awareness of available services and how to access them appears to be a key barrier to receipt of services. They felt that a centralized and consumer-facing interface for access to potential resources would be helpful.

2. *Need for increased service level and greater consistency of service across the District.*

   Several stakeholders noted that services that are available in one ward may not be available in others, many services are narrow in scope, and services may only be available for a limited time (e.g. due to program restrictions or because the service is grant funded). They recommended that continuity in service availability across DC wards and across time would benefit the community of persons living with cognitive impairment and caregivers for persons with dementia.

3. *Need for increased training for those who interact in a professional capacity with persons who have dementia.*

   Organizational stakeholders felt that persons who will interact with persons living with dementia as part of their professional duties (e.g. providers of in-home personal care, first responders, case managers) would benefit from additional training around dementia. Specifically, they advocated for additional training for all professionals, and especially for home health aides, to provide a better understanding of dementia and its symptoms and how to interact effectively with persons living with dementia. In addition, they note that training for law enforcement and emergency personnel that provides information about how decisions or documentation made in their professional roles may impact eligibility for resource utilization would be helpful.

4. *Need for community messaging and caregiver education about dementia.*

   Many note that fear and stigma remain barriers to recognition and appropriate management of dementia in many DC communities, and that persons living with dementia and their caregivers also struggle with recognition and appropriate management of dementia. Organizational stakeholders find that caregivers often enter their role with little understanding of the disease and its progression, strategies on how to live with the symptoms of dementia, and what services they would benefit from. Generally, stakeholders felt that community messaging and caregiver education may help promote increased recognition and appropriate management of dementia.

5. *Need for dedicated services to protect safety and autonomy of persons living with dementia.*

> Organizational stakeholders found that DC residents who are living with dementia or who are caregivers for someone living with dementia often need help with navigating insurance, legal services, and financial services. In their experience, persons living with dementia often lack necessary authorizations or guardianship to enable others to ensure their care, finances, and personal safety are managed in accordance with their wishes, and are also at increased risk of financial exploitation or physical abuse. They note that this is particularly important for isolated persons living with dementia who may not have a primary, involved caregiver.

### *Common Themes*

There was substantial overlap in the challenges and unmet needs identified by caregivers and organizational stakeholders.

Both primary caregivers and organizational stakeholders recognized that caregivers of persons living with dementia need help in identifying and accessing resources and services. However, while organizational stakeholders suggested a centralized, consumer-facing interface for sharing information may help to solve this issue, primary caregivers expressed a preference for help from a care navigator (e.g. a case manager or case worker) who can guide them throughout their time as a caregiver. Many caregivers were overwhelmed with the information they received, and felt the need for help from a person who can understand the individual circumstances and values of the caregiver and care recipient, and who can use this information to guide them to the appropriate services and resources.

Organizational stakeholders noted need for consistency and continuity of services and resources across geography and time. While this did not arise as a primary concern in our focus groups of primary caregivers, it is possible that such inconsistencies contributed to areas where awareness and use of particular services varied across participants.

Concerns about eligibility requirements were highlighted by both groups, although in different ways. Primary caregivers were most concerned about financial eligibility requirements, which often prevented receipt of needed services that they are financially unable to pay for out-of-pocket. One organizational stakeholder raised concerns that the choices and documentation of first responders, including law enforcement and emergency personnel, can have long-lasting impact on eligibility for services, and they recommended professional education around these issues may help to solve this problem.

Both groups highlighted a clear need for additional training of home health aides around dementia and how to best interact with and care for a person living with dementia. Similarly, both groups also suggested a need for increased education about dementia in the community.

Finally, both groups highlighted a need for legal assistance around areas of establishing wills, living trusts and advance directives, and powers of attorney for health and financial matters.

Organizational caregivers also pointed out that those without primary caregivers are at increased risk of financial exploitation or physical abuse, and need help to ensure their care, safety, and finances are managed according to their wishes.

## Objective #4: Develop a guide identifying services and resources available to DC residents related to the needs of persons living with dementia and their caregivers

To fulfill Objective #4, we created and submitted to DC Health, along with this report, a stand-alone guide titled *Services and Resources for Memory Loss and Dementia Care: A Guide for the District of Columbia*. The guide identifies services and resources available in the DC community for persons with cognitive impairment or dementia and their caregivers. This information was gathered from publicly available information including online searches, handbooks and guides, and through interviews with community partners. Stakeholders interviewed in the generation of this guide include DC Lead Agencies, DC Villages, partners in DC government organizations, and community partners. For a comprehensive list of engaged stakeholders, see **Appendix F.**

This information was gathered from online searches and phone calls to service providers, existing handbooks and guides, and interviews with community partners. It is important to note that this guide was prepared during the COVID-19 pandemic, during which time service availability was fluid and evolving. Whenever possible, we confirmed accuracy of provided information directly with each resource or service provider. In situations where it was known that these services were operating prior to the onset of the pandemic in early 2020, these services were included in the guide for completeness. However ongoing service may not have been confirmed in all cases.

The guide is organized into five main sections:

*Section 1: Introduction to Resources and Services*
*Section 2: Description of Resource and Service Categories*
*Section 3: Directory of Resources and Services by Type*
*Section 4: Directory of Major Service Providers*
*Section 5: Dementia Prevention - Risk Factors for Memory Loss or Dementia*

The first section describes categories of resources that may be needed based on stage of disease, as well as resources that are available to special populations, such as Veterans and individuals who qualify for services through DC Medicaid. The second section of the guide describes categories of resources or services frequently needed to support persons living with dementia. The third section lists contact information for organizations, agencies, and businesses in DC, grouped by resource or service category. The fourth section of the guide lists several key organizations, agencies and businesses in DC that provide many of the local resources for memory or dementia care for individuals and caregivers. Core services provided by each organization are also listed. The final section of the guide provides nationally recognized resources to support individuals who may wish to reduce their risk factor burden.

Categories of resources and services included in the guide are provided in **Table 7**.

**Table 7.** Summary of resources and service categories included in the guide

| Resource/Service | Subcategories |
|---|---|
| Home-Based Services: Personal Care Aides and Companionship Services | Private Aid Agencies, Veterans Affiliated Services, Medicaid and Income-Based Services |
| Home-Based Services: Homemaker Services | DC Villages, District Organizations, Private Agencies |
| Medication Support | Bubble or Pre-packaging, Medication Delivery, Medication Administration, Medication Management, Pharmacy Services |
| Individual and Home Safety | Emergency Response Preparedness, Safety Consultations, Home Modifications, Mobility Supplies, Daily Check-In Calls, Individual Grants, Personal Safety Devices (fall alerts, video monitoring, personal trackers) |
| Food and Nutrition | Supplements, Delivery, Nutrition Counseling, Groceries |
| Transportation | Metro Access & Sponsored Transportation, Private Ride Services, Taxi Services |
| Money Management and Financial Literacy | Bill Pay and Money Management, Insurance Access, Insurance Education, Financial Literacy, Planning for Long Term Care |
| Connection to Services, Helplines, and Crisis Care | Connection and Referral, Helplines, Crisis/Problem Management |
| Advocacy, Legal Advice, and Concerns about Care | Healthcare Ombudsman Programs, Advocacy Organizations & Legal Advice |
| Advance Care Planning and Legal Preparations for Future Needs | Advance Care Planning (Health Care Power of Attorney/HCPOA and Advance Directives); Guardianship and Conservatorship, Wills, Trusts, and Estate Planning (Including Non-medical Powers of Attorney) |
| Case Management, Care Planning and Care Navigation | Care Navigation and Care Planning Services, Lead Agencies, Private Care Management Services |
| Healthcare for Homebound Older Adults and End of Life Care | Housecalls and Visiting Doctors, Hospice & Palliative Care, Services for Homebound Older Adults |
| Social Connection, Engagement, and Networking | Senior Centers, DC Villages, Social Networking and Online Community, Support Groups for Individuals with Dementia or Memory Loss, Art and Music Programs, Social Clubs |
| Community-Based Dementia Care Programs and Respite Care | Adult Day Programs, Respite Care Through DC Lead Agencies, Other Respite Care Options |
| Dementia Education and Caregiver Support | Dementia Education for Individuals, Caregivers, or the Community; Support Groups for Caregivers and Shared Support Groups; Counseling, Mental Health Services, and Bereavement Services |
| Residential Long-Term Memory Care | Assisted Living Facilities, Nursing Homes |
| Clinical Studies Finder | Clinical Studies Finder |

Please note that the guide focuses on services and resources that are designed for individuals with cognitive impairment or dementia, or are dementia inclusive. Services intended for seniors that deliver helpful or needed services for individuals with cognitive impairment or dementia may be included, even if they are not dementia-specific. For example, this guide includes legal services for developing powers of attorney and living wills. While these are not dementia-inclusive services, they are particularly important to individuals with dementia. Likewise, this guide includes several pharmacies that offer medication delivery, pre-packaged medications by date and time, pharmacy consultations, and medication administration, as these services are highly useful in dementia care, but omits pharmacies in DC that do not offer these services. In addition, this guide does not include resources that are more generally used by older adults, such as connection to food delivery or non-dementia specific mental health services.

# Conclusions, Recommendations, and Future Directions

The prevalence of dementia varies across the eight DC Wards, as a function of their demographics. Older, Black DC residents are the most likely to have dementia. As such, Wards 4, 5, and 7 have both the highest dementia prevalence and the greatest number of persons living with dementia.

There is moderate to strong evidence linking vascular risk factors, including associated lifestyle factors (smoking, physical inactivity), to cognitive decline and dementia. These risk factors are common in the adult DC population. Black DC residents are generally more likely than other DC residents to have vascular risk factors linked to cognitive decline and dementia. As such, Wards 4 through 8 generally have the highest prevalence of these risk factors. Other modifiable risk factors supported by strong to moderate evidence include severe head injury, education, depression, and heavy alcohol use.

While there are a number of services and resources available to persons living with dementia and their caregivers, challenges and unmet needs remain. Caregivers need help in identifying and accessing resources and services, have concerns about eligibility requirements, and consistently suggest value in greater access to qualified home health aides for caregiver relief and care recipient well-being. Caregivers and organizational stakeholders both identified needs for educating the community, home health aides, and first responders. Organizational stakeholders also highlighted the needs of isolated individuals living with dementia.

Within this context, we make nine recommendations based on this work:

1. *Efforts to promote brain health should focus on vascular risk factors and associated lifestyle factors (physical activity, smoking).*

   The evidence supporting a link between vascular risk factors and cognitive decline and dementia is relatively strong -- what is good for your heart is good for your brain! Vascular risk factors are also common in the DC population, and efforts to reduce the burden of vascular risk factors will have a positive impact on the overall health of DC residents, irrespective of its ultimate impact on dementia. In DC, Black residents are most likely to have vascular risk factors, be current smokers, or be physically inactive. Given this, any successful public health campaign around brain health that works to reduce vascular risk factors and improve lifestyle factors should be designed to reach Black DC residents.

2. *The District should engage in public health messaging in the community to increase dementia literacy.*

   Caregivers and organizational stakeholders agreed that greater awareness of dementia, how it presents, and how to interact with a person living with dementia are needed.

Although not confirmed by the work here, we anticipate that many misconceptions around dementia are common in the DC community. Poor dementia literacy harms persons living with dementia and their caregivers, and is likely to be a barrier to an effective brain health campaign around risk factor reduction.

3. *Caregivers for persons living with dementia should have equal ability to access a care navigator through the District who can assist with identifying, navigating, and applying for resources and services that are appropriate to the circumstances of a caregiver or care recipient, independent of income.*

   Caregivers report the process of navigating the system to identify and apply for relevant resources and services to be challenging and overly complex. While stakeholders suggested a consumer-facing website or other materials, caregivers expressed a preference for interfacing with a person who is familiar with the resources and can help cut through the complexity and provide focused advice based on individual need. Approaches relying on an internet website or app can also be difficult for the older adult population to navigate, and will be inaccessible to some.

4. *Access to qualified home health aides or other services that allow caregiver relief and increased social and physical activity for care recipients should be prioritized when considering resources and services to provide to caregivers of persons living with dementia.*

   The most crucial and consistently reported unmet need of focus group participants was the need for regular caregiving support and caregiver relief. Home health aides can provide regular caregiving support and caregiver relief, as well as social, language, and intellectual stimulation and exercise for the person living with dementia. Home health aides can also accompany care recipients to attend adult daycare and other senior center programs if the primary caregiver is unable to do so, per senior center requirements. While there may be other approaches to providing caregiver support, caregiver relief, and increased social and physical activity for the care recipient, home health aides appeared to be the most helpful to caregivers.

5. *Un-befriended and isolated older adults living with dementia should be supported by an independent agency that will advocate for their needs, ensure and facilitate guardianship, protect property, prioritize autonomy, and enable trusts to allow for asset protection.*

   In our conversations with caregivers and organizational stakeholders, it was clear that having an invested partner or advocate is beneficial to persons living with dementia. At the same time, persons living with dementia without a primary, supportive caregiver are at increased risk of neglect, as well as physical and financial abuse, and will become less able to advocate for themselves as the disease progresses. In addition, financial abuse of older adults is well recognized and individuals with cognitive impairment are at risk of being targeted.

6. *The District should develop a certificate or training program for home health aides around caring for a person living with dementia and recognize individuals or organizations who have undergone this training.*

   Both caregivers and organizational stakeholders agree that home health aides need additional training around dementia. Required training should cover several topics, including: what is dementia, care needs of persons living with dementia, best practices around interacting with and communicating with persons living with dementia, and best practices for managing behavioral and psychiatric symptoms of dementia.

7. *The District should develop a certificate or training program with dementia-specific education for first responders.*

   This training should include information about how the disease may manifest, how to best manage interpersonal interactions with a person living with dementia, and education around documentation of individuals with mental health and cognitive disorders with the understanding that this can impact access to future resource utilization.

8. *Persons living with dementia and their caregivers should have greater awareness of access to legal services around establishing wills, living trusts and advance directives, and powers of attorney for health and financial matters.*

   While focus group participants were aware of and satisfied with the legal assistance for qualifying for services, there appeared to be a need for services related establishing wills, living trusts and advance directives, and powers of attorney for health and financial matters.

9. *If the COVID-19 pandemic continues to disrupt routines and access to resources and services, efforts to help caregivers compensate for lost support, particularly loss of access to adult daycare programs, should be prioritized.*

   Many organizations and services are temporarily closed or otherwise disrupted during the pandemic. Caregivers consistently highlighted the closure of adult daycare centers as particularly difficult. The closing of adult daycares has disrupted routines, as well as care recipients' opportunities for socialization and exercise, all of which are crucial for the well-being of persons living with dementia. The lack of adult daycare availability has also placed greater burden on caregivers, most of whom have been unable to find alternative care support services. While not confirmed by this work, it is reasonable to assume that adult daycare may also allow caregivers to maintain employment, which is critical to maintaining income and avoiding premature or forced retirement.

Our work also suggests a number of future directions, building off the findings of the current needs assessment, that may be of interest to DC Health and the greater DC community:

1. A representative, community-based study of DC residents may provide insight into many areas.
    a. The prevalence of dementia in DC will likely be impacted by the COVID-19 pandemic. A representative, community-based study of dementia prevalence may be warranted, and could be leveraged to help answer a variety of other questions related to persons living with dementia and their caregivers.
    b. A large-scale, representative survey of caregivers for persons living with dementia may better capture the patterns of challenges and unmet needs across DC, and would allow investigation of geographic differences and differences across key subgroups.
    c. A community-based study may also be valuable for assessing the level of community understanding and knowledge of persons with dementia, including signs and symptoms, when to advocate for assessment with a healthcare professional, how to provide support to loved ones with dementia, and how to provide support to people caring for someone with dementia. This information would be helpful to identifying gaps in knowledge and methods to educate the community.

2. Our discussions with organizational stakeholders were informal and limited. Formal focus groups with case managers (DC Medicaid), and community social workers (lead agencies, villages) may yield additional insight into how DC residents access and use services, and what barriers to use may exist.

3. Challenges and unmet needs of caregivers related to resource and service use may differ among groups who were underrepresented in our initial focus groups (e.g., persons who are not connected to our community partners, persons without the ability to participate in a virtual focus group, persons who do not speak English or for whom an English language format would be a barrier to participation). Additional investigation targeting these groups may be warranted.

4. Other areas of potentially unmet caregiver needs remain to be explored, including psychosocial and financial needs, caregiver physical and mental well-being, caregiver employment issues, and long-term care needs.

5. In-depth exploration of the various challenges identified may be of interest. For example:

   a. Investigation of how caregivers use education/training services and sources of information (e.g. written materials, websites) may allow identification of mechanisms through which information can be delivered more effectively.
   b. Closer examination of how caregiver experience and perception of resource availability/accessibility aligns with actual resource availability/accessibility may allow identification of what is driving the gaps and how to address them.
   c. Whether insurance status (e.g. VA, Medicaid, Medicare Advantage, Traditional Medicare) influences use and access to resources and services, as well as challenges and areas of unmet need, remains unknown.

6. Medicaid provides a number of services and resources to persons living with dementia. Exploration of data on Medicaid service use may help us to better understand how current services and resources are (or are not) being used.

7. Caregivers and stakeholders both identified a need for better education and training of home health aides. Further research could better identify the needed scope of this training, and impact on the satisfaction and well-being of both caregivers and care recipients.

8. Caring for a person living with dementia is costly. Estimation and comparison of the costs of providing support services and resources (potentially including unpaid caregiver support) to facilitate in-home care versus the cost of institutionalization in DC may be valuable.

## Appendices

**Appendix A.** Methods used to estimate the prevalence of dementia in Washington, DC

**Appendix B.** Methods used to estimate the prevalence of risk factors for cognitive decline and dementia in Washington, DC

**Appendix C.** Tables summarizing the prevalence of modifiable risk factors in Washington, DC, overall and by selected subgroups

**Appendix D.** Figures summarizing the prevalence of modifiable risk factors in Washington, DC, overall and by selected subgroups

**Appendix E.** Methods used for qualitative research around challenges and unmet needs of primary, unpaid DC caregivers

**Appendix F.** Narrative summary of findings about current use of resources and services in DC by focus group participants

**Appendix G.** Stakeholders interviewed or engaged during the development of the services and resources guide

**Appendix A.** Methods used to estimate the prevalence of dementia in Washington, DC

We used a risk-assessment approach. This approach uses a logical, scientific process to generate actionable information based on available, if imperfect information. It is commonly used in other disciplines (e.g. risk assessment to understand potential impact of an environmental hazard).[14] Here we reviewed the published literature and cohort websites for reports of dementia prevalence or incidence, stratified by age, sex, and/or race-ethnicity. We then selected a subset of these reports, selected based on availability of prevalence or incidence estimates stratified by demographic characteristics, racial/ethnic diversity of the sample, and calendar period for the reported risk estimates in order to develop age-, sex-, and race/ethnicity specific dementia prevalence estimates. These stratum-specific dementia prevalence estimates were then combined with census data to estimate dementia prevalence in Washington, DC.

To begin, we used data from four samples -- the Atherosclerosis Risk in Communities (ARIC) [35] cohort study, the Chicago Health and Aging Population (CHAP)[34] cohort study, the Kaiser Permanente Northern California membership (Kaiser)[37], and a combined sample consisting of both the Rush Memory and Aging Project (MAP)[152] and Rush Minority Aging Research Study (MARS)[153] – as the basis for estimates of dementia prevalence for non-Hispanic Black and non-Hispanic white participants. These samples were used because they reported relevant statistics (i.e., dementia incidence or prevalence) in strata defined by at least 2 of our three demographic characteristics of interest (age, sex, and race/ethnicity), reported on relevant statistics in more than one racial/ethnic group, and reported on relevant statistics for relatively recent calendar years or in an urban setting. Data from ARIC, CHAP, and Kaiser were based on peer-reviewed reports. Data from MAP/MARS was obtained from RADC Research Resource Sharing Hub on June 11, 2020.[154]

As none of the samples reported dementia prevalence in the desired age-, sex- and racial categories, we needed to derive comparable statistics across each sample. ARIC did not provide estimates of dementia prevalence for persons ages 90+; we extrapolated to obtain an estimate of dementia prevalence in this age group based on the exponential increase in dementia prevalence observed across lower age groups. We then used a weighted average across smaller age groups to derive estimates for the desired, larger age categories. For Kaiser, we converted incidence estimates to prevalence estimates based on mathematical formulae and an estimate of the average duration of dementia of 7.4 years, which was based on data from CHAP. We then used a weighted average of dementia prevalence statistics in 5-year age groups to create estimates for larger, desired age categories. CHAP only provided dementia prevalence statistics by age and race. We were able to solve for age-sex-race-specific dementia prevalence in CHAP using the reported statistics, the proportion of women and men in each age-race category from census data, and an estimate of the relative dementia prevalence across women and men from the Aging, Demographics and Memory Study (ADAMS).[155] Finally, MAP/MARS did not provide dementia prevalence statistics in the desired age groups. Therefore, we extrapolated to obtain an estimate of dementia prevalence in the desired categories based on the exponential increase in dementia prevalence across reported age groups.

After completing the steps above, we had estimates of dementia prevalence within subcategories defined by age (65-74, 75-84, and 85+), gender (male and female), and two racial categories (Black, white) in all four primary samples (ARIC, CHAP, Kaiser, MAP/MARS). We averaged these estimates across the four samples to create a single set of age/sex/race-specific dementia prevalence estimates. Finally, we applied a multiplier to the age-sex dementia prevalence estimates for non-Hispanic whites to derive expected age-sex dementia prevalence estimates for Asian and Hispanic subgroups. For Asians, this multiplier was based on the ratio of dementia prevalence in Asians versus non-Hispanic whites in Kaiser data, which was the only large, recent study we could identify with estimates for both Asian and non-Hispanic white subgroups. For Hispanics, our multiplier was the average dementia prevalence ratio comparing Hispanic to non-Hispanic whites in Kaiser and in the Washington Heights and Inwood Cornell Aging Project – Phase I (WHICAP-I)[36], which include different Hispanic/Latinx subpopulations.

Finally, we combined these age-, sex-, and race/ethnicity specific dementia prevalence estimates with information on the number of persons within each age-, sex-, and race/ethnicity specific category in DC from the 2018 5-year American Communities Survey estimates for Washington, DC. This allowed us to derive estimates of dementia prevalence in DC overall, by key demographic subgroups, and by DC ward. As a proof-of-concept, we also validated this approach against existing estimates of dementia prevalence at the national level.

Our approach can produce reasonable estimates of dementia prevalence in the setting where a dementia surveillance study is infeasible due to time or resource constraints. However, our results are based on the relatively small number of studies with recent, relevant data, and the available data were not presented in a uniform way. Therefore, we were required to make additional assumptions in order to create a common set of statistics that could be used in our dementia calculator. While our approach makes use of the available data, and is rational and well-considered, our choices are not the only possible choices. We assume patterns and results from other U.S.-based samples can be generalized to Washington, DC; this assumption may be less valid for the Hispanic subgroup, given heterogeneity of risk across persons of different heritage. We also rely on the 2018 5-year ACS estimates for population information in DC, rather than 1-year estimates, given that 1-year data is not available for geographic areas as small as a ward.[156,157] Finally, given COVID-19 appears more likely to kill older adults, adults with chronic conditions, and adults of color,[16-20] the demographic data upon which our reported estimates are based may no longer reflect the current demographics DC or its wards. In the absence of evidence to the contrary, our estimates of dementia prevalence in DC should not be considered a reasonable proxy for dementia prevalence from March 2020 onwards.

**Appendix B.** Methods used to estimate the prevalence of risk factors for cognitive decline and dementia in Washington, DC

Our first task was to identify potential risk factors for cognitive decline and dementia, and to provide an assessment of the strength of the evidence. To do so, we used data from several sources. We searched and reviewed reports obtained from PubMed, the Cochrane Library, the Agency for Healthcare Research and Quality (AHRQ) database, and the AlzRisk database (alzrisk.org). We also consulted the websites of the US Centers for Disease Control (CDC), National Institutes of Health (NIH), National Institute on Aging (NIA) and the World Health Organization (WHO) to identify evidence-based summaries and trusted public health messaging around risk factors for dementia. We also reviewed public health messaging and reports from expert panels convened by advocacy groups. We then considered the strength of the evidence, based on the availability of evidence from randomized controlled trials, systematic reviews, and original studies, as well as the consensus among scientists reflected in governmental reports or public health messaging (e.g. NIH, CDC, AHRQ, WHO) and peer-reviewed consensus reports (e.g. from the *Lancet* Commission). As such, this is not a comprehensive evaluation of all risk factors examined in relation to cognitive decline and dementia. Instead, we focus on risk factors with substantial evidence linking them to cognitive decline and dementia, as well as risk factors that have been previously highlighted in public health messaging.

Our second task was to use available data to estimate the prevalence of these risk factors for dementia in Washington, DC. To do so, we used data from the Behavioral Risk Factor Surveillance System (BRFSS).[21] The goal of BRFSS is to assess health-related risk behaviors, chronic health conditions, and use of preventive services. BRFSS data is collected in all 50 states through telephone surveys among individuals ages 18 and older. We considered data from Washington, DC, and used data from the 2017 BRFSS survey because it was the most recent year of data which contained the optional module questions relevant to our task.

Our literature review evaluating the level of evidence for ADRD risk factors informed which of the available variables we included in the analysis. For vascular risk factors, participants self-reported whether they have ever received a diagnosis of diabetes, hypertension, high cholesterol, coronary heart disease, or had a stroke or heart attack. If they reported a diagnosis of hypertension or high cholesterol, they were asked if they are currently taking medicine for their condition. Participants self-reported their height and weight to determine category for body mass index (BMI). Participants also self-reported whether they had consumed fruit or vegetables at least once a day, whether they had participated in leisure time physical activity or exercise in the past month, and additional information on their physical activity used to determine whether they met the current guidelines for physical activity in adults. We created categories of alcohol consumption based on self-reported frequency of alcohol intake. Smoking status, average number of hours of sleep per night, history of depression, marital status, household size, and education level were self-reported. Unfortunately, BRFSS did not collect data on cognitive training, cognitive activities, air pollution, or head injuries. Therefore, we were unable to provide estimates of the burden of these risk factors in Washington, DC.

Although BRFSS does collect data about whether a participant is deaf or hard of hearing, we did not present this data because it does not differentiate between age-related hearing loss from other causes of deafness or hearing loss (e.g. congenital deafness).

Statistical analysis was conducted in SAS 9.4 and figures were created in R Studio, Version 1.3.959, running R, Version 4.0.1. All analyses were weighted using the provided BRFSS weights, which are designed to recover DC-representative estimates. We generated prevalence statistics for all variables in DC overall, as well as by gender, race, and ward. For vascular risk factors, there is evidence that presence of these risk factors in midlife, but not late life, increases dementia risk. Therefore, we restricted the data to participants in midlife (ages 45-64) to provide estimates of prevalence of hypertension, high cholesterol, and obesity among DC residents in this age group.

## **Appendix C.** Tables summarizing the prevalence of modifiable risk factors in Washington, DC, overall and by selected subgroups

**Appendix Table C1.** Prevalence of Vascular Risk Factors Among Adult DC Residents in 2017 by Demographic Characteristics

| **Risk factor** | **Overall** | **Gender** | | **Race/ethnicity** | | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **NH white** | **NH Black** | **Hispanic** | **Other** |
| *Diabetes* | | | | | | | |
| Diabetic | 7% | 7% | 8% | 4% | 13% | 2% | 4% |
| Pre-/borderline diabetic | 2% | 1% | 2% | 0% | 3% | 2% | 2% |
| Not diabetic | 91% | 92% | 90% | 96% | 84% | 96% | 94% |
| *Hypertension* | | | | | | | |
| Hypertensive | 26% | 27% | 26% | 17% | 41% | 11% | 17% |
| Among hypertensives, taking medication | 74% | 69% | 79% | 66% | 81% | 54% | 56% |
| Pre-/Borderline hypertensive | 2% | 2% | 2% | 1% | 2% | 5% | 2% |
| Not hypertensive | 72% | 72% | 72% | 82% | 57% | 85% | 81% |
| *Cholesterol* | | | | | | | |
| Has high cholesterol | 23% | 24% | 23% | 24% | 27% | 14% | 16% |
| Among those with high cholesterol, taking medication | 49% | 52% | 47% | 48% | 55% | 19% | 41% |
| Does not have high cholesterol | 67% | 65% | 69% | 68% | 63% | 74% | 73% |
| DK/RF/M | 10% | 11% | 9% | 9% | 10% | 13% | 11% |
| *Smoking Status* | | | | | | | |
| Never | 65% | 59% | 70% | 68% | 60% | 73% | 71% |
| Former smoker | 18% | 20% | 16% | 23% | 15% | 14% | 11% |
| Current smoker | 14% | 17% | 11% | 7% | 22% | 11% | 13% |
| DK/RF/M | 3% | 4% | 3% | 3% | 3% | 3% | 5% |
| *Body Mass Index Categories* | | | | | | | |
| Underweight | 2% | 2% | 3% | 3% | 2% | 0% | 4% |
| Normal weight | 44% | 40% | 47% | 55% | 30% | 46% | 58% |
| Overweight | 31% | 40% | 23% | 30% | 32% | 35% | 27% |
| Obese | 23% | 19% | 27% | 12% | 36% | 19% | 12% |
| *Cardiovascular disease* | | | | | | | |
| History of heart attack | 3% | 3% | 2% | 2% | 4% | 0% | 3% |
| History of stroke | 3% | 3% | 3% | 1% | 6% | 2% | 2% |
| Angina or coronary heart disease | 2% | 2% | 2% | 2% | 3% | 0% | 1% |

Abbreviations: NH = non-Hispanic; DK = don’t know; RF = refused; M = missing
Percentages may not add to 100% due to rounding.
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C2.** Prevalence of Vascular Risk Factors Among Adult DC Residents in 2017 by DC Ward

| **Risk factor** | **Overall** | **Ward** | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |
| *Diabetes* | | | | | | | | | |
| Diabetic | 7% | 10% | 5% | 5% | 7% | 11% | 8% | 10% | 13% |
| Pre-/borderline diabetic | 2% | 4% | 0% | 1% | 1% | 1% | 1% | 3% | 3% |
| Not diabetic | 91% | 86% | 95% | 94% | 92% | 88% | 92% | 86% | 84% |
| *Hypertension* | | | | | | | | | |
| Hypertensive | 26% | 23% | 19% | 27% | 28% | 34% | 31% | 36% | 37% |
| Among hypertensives, taking medication | 74% | 67% | 87% | 79% | 69% | 76% | 80% | 83% | 78% |
| Pre-/Borderline hypertensive | 2% | 4% | 0% | 2% | 1% | 1% | 5% | 2% | 1% |
| Not hypertensive | 72% | 74% | 80% | 71% | 71% | 65% | 63% | 61% | 62% |
| *Cholesterol* | | | | | | | | | |
| Has high cholesterol | 23% | 30% | 25% | 35% | 22% | 24% | 31% | 24% | 24% |
| Among those with high cholesterol, taking medication | 49% | 39% | 59% | 58% | 59% | 53% | 40% | 51% | 52% |
| Does not have high cholesterol | 67% | 65% | 66% | 59% | 68% | 67% | 63% | 67% | 69% |
| DK/RF/M | 10% | 5% | 9% | 6% | 10% | 9% | 6% | 9% | 7% |
| *Smoking Status* | | | | | | | | | |
| Never | 65% | 60% | 67% | 67% | 69% | 64% | 67% | 61% | 60% |
| Former smoker | 18% | 25% | 21% | 27% | 18% | 16% | 20% | 16% | 14% |
| Current smoker | 14% | 11% | 10% | 5% | 11% | 16% | 11% | 20% | 24% |
| DK/RF/M | 3% | 4% | 2% | 2% | 2% | 4% | 3% | 3% | 3% |
| *Body Mass Index Categories* | | | | | | | | | |
| Underweight | 2% | 2% | 3% | 2% | 2% | 1% | 3% | 1% | 2% |
| Normal weight | 44% | 48% | 55% | 53% | 44% | 47% | 41% | 28% | 25% |
| Overweight | 31% | 24% | 32% | 32% | 31% | 31% | 35% | 32% | 27% |
| Obese | 23% | 26% | 10% | 14% | 23% | 22% | 22% | 39% | 47% |
| *Cardiovascular disease* | | | | | | | | | |
| History of heart attack | 3% | 2% | 3% | 2% | 2% | 3% | 2% | 3% | 5% |
| History of stroke | 3% | 3% | 2% | 1% | 4% | 3% | 3% | 6% | 5% |
| Angina or coronary heart disease | 2% | 1% | 4% | 2% | 1% | 3% | 1% | 3% | 3% |

Abbreviations: DK = don’t know; RF = refused; M = missing

Percentages may not add to 100% due to rounding.

Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C3.** Prevalence of Vascular Risk Factors Among Adult DC Residents in Midlife (Ages 45-65) in 2017 by Demographic Characteristics

| **Risk factor** | **Overall** | **Gender** | | **Race/ethnicity** | | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **NH white** | **NH Black** | **Hispanic** | **Other** |
| *Hypertension* | | | | | | | |
| Hypertensive | 39% | 37% | 41% | 23% | 52% | 32% | 37% |
| Among hypertensives, taking medication | 80% | 78% | 82% | 71% | 84% | 82% | 66% |
| Pre-/Borderline hypertensive | 2% | 2% | 2% | 1% | 3% | 3% | 5% |
| Not hypertensive | 59% | 61% | 57% | 76% | 46% | 64% | 58% |
| *Cholesterol* | | | | | | | |
| Has high cholesterol | 32% | 33% | 31% | 30% | 35% | 23% | 22% |
| Among those with high cholesterol, taking medication | 56% | 58% | 54% | 52% | 59% | 59% | 71% |
| Does not have high cholesterol | 64% | 63% | 66% | 69% | 59% | 74% | 77% |
| DK/RF/M | 4% | 4% | 4% | 2% | 5% | 3% | 1% |
| *Body Mass Index Categories* | | | | | | | |
| Underweight | 2% | 1% | 2% | 2% | 2% | 3% | 1% |
| Normal weight | 34% | 29% | 39% | 49% | 23% | 32% | 39% |
| Overweight | 34% | 43% | 25% | 33% | 34% | 45% | 31% |
| Obese | 30% | 26% | 34% | 16% | 42% | 20% | 29% |

Abbreviations: NH = non-Hispanic; DK = don't know; RF = refused; M = missing
Percentages may not add to 100% due to rounding.
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C4.** Prevalence of Vascular Risk Factors Among Adult DC Residents in Midlife (Ages 45-65) in 2017 by DC Ward

| **Risk factor** | **Overall** | **Ward** | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |
| *Hypertension* | | | | | | | | | |
| Hypertensive | 39% | 24% | 25% | 26% | 35% | 48% | 46% | 49% | 48% |
| Among hypertensives, taking medication | 80% | 70% | 79% | 77% | 83% | 80% | 76% | 87% | 82% |
| Pre-/Borderline hypertensive | 2% | 6% | 1% | 3% | 2% | 2% | 1% | 3% | 1% |
| Not hypertensive | 59% | 70% | 74% | 71% | 63% | 51% | 53% | 47% | 51% |
| *Cholesterol* | | | | | | | | | |
| Has high cholesterol | 32% | 29% | 26% | 29% | 28% | 32% | 38% | 33% | 35% |
| Among those with high cholesterol, taking medication | 56% | 49% | 57% | 52% | 62% | 58% | 36% | 60% | 60% |
| Does not have high cholesterol | 64% | 69% | 73% | 67% | 68% | 64% | 59% | 63% | 63% |
| DK/RF/M | 4% | 2% | 1% | 4% | 3% | 4% | 3% | 4% | 2% |
| *Body Mass Index Categories* | | | | | | | | | |
| Underweight | 2% | 3% | 3% | 1% | 2% | 0% | 0% | 0% | 3% |
| Normal weight | 34% | 40% | 51% | 50% | 35% | 33% | 33% | 26% | 18% |
| Overweight | 34% | 29% | 30% | 38% | 34% | 31% | 33% | 37% | 35% |
| Obese | 30% | 28% | 18% | 11% | 30% | 36% | 34% | 37% | 45% |

Abbreviations: DK = don’t know; RF = refused; M = missing

Percentages may not add to 100% due to rounding.

Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C5.** Prevalence of Lifestyle Risk Factors Among Adult DC Residents in 2017 by Demographic Characteristics

| **Risk factor** | **Overall** | **Gender** | | **Race/ethnicity** | | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **NH white** | **NH Black** | **Hispanic** | **Other** |
| *Leisure time physical activity or exercise* | | | | | | | |
| Any in past 30 days | 73% | 75% | 72% | 86% | 64% | 61% | 73% |
| None in past 30 days | 23% | 21% | 25% | 12% | 33% | 35% | 21% |
| DK/RF/M | 4% | 4% | 3% | 2% | 4% | 4% | 6% |
| *Met recommendations for aerobic physical activity* | | | | | | | |
| 150+ minutes (or equivalent) of physical activity | 49% | 51% | 47% | 62% | 40% | 40% | 45% |
| 0-149 minutes (or equivalent) of physical activity | 43% | 41% | 45% | 33% | 50% | 55% | 46% |
| DK/RF/M | 8% | 8% | 8% | 5% | 10% | 5% | 9% |
| *Daily fruit consumption* | | | | | | | |
| 1+ times/day | 62% | 59% | 65% | 70% | 55% | 58% | 68% |
| <1 times/day | 28% | 30% | 27% | 25% | 32% | 32% | 21% |
| DK/RF/M | 10% | 11% | 8% | 5% | 13% | 10% | 11% |
| *Daily vegetable consumption* | | | | | | | |
| 1+ times/day | 77% | 75% | 78% | 87% | 67% | 74% | 80% |
| <1 times/day | 11% | 11% | 11% | 6% | 15% | 14% | 8% |
| DK/RF/M | 13% | 14% | 11% | 8% | 17% | 12% | 13% |
| *Alcohol use Status* | | | | | | | |
| Never | 30% | 25% | 34% | 13% | 45% | 31% | 34% |
| Occasional use | 58% | 63% | 53% | 71% | 45% | 56% | 60% |
| Heavy use | 9% | 8% | 10% | 14% | 6% | 6% | 4% |
| DK/RF/M | 4% | 4% | 3% | 2% | 5% | 7% | 3% |
| *Sleep* | | | | | | | |
| Sleeps <7 hours/day | 28% | 29% | 27% | 18% | 38% | 30% | 24% |
| Sleeps 7-9 hours/day | 54% | 53% | 54% | 63% | 46% | 53% | 51% |
| Sleeps >9 hours/day | 2% | 2% | 2% | 1% | 4% | 1% | 2% |
| DK/RF/M | 16% | 15% | 16% | 19% | 12% | 15% | 23% |

Abbreviations: NH = non-Hispanic; DK = don’t know; RF = refused; M = missing
Percentages may not add to 100% due to rounding.
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C6.** Prevalence of Lifestyle Risk Factors Among Adult DC Residents in 2017 by Ward

| **Risk factor** | **Overall** | **Ward** | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |
| *Leisure time physical activity or exercise* | | | | | | | | | |
| Any in past 30 days | 73% | 77% | 82% | 85% | 70% | 66% | 76% | 65% | 61% |
| None in past 30 days | 23% | 20% | 16% | 13% | 26% | 31% | 22% | 30% | 36% |
| DK/RF/M | 4% | 3% | 2% | 3% | 4% | 3% | 2% | 5% | 3% |
| *Met recommendations for aerobic physical activity* | | | | | | | | | |
| 150+ minutes (or equivalent) of physical activity | 49% | 55% | 58% | 59% | 48% | 43% | 55% | 42% | 38% |
| 0-149 minutes (or equivalent) of physical activity | 43% | 38% | 36% | 35% | 44% | 51% | 39% | 45% | 52% |
| DK/RF/M | 8% | 7% | 6% | 6% | 8% | 6% | 6% | 12% | 10% |
| *Daily fruit consumption* | | | | | | | | | |
| 1+ times/day | 62% | 71% | 60% | 75% | 66% | 58% | 66% | 56% | 57% |
| <1 times/day | 28% | 19% | 34% | 22% | 27% | 29% | 28% | 30% | 33% |
| DK/RF/M | 10% | 11% | 6% | 3% | 8% | 13% | 6% | 14% | 10% |
| *Daily vegetable consumption* | | | | | | | | | |
| 1+ times/day | 77% | 78% | 75% | 85% | 79% | 77% | 81% | 69% | 71% |
| <1 times/day | 11% | 10% | 12% | 7% | 10% | 11% | 8% | 14% | 15% |
| DK/RF/M | 13% | 12% | 13% | 8% | 12% | 12% | 11% | 17% | 14% |
| *Alcohol use* | | | | | | | | | |
| Never | 30% | 24% | 19% | 16% | 31% | 33% | 29% | 37% | 46% |
| Occasional use | 58% | 59% | 67% | 69% | 62% | 56% | 60% | 53% | 44% |
| Heavy use | 9% | 15% | 12% | 11% | 5% | 9% | 8% | 4% | 6% |
| DK/RF/M | 4% | 3% | 3% | 5% | 3% | 3% | 4% | 6% | 5% |
| *Sleep* | | | | | | | | | |
| Sleeps <7 hours/day | 28% | 30% | 26% | 24% | 31% | 31% | 31% | 35% | 38% |
| Sleeps 7-9 hours/day | 54% | 61% | 68% | 70% | 56% | 61% | 58% | 51% | 50% |
| Sleeps >9 hours/day | 2% | 1% | 2% | 1% | 3% | 2% | 3% | 4% | 4% |
| DK/RF/M | 16% | 8% | 3% | 5% | 10% | 5% | 8% | 11% | 9% |

Abbreviations: DK = don’t know; RF = refused; M = missing
Percentages may not add to 100% due to rounding.
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C7.** Prevalence of Psychosocial and Other Risk Factors Among Adult DC Residents in 2017 by Demographic Characteristics

| **Risk factor** | **Overall** | **Gender** | | **Race/ethnicity** | | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **NH white** | **NH Black** | **Hispanic** | **Other** |
| *Education* | | | | | | | |
| Less than high school | 10% | 10% | 10% | 2% | 17% | 17% | 5% |
| High school | 18% | 20% | 17% | 4% | 32% | 23% | 14% |
| Some college/technical school | 19% | 18% | 20% | 10% | 28% | 19% | 19% |
| College/technical or greater | 52% | 52% | 52% | 84% | 23% | 41% | 61% |
| *Marital status* | | | | | | | |
| Married | 30% | 30% | 29% | 43% | 19% | 25% | 25% |
| Member of unmarried couple | 7% | 8% | 6% | 10% | 4% | 8% | 5% |
| Divorced or separated | 12% | 12% | 12% | 8% | 17% | 12% | 8% |
| Widowed | 4% | 2% | 6% | 2% | 7% | 1% | 3% |
| Never married | 46% | 47% | 45% | 37% | 52% | 52% | 59% |
| DK/RF/M | 2% | 2% | 2% | 0% | 2% | 2% | 2% |
| *Household size* | | | | | | | |
| Lives alone | 30% | 32% | 29% | 30% | 32% | 19% | 36% |
| Lives with one other person | 29% | 30% | 28% | 37% | 24% | 22% | 29% |
| Lives with 2-4 other people | 33% | 31% | 34% | 28% | 37% | 43% | 25% |
| Lives with 5+ other people | 5% | 4% | 6% | 2% | 6% | 11% | 5% |
| DK/RF/M | 3% | 3% | 3% | 4% | 1% | 5% | 5% |
| *Depression* | | | | | | | |
| History of Depression | 14% | 12% | 16% | 16% | 14% | 9% | 15% |

Abbreviations: NH = non-Hispanic; DK = don't know; RF = refused; M = missing
Percentages may not add to 100% due to rounding.
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix Table C8.** Prevalence of Psychosocial and Other Risk Factors Among Adult DC Residents in 2017 by Ward

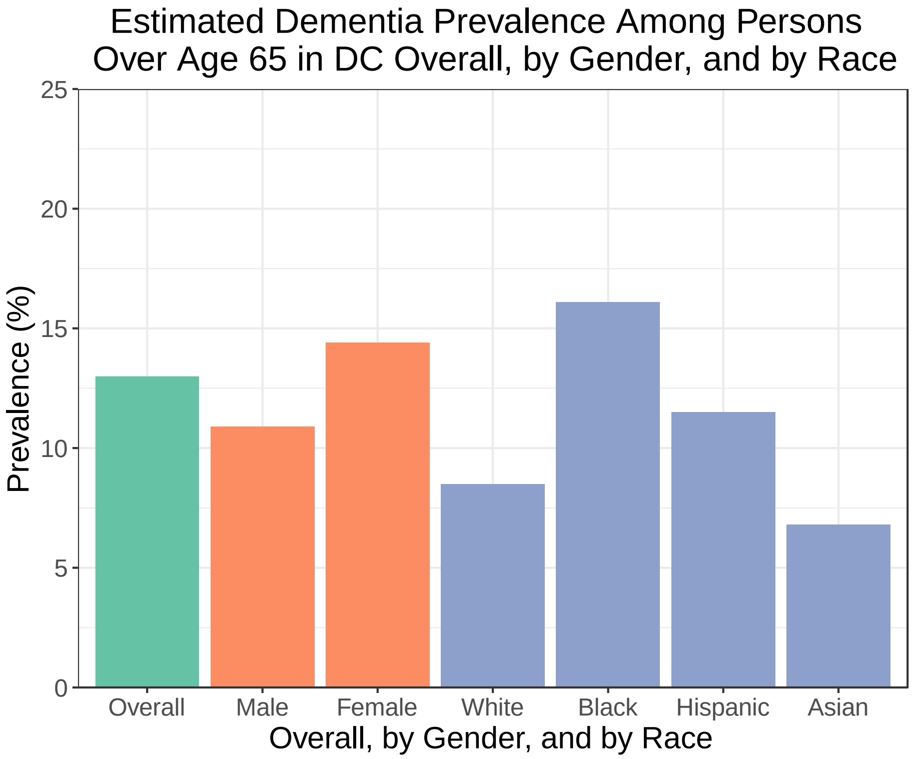
| **Risk factor** | **Overall** | **Ward** | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |
| *Education* | | | | | | | | | |
| Less than high school | 10% | 4% | 6% | 4% | 8% | 15% | 11% | 17% | 20% |
| High school graduate | 18% | 12% | 6% | 5% | 19% | 18% | 13% | 31% | 37% |
| Some college/technical school | 19% | 12% | 10% | 7% | 28% | 25% | 15% | 30% | 27% |
| College/technical graduate or greater | 52% | 73% | 79% | 85% | 46% | 42% | 61% | 23% | 16% |
| *Marital status* | | | | | | | | | |
| Married | 30% | 38% | 33% | 53% | 36% | 31% | 39% | 20% | 17% |
| Member of unmarried couple | 7% | 10% | 11% | 9% | 3% | 7% | 6% | 2% | 4% |
| Divorced or separated | 12% | 10% | 11% | 11% | 13% | 15% | 13% | 16% | 17% |
| Widowed | 4% | 4% | 3% | 4% | 5% | 5% | 4% | 6% | 6% |
| Never married | 46% | 37% | 39% | 22% | 42% | 41% | 37% | 54% | 53% |
| DK/RF/M | 2% | 1% | 3% | 0% | 1% | 1% | 1% | 1% | 3% |
| *Household size* | | | | | | | | | |
| Lives alone | 30% | 37% | 45% | 32% | 24% | 26% | 32% | 23% | 29% |
| Lives with one other person | 29% | 32% | 38% | 36% | 25% | 33% | 32% | 24% | 22% |
| Lives with 2-4 other people | 33% | 28% | 16% | 30% | 39% | 34% | 32% | 44% | 40% |
| Lives with 5+ other people | 5% | 4% | 2% | 2% | 8% | 7% | 3% | 7% | 7% |
| DK/RF/M | 3% | 0% | 0% | 1% | 4% | 1% | 1% | 2% | 2% |
| *Depression* | | | | | | | | | |
| History of depression | 14% | 17% | 15% | 16% | 10% | 13% | 14% | 14% | 13% |

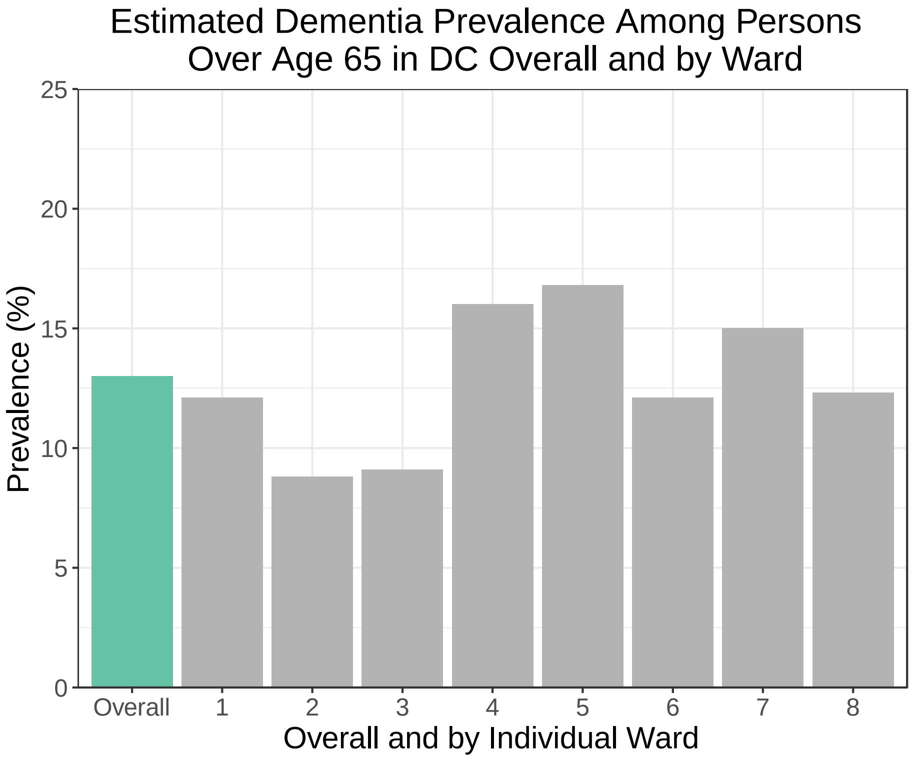
Abbreviations: DK = don’t know; RF = refused; M = missing

Percentages may not add to 100% due to rounding.

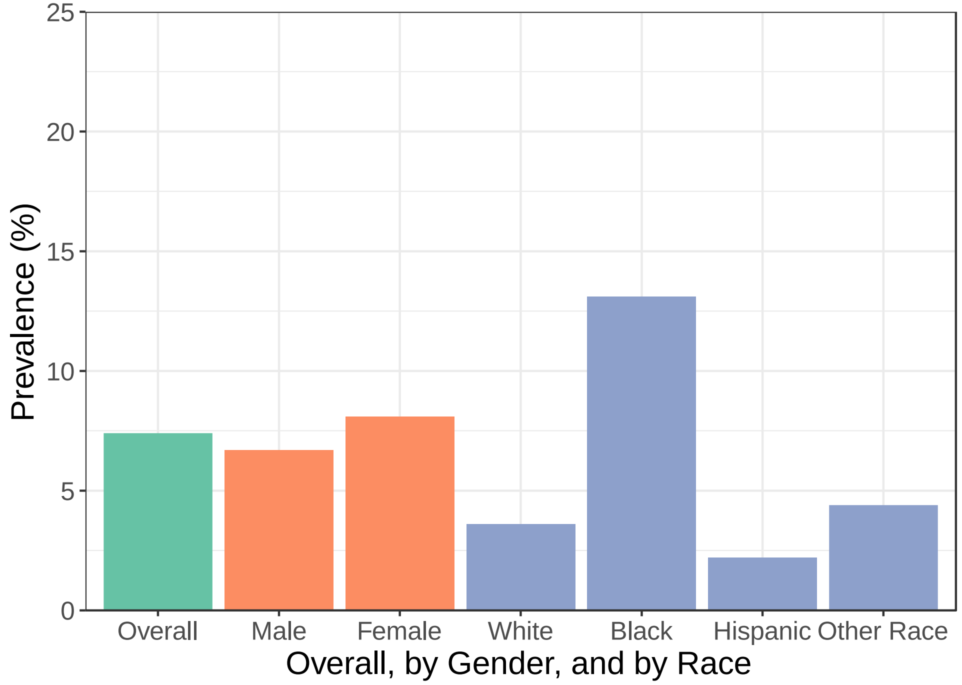
Data Source: Behavioral Risk Factor Surveillance System Survey (BRFSS), 2017. All estimates incorporate sampling weights to recover DC-representative estimates.

**Appendix D.** Figures summarizing the prevalence of modifiable risk factors in Washington, DC, overall and by selected subgroups



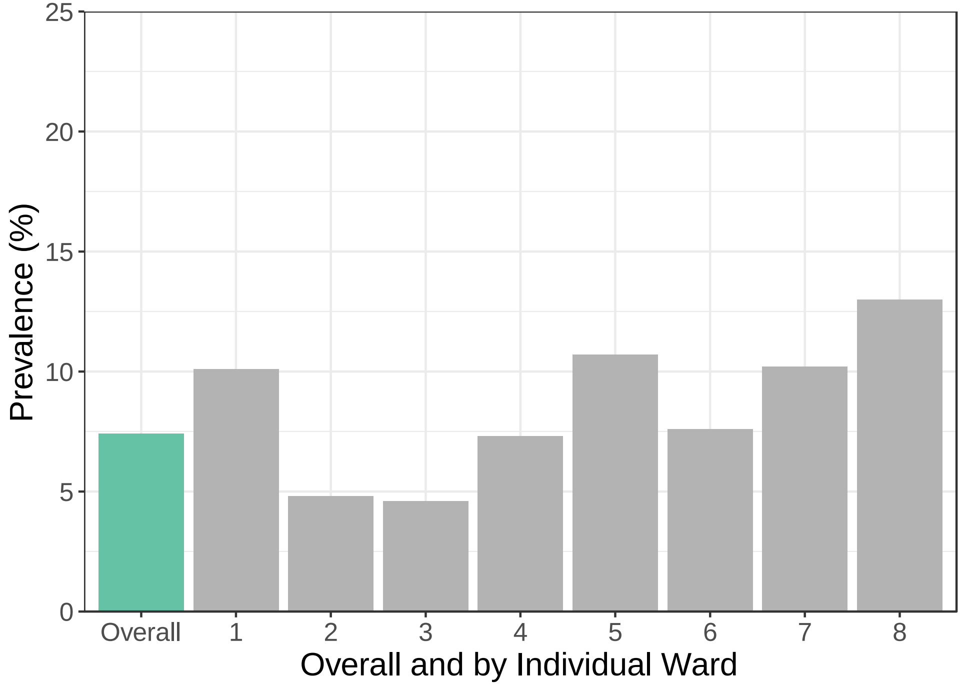


Prevalence of Diabetes Among Adult
DC Residents Overall, by Gender, and by Race

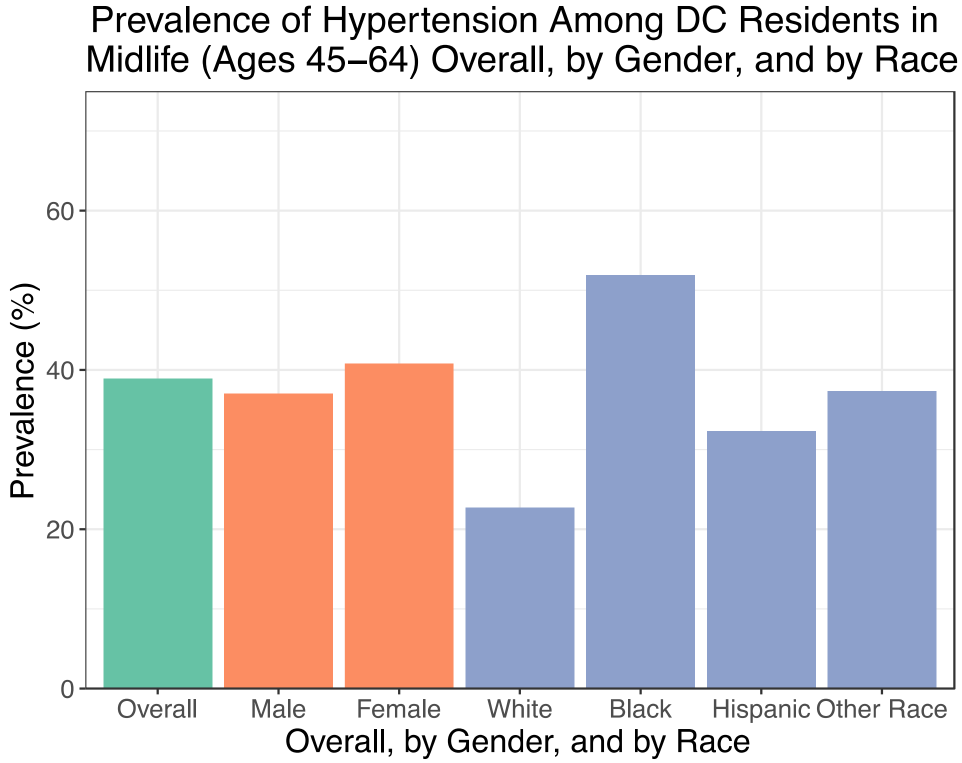


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

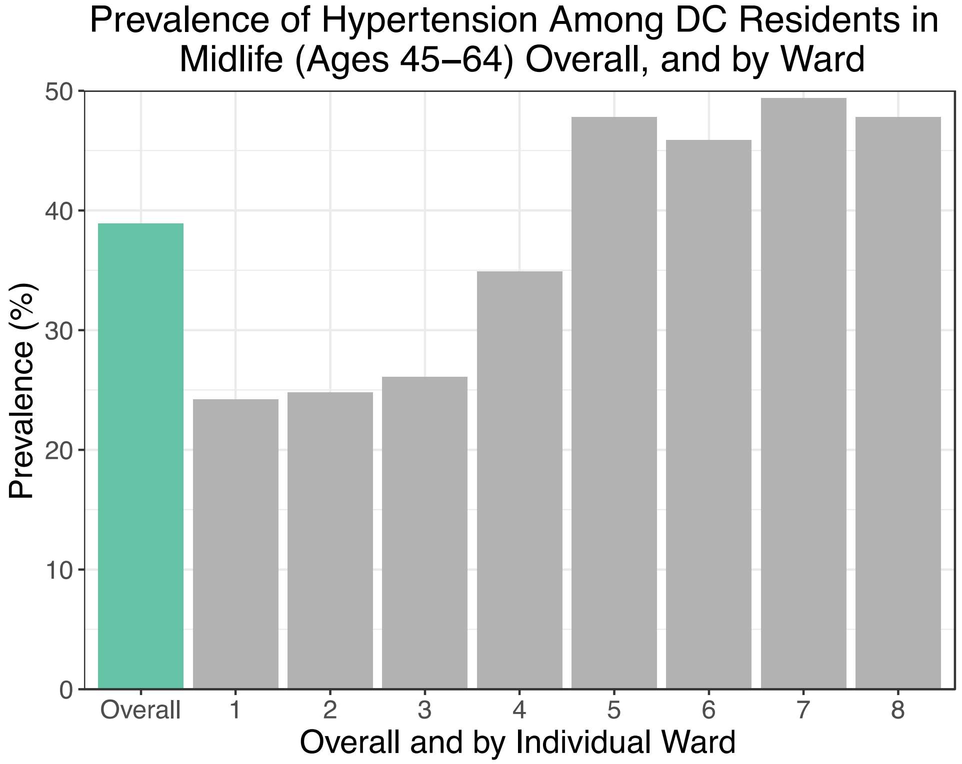
Prevalence of Diabetes Among Adult
DC Residents Overall and by Ward



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

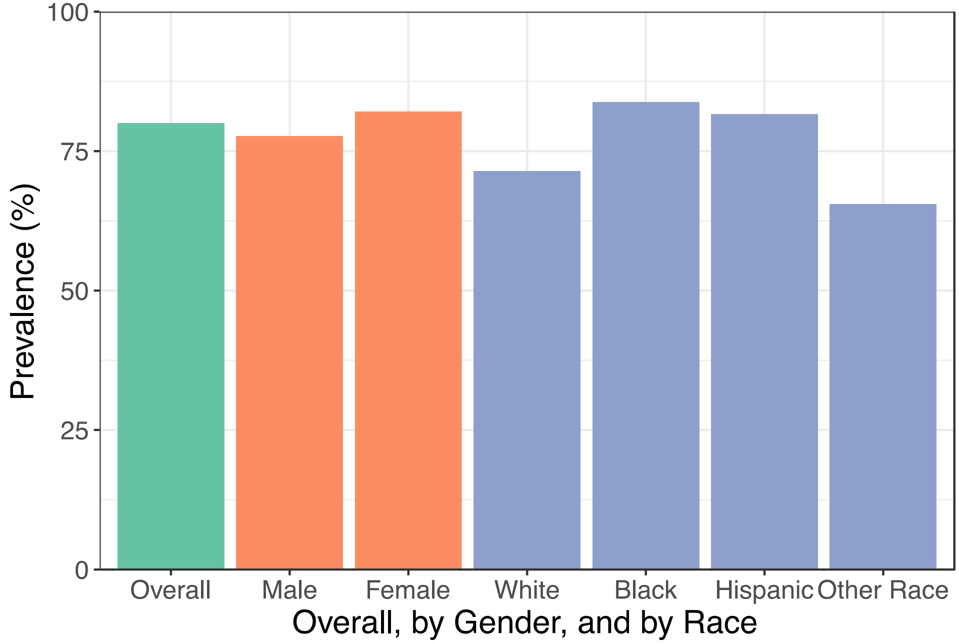


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



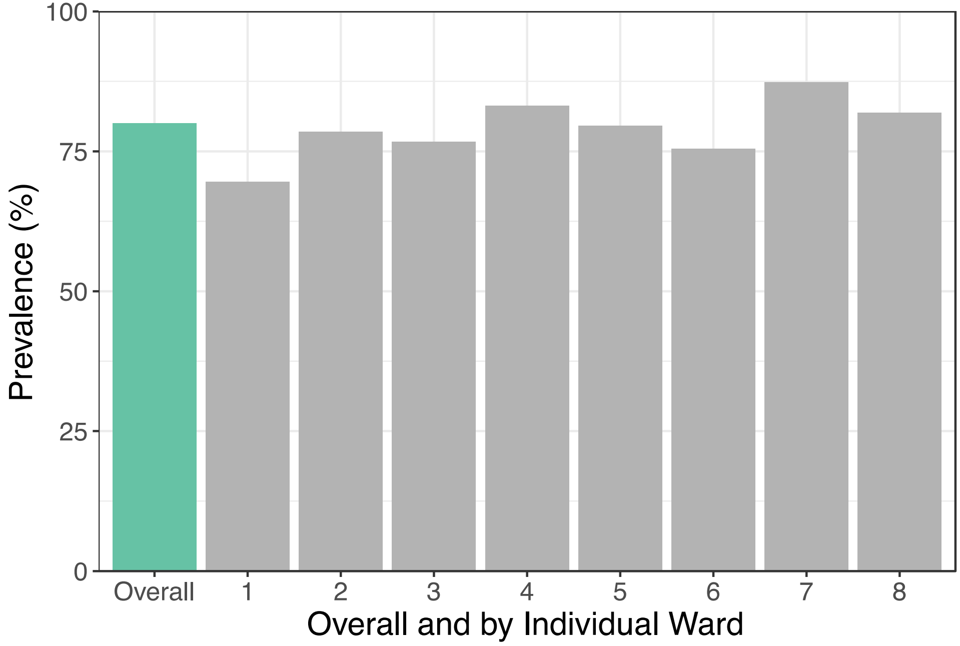
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Antihypertensive Medication Use Among Adult DC Residents with Hypertension in Midlife (Ages 45–64) Overall, by Gender, and by Race

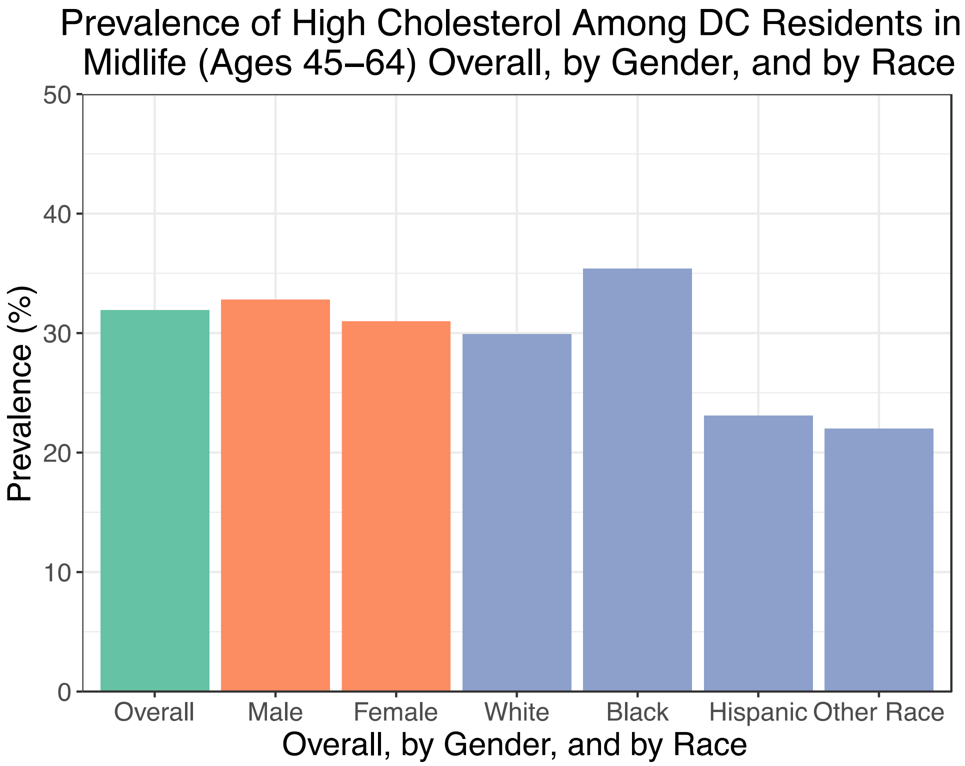


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Antihypertensive Medication Use Among Adult DC Residents with Hypertension in Midlife (Ages 45–64) Overall and by Ward

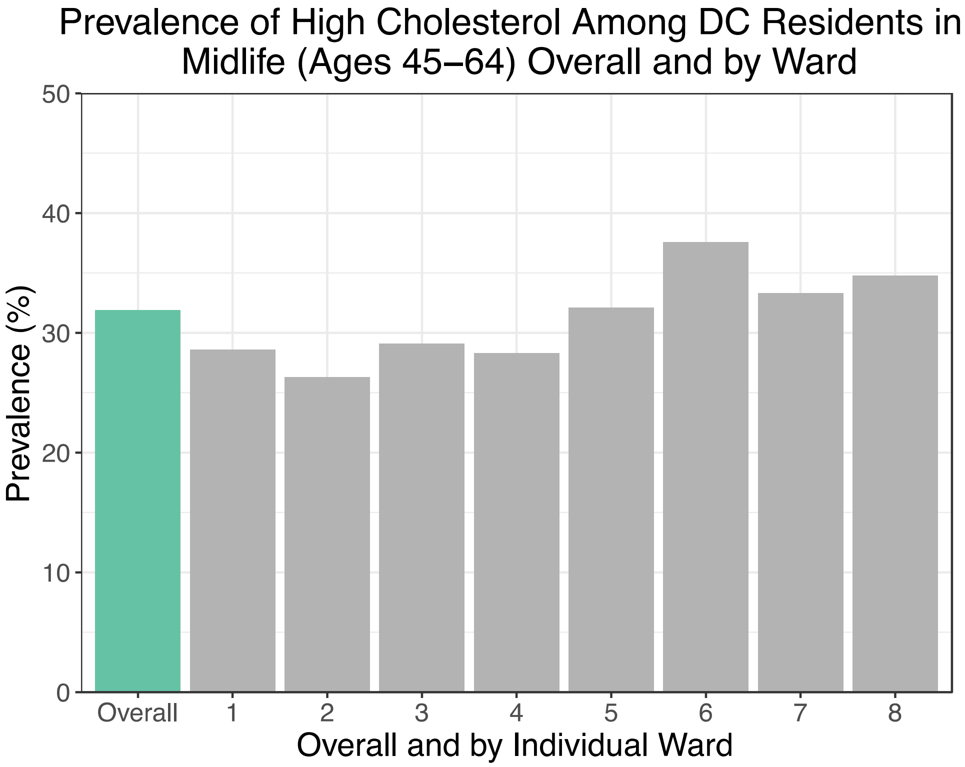


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Prevalence of High Cholesterol Among DC Residents in Midlife (Ages 45–64) Overall, by Gender, and by Race

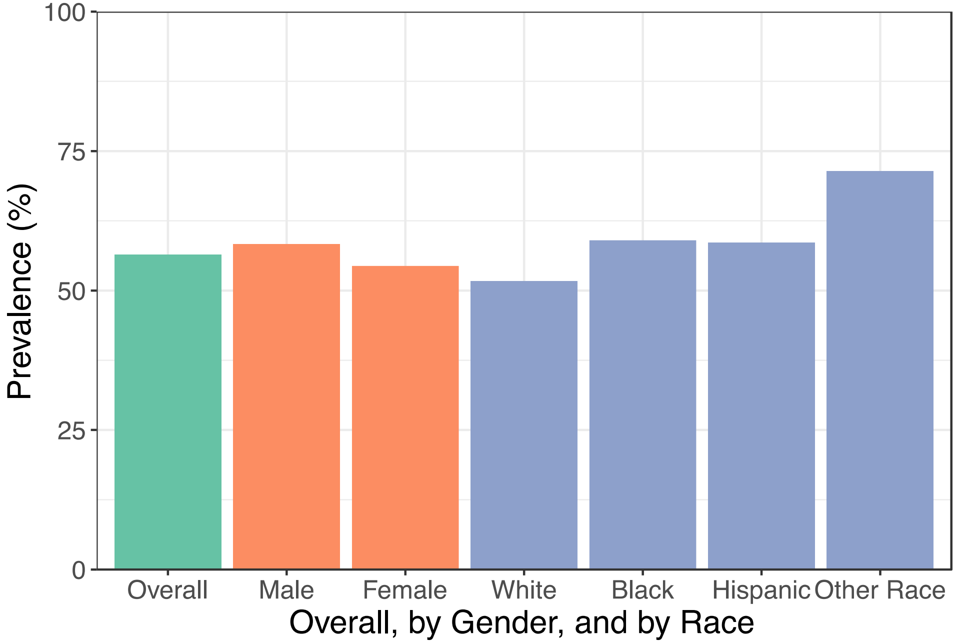
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Prevalence of High Cholesterol Among DC Residents in Midlife (Ages 45–64) Overall and by Ward

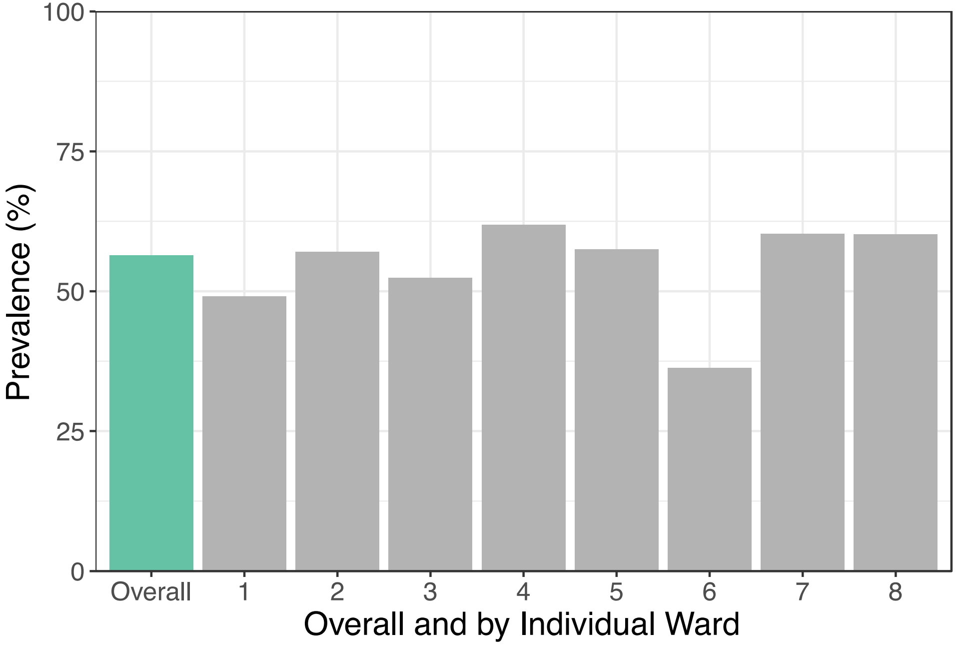
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Medication Use Among Adult DC Residents with
High Cholesterol in Midlife (Ages 45–64)
Overall, by Gender, and by Race



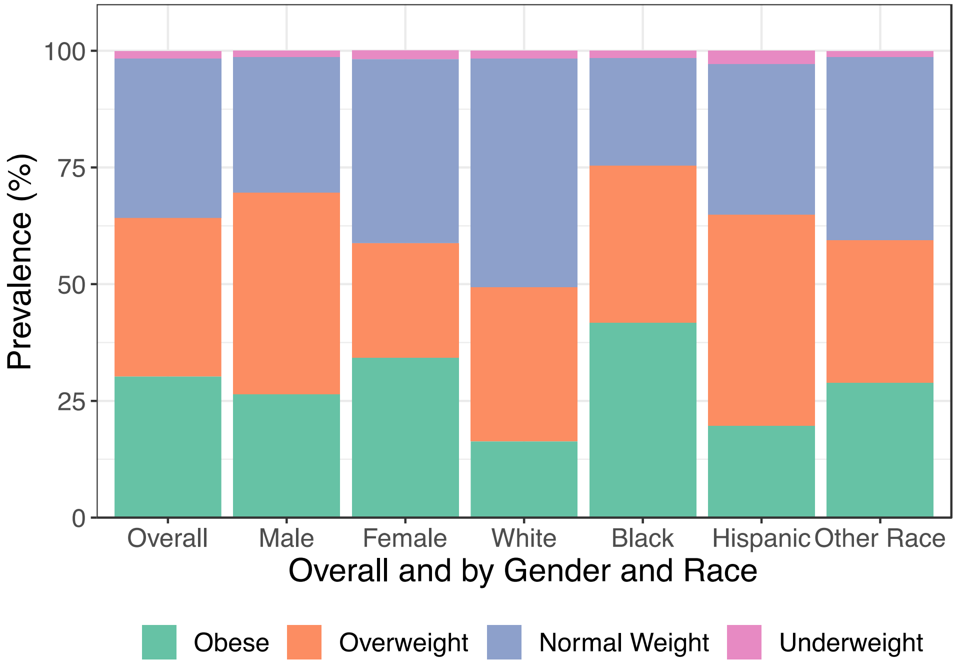
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Medication Use Among Adult DC Residents with
High Cholesterol in Midlife (Ages 45–64)
Overall and by Ward



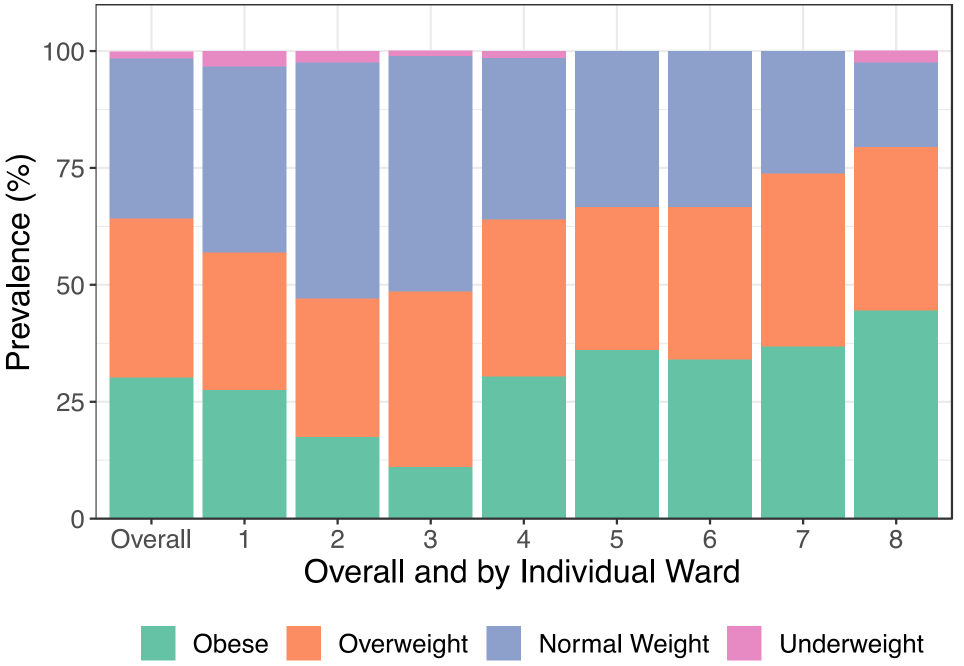
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Body Mass Index Categories Among DC Residents in Midlife (Ages 45–64) Overall, by Gender, and by Race

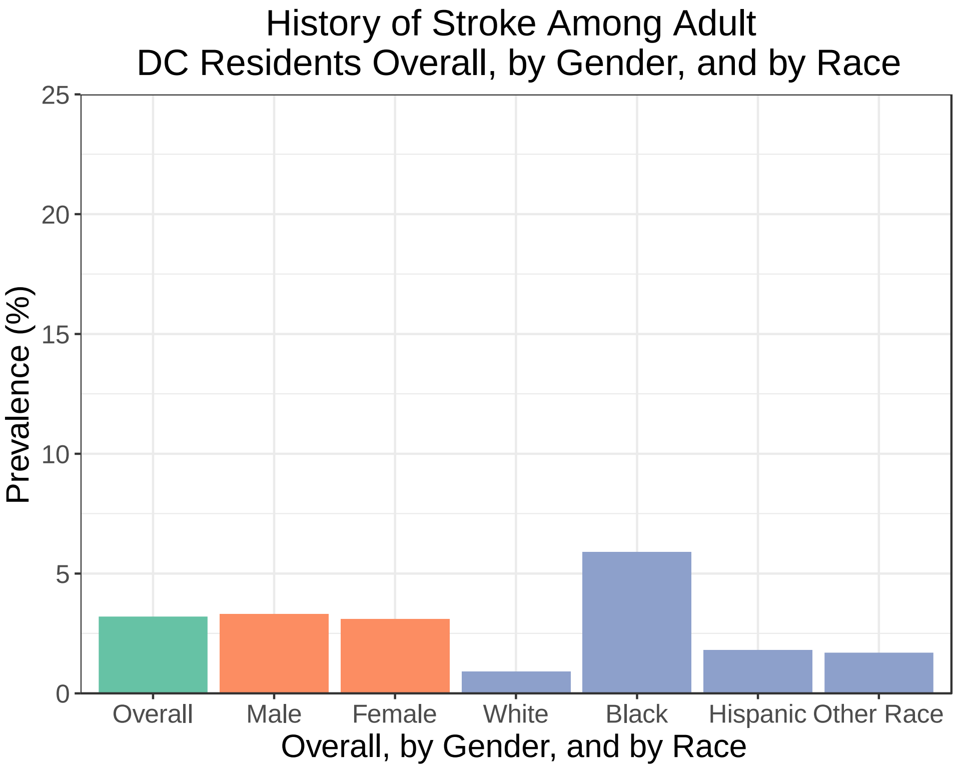


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

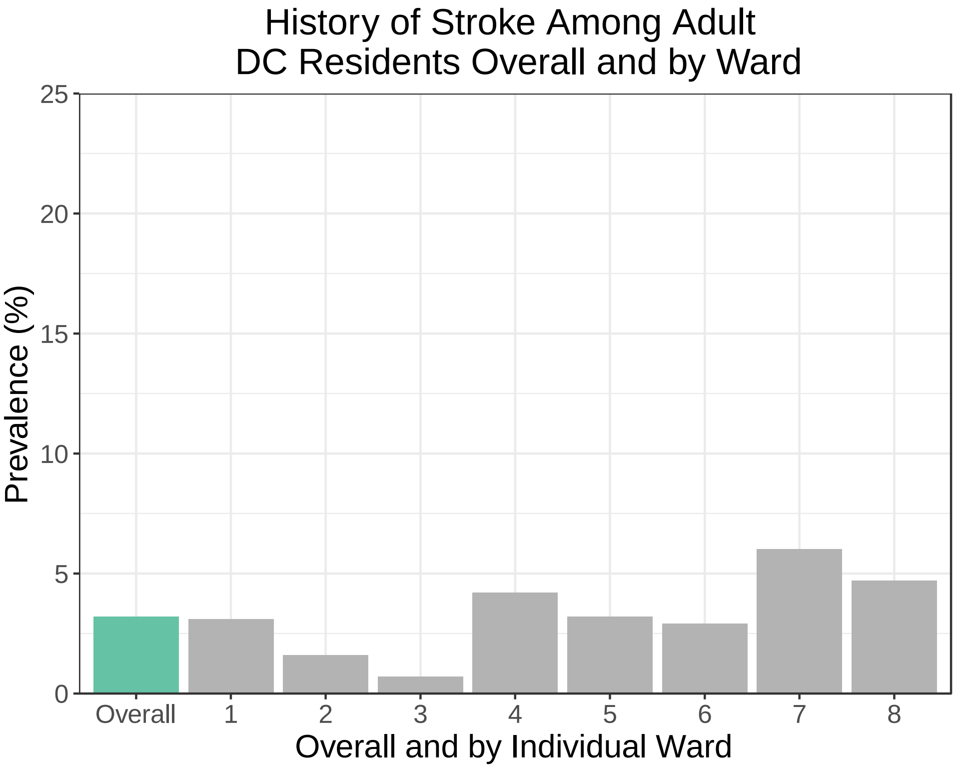
Body Mass Index Categories Among DC Residents in Midlife (Ages 45–64) Overall and by Ward



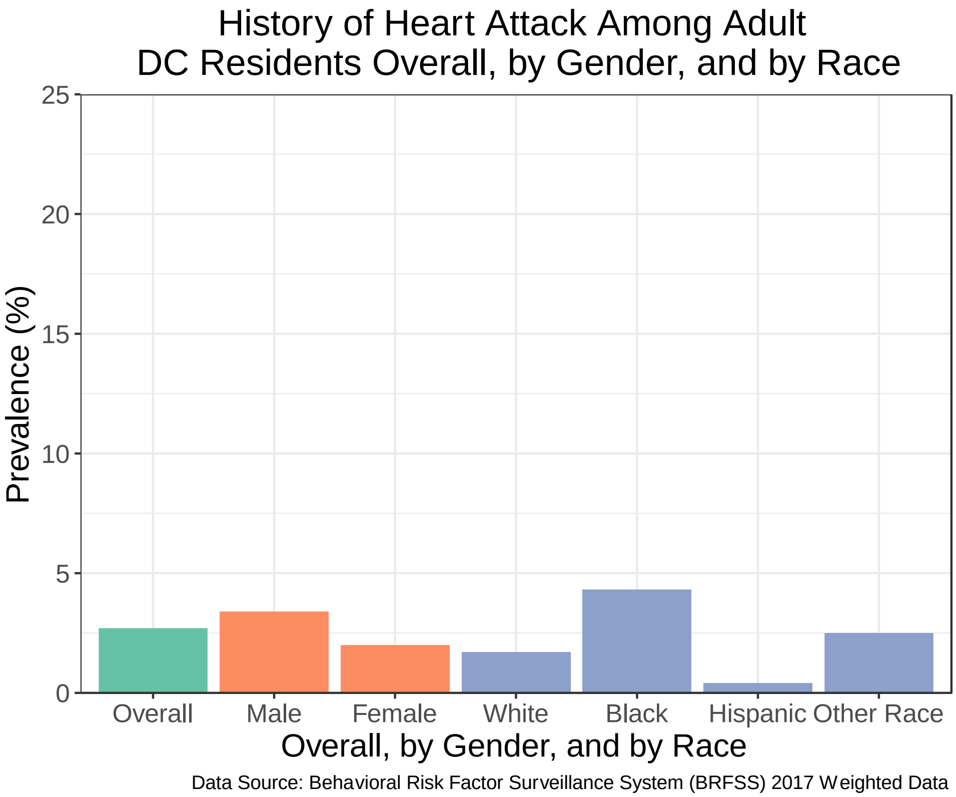
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

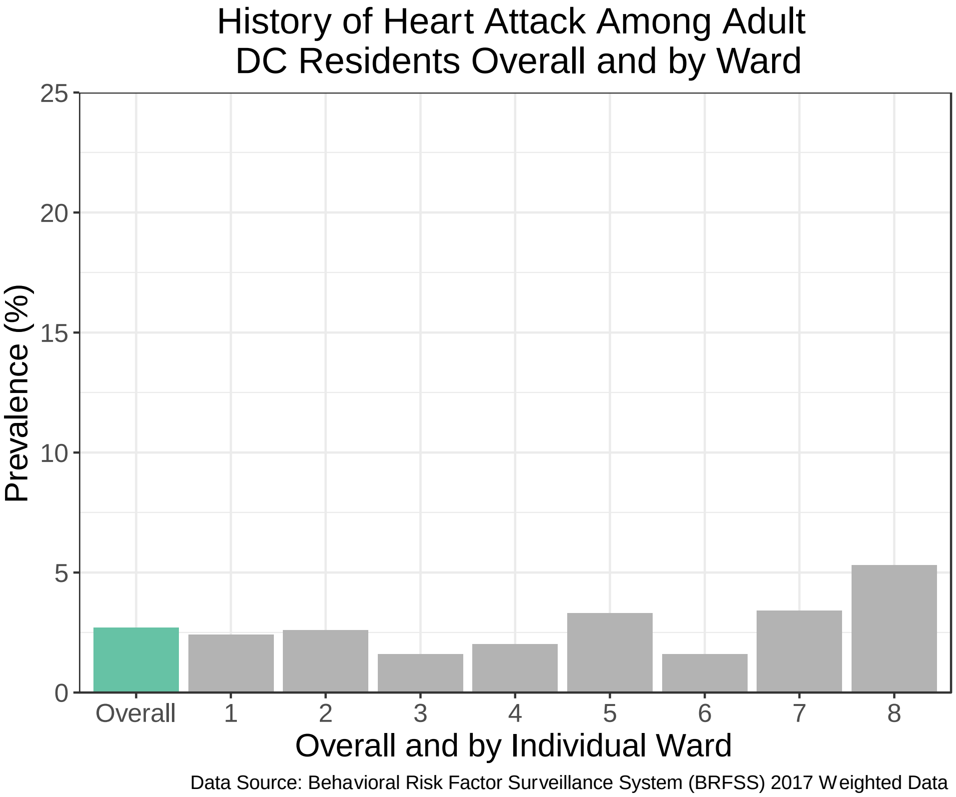


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

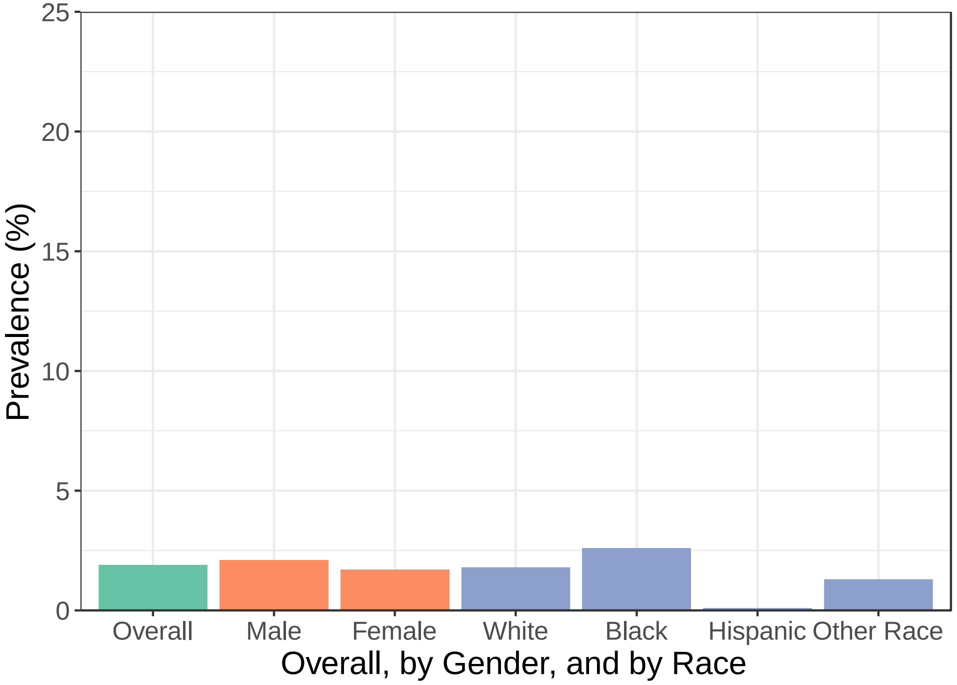


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data


History of Heart Attack Among Adult
DC Residents Overall, by Gender, and by Race
Prevalence (%)
0
5
10
15
20
25
Overall
Male
Female
White
Black
Hispanic
Other Race
Overall, by Gender, and by Race
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

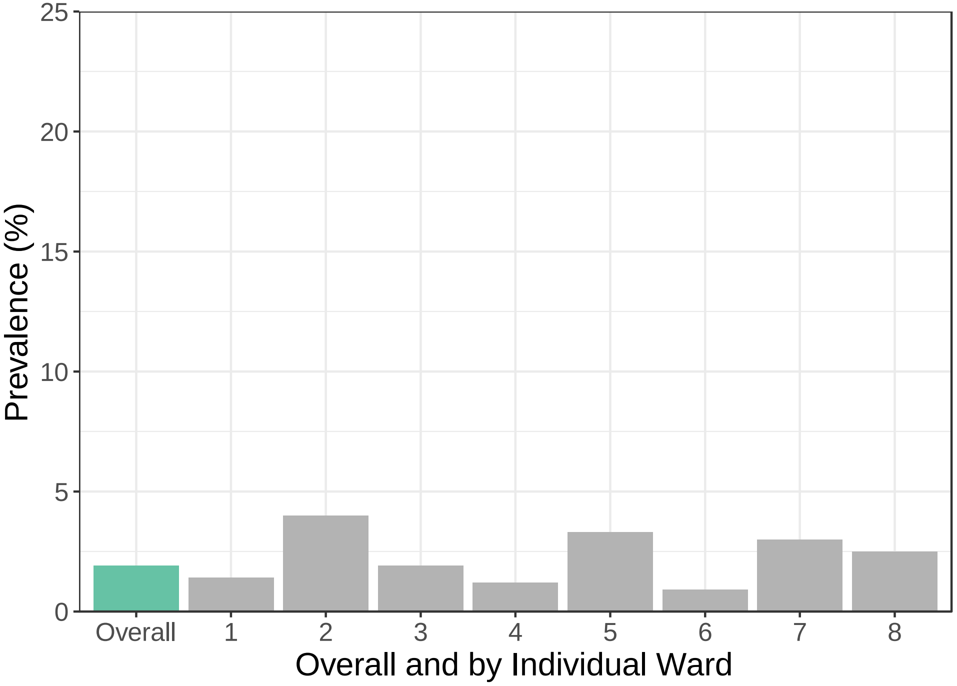

History of Heart Attack Among Adult
DC Residents Overall and by Ward
Prevalence (%)
0
5
10
15
20
25
Overall
1
2
3
4
5
6
7
8
Overall and by Individual Ward
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Prevalence of Angina or Heart Disease Among Adult DC Residents Overall, by Gender, and by Race



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

Prevalence of Angina or Heart Disease Among Adult DC Residents Overall and by Ward



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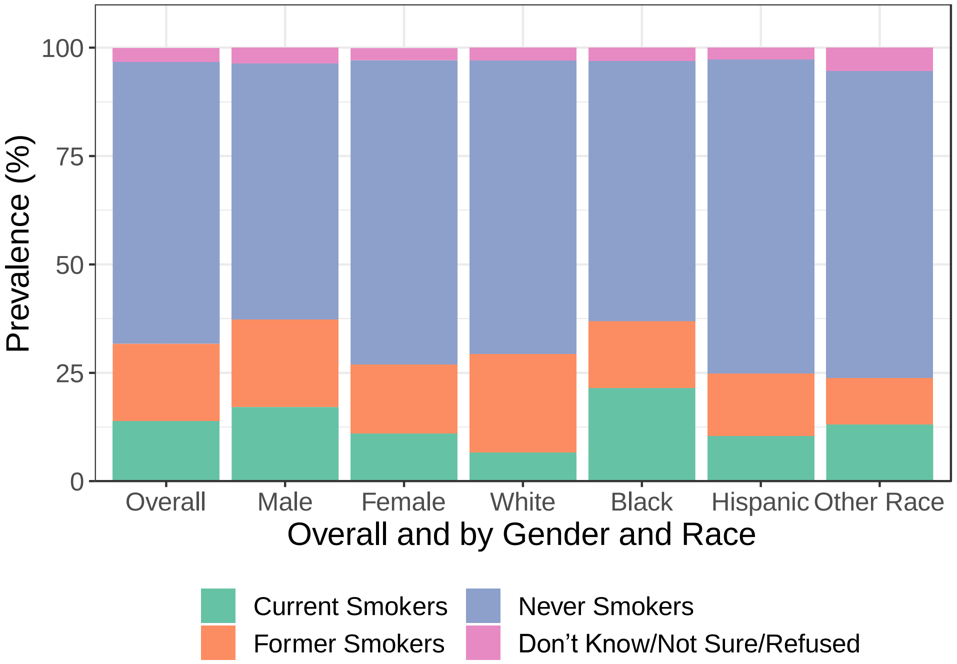
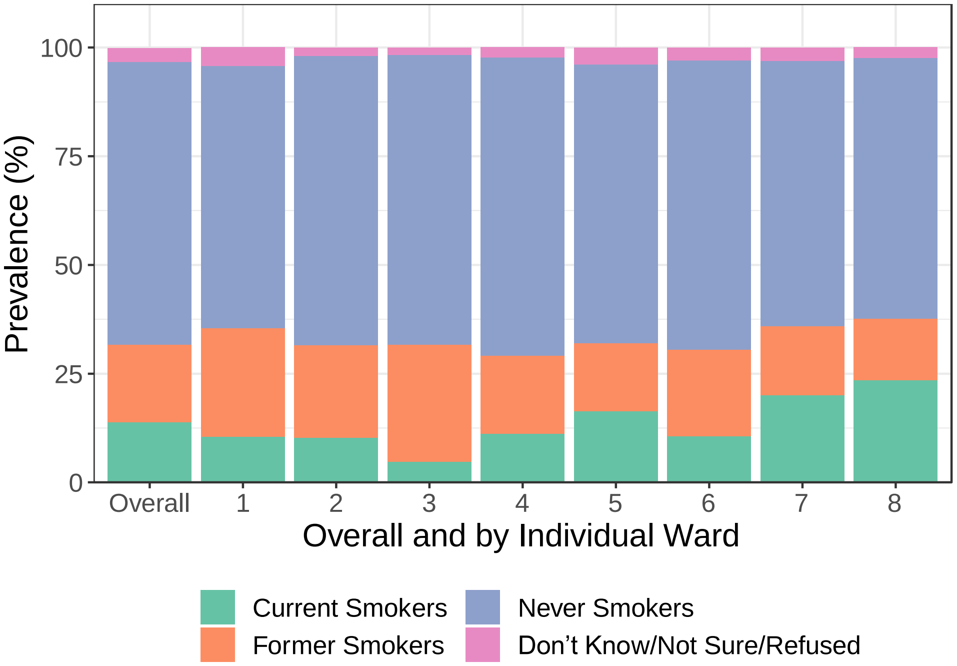


Smoking Status Among Adult
DC Residents Overall, by Gender, and by Race

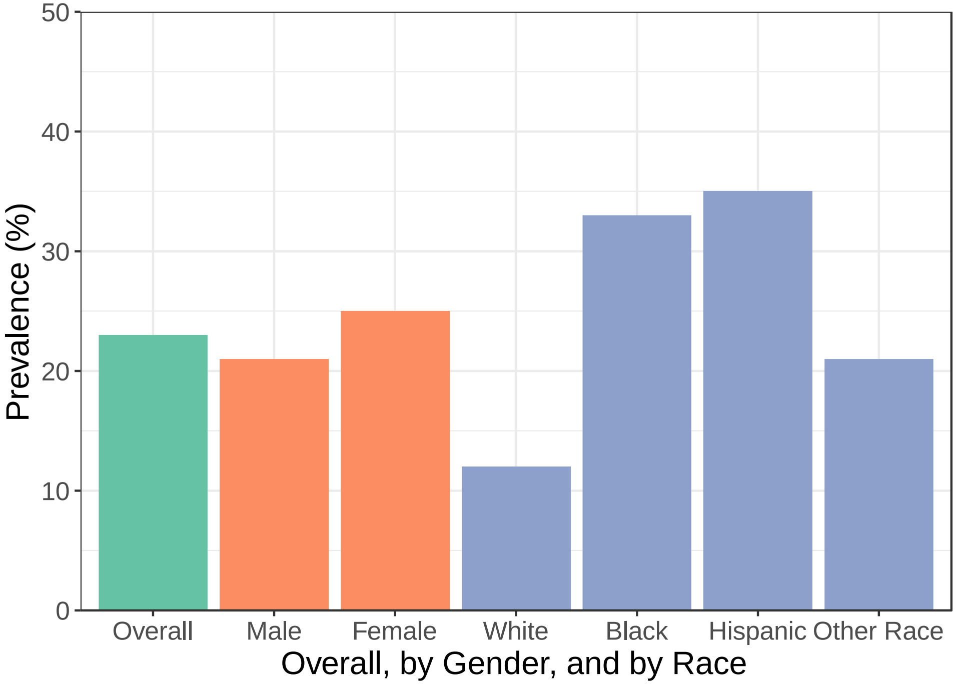
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Smoking Status Among Adult
DC Residents Overall and by Ward

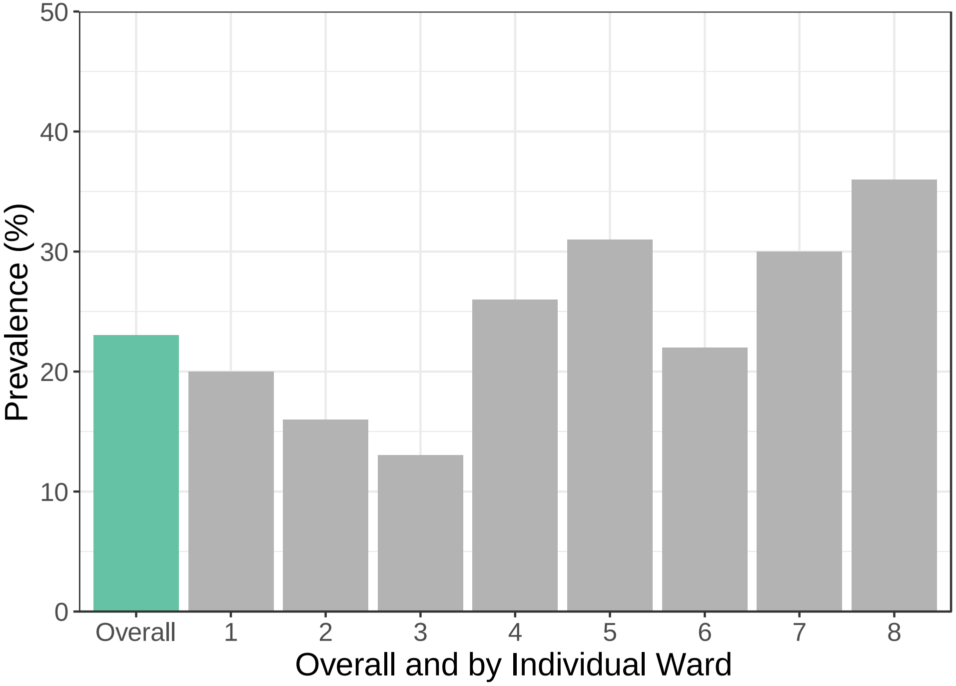
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

No Leisure Time Physical Activity in Past Month Among Adult DC Residents Overall, by Gender, and by Race

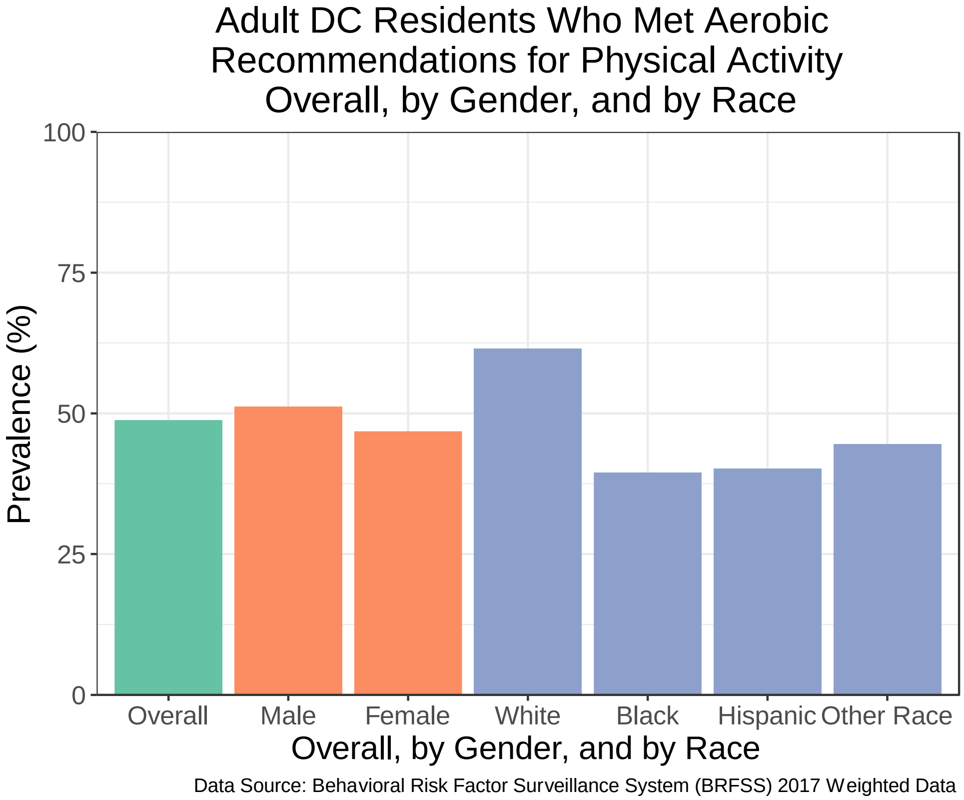


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

No Leisure Time Physical Activity in Past Month Among Adult DC Residents Overall and by Ward



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



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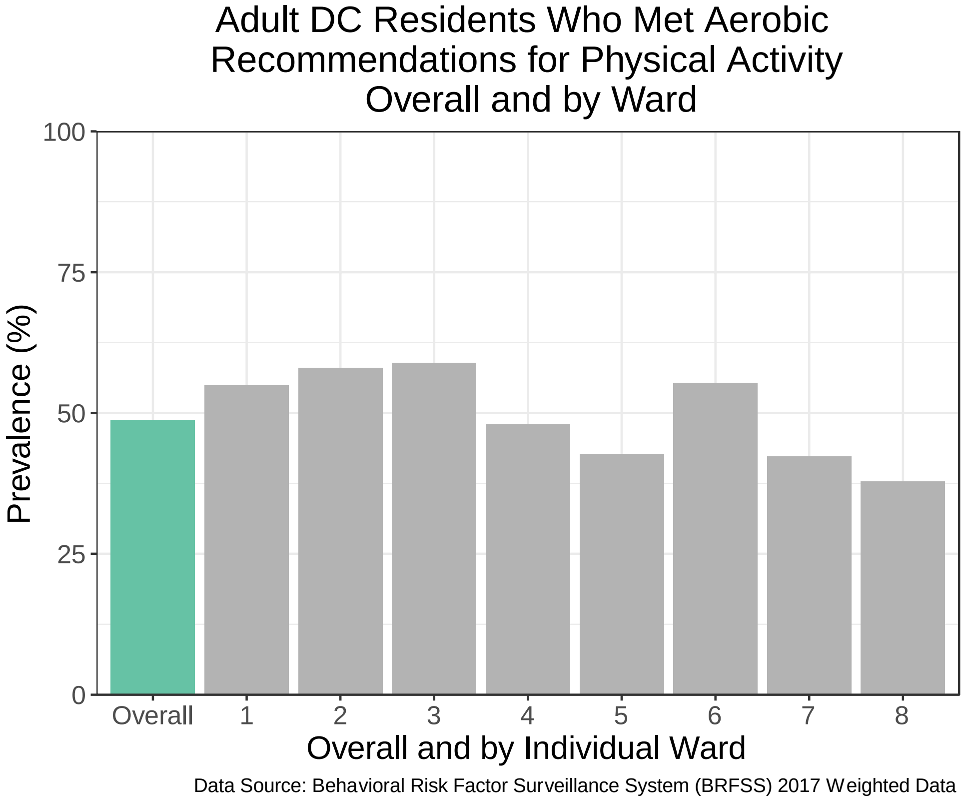

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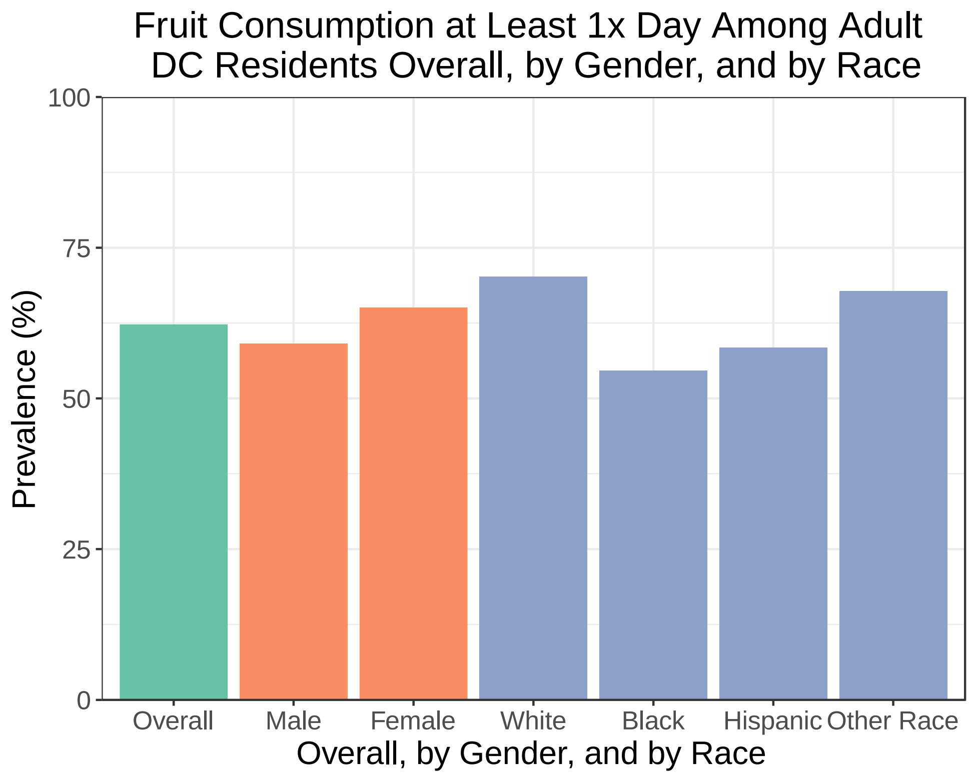
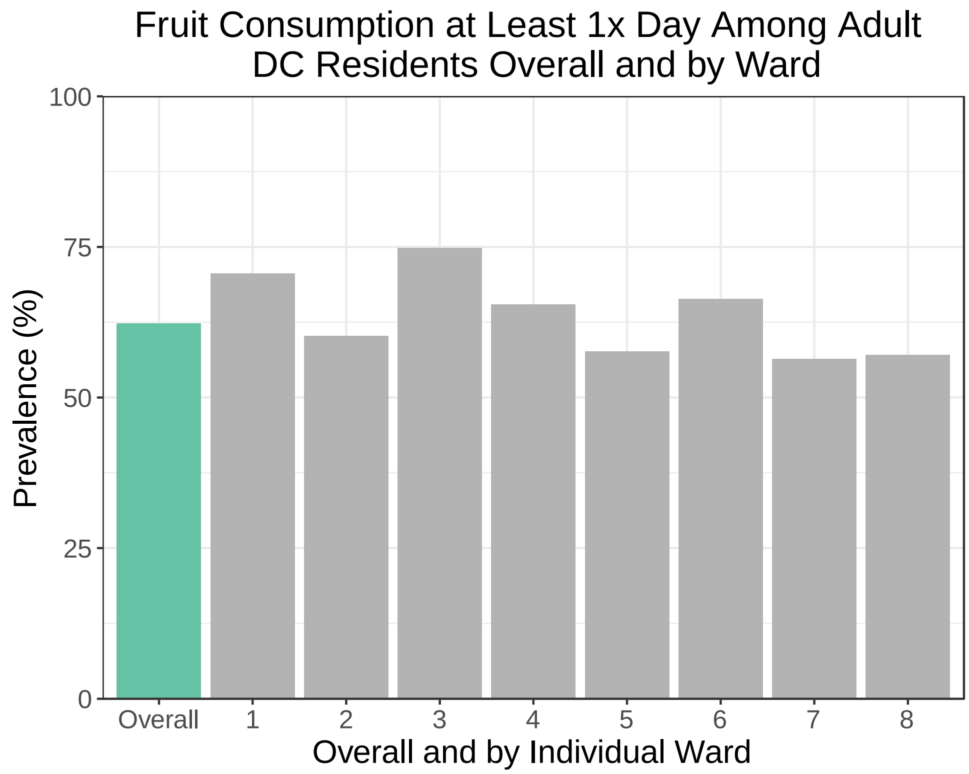
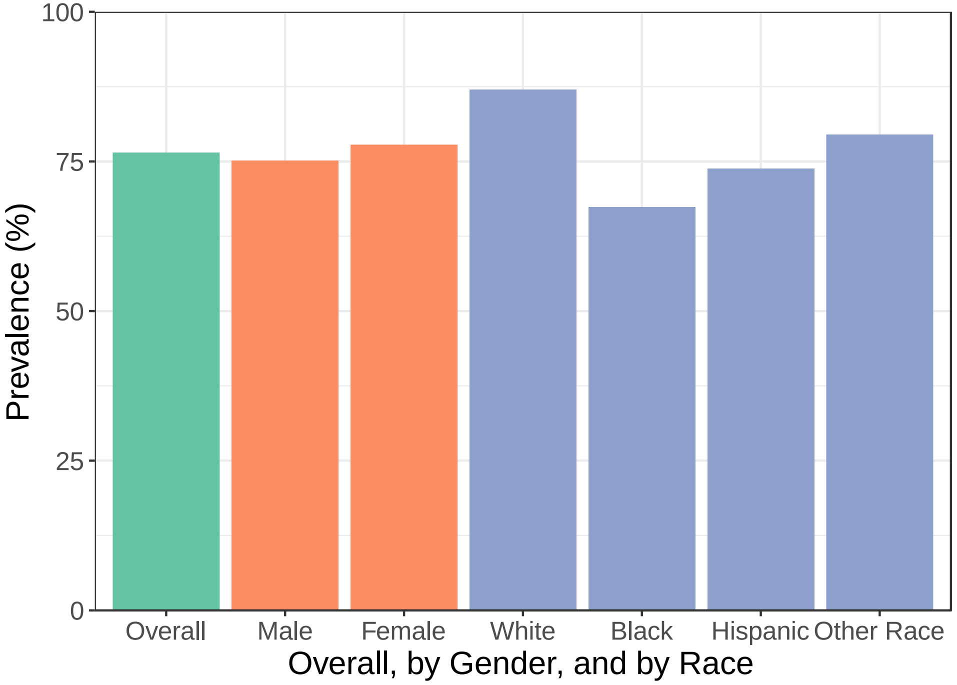


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

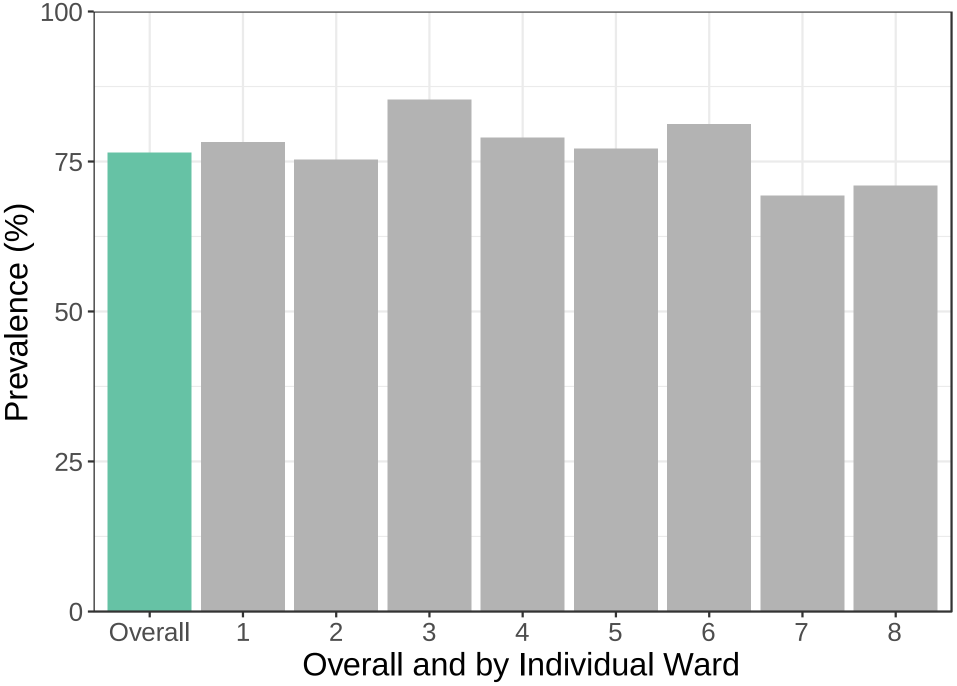


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Vegetable Consumption at Least 1x Day Among Adult DC Residents Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Vegetable Consumption at Least 1x Day Among Adult DC Residents Overall, by Gender, and by Race

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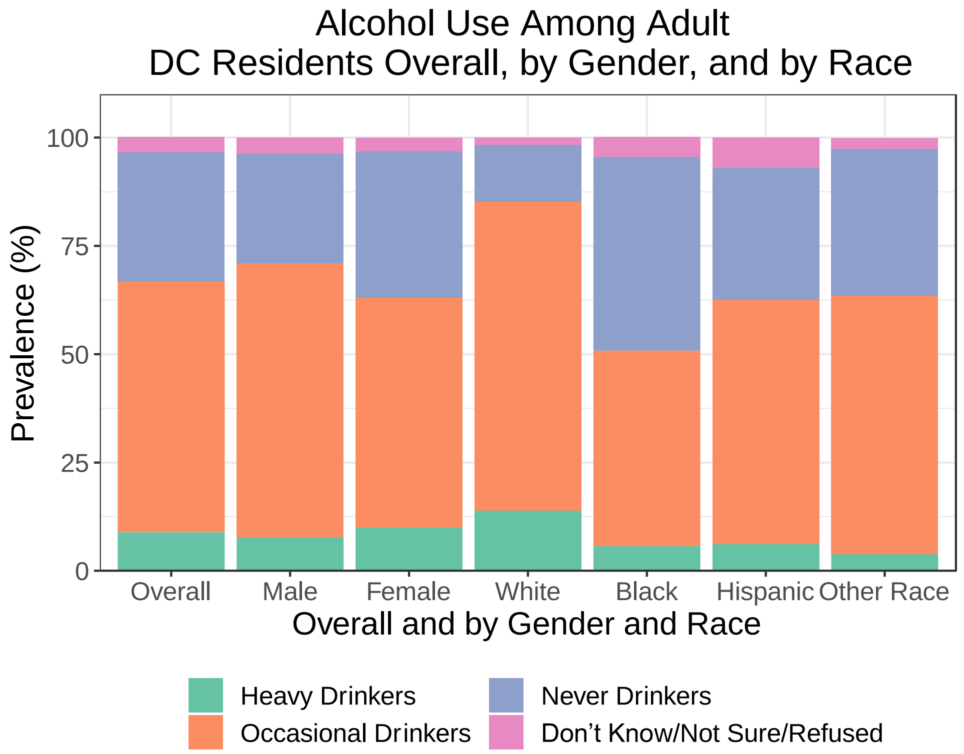
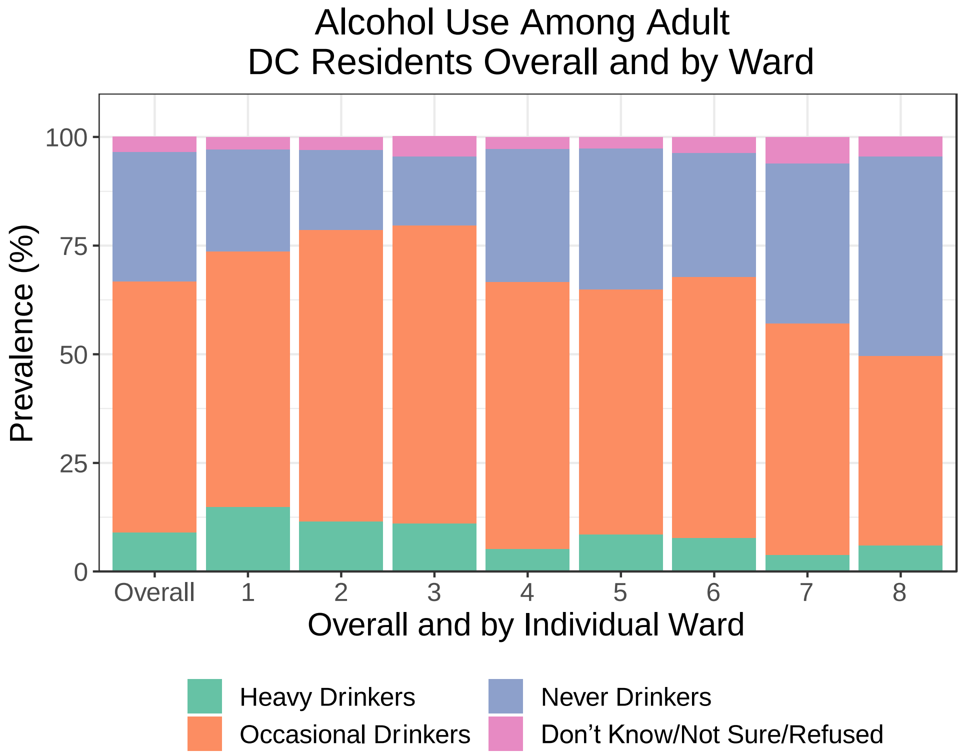


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



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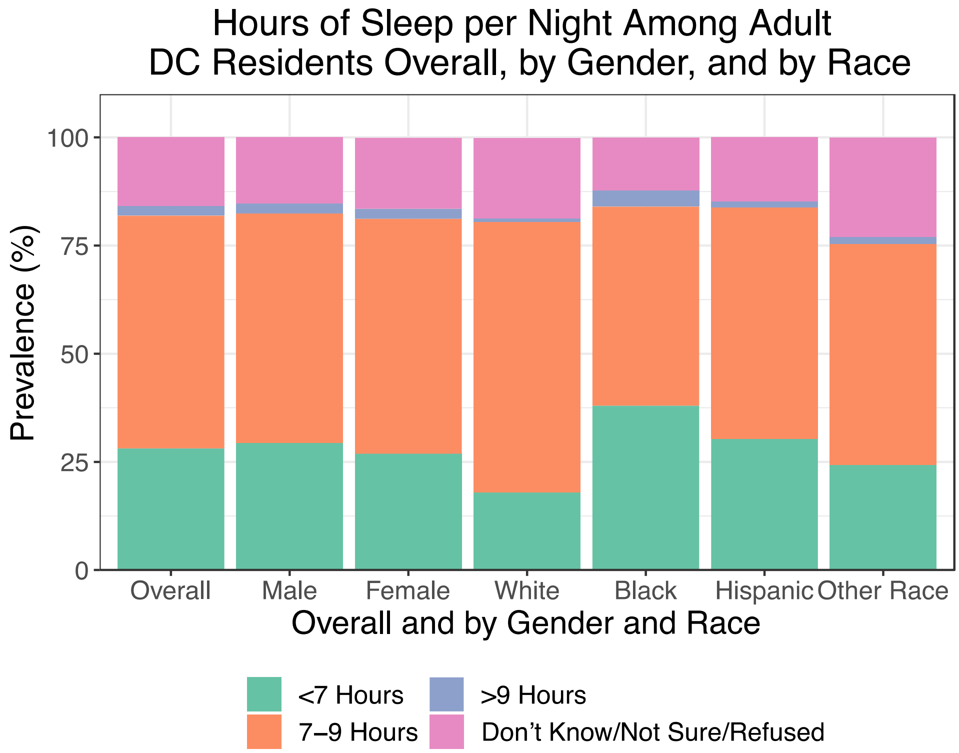

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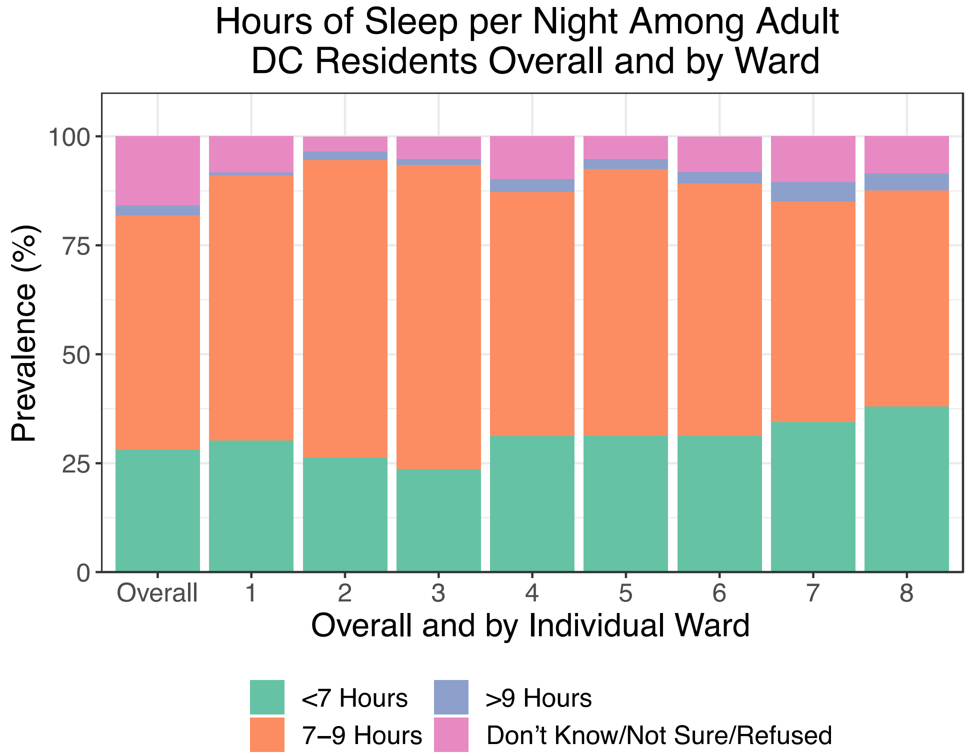

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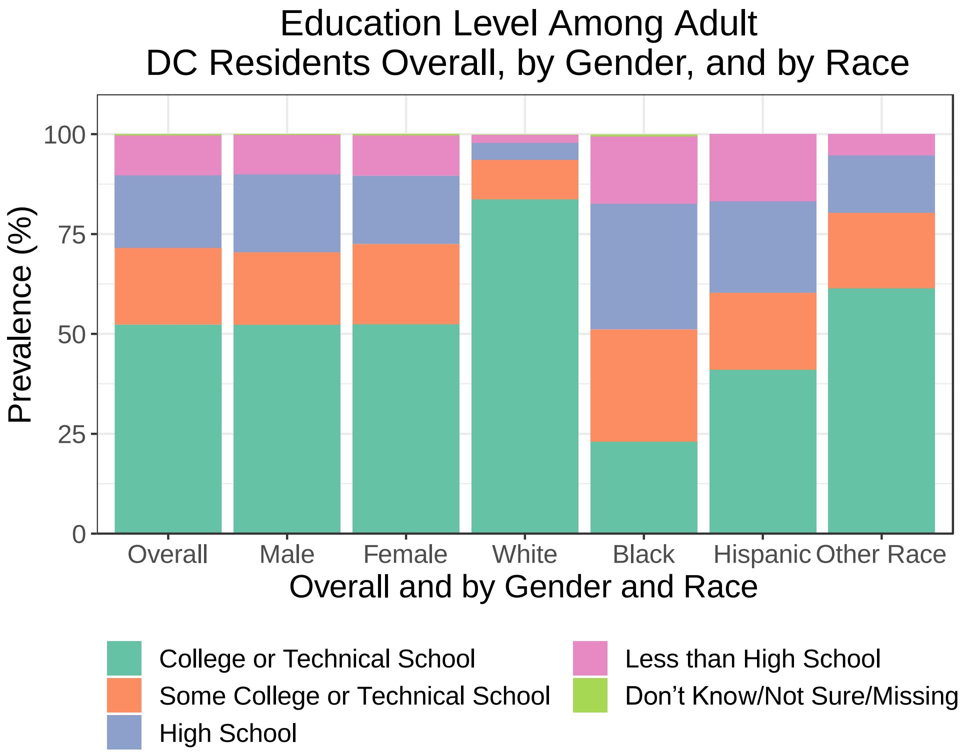

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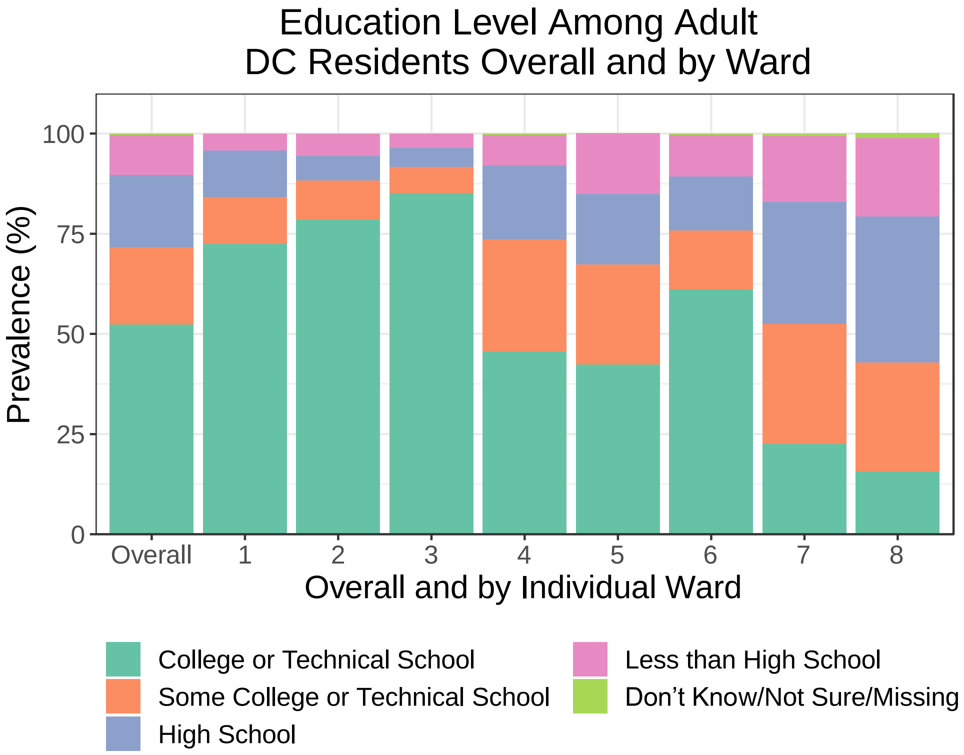

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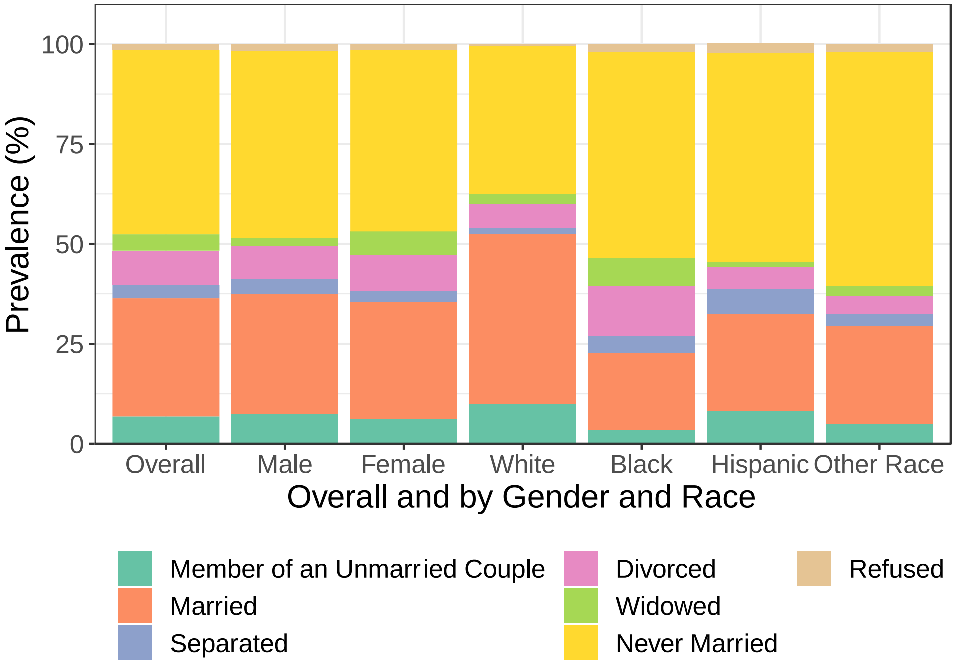
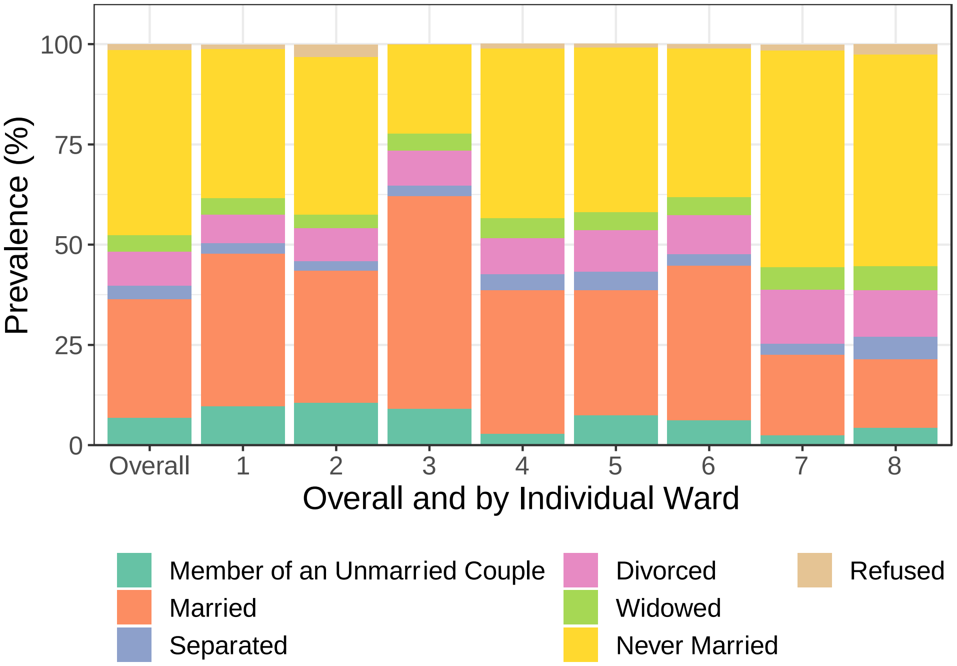


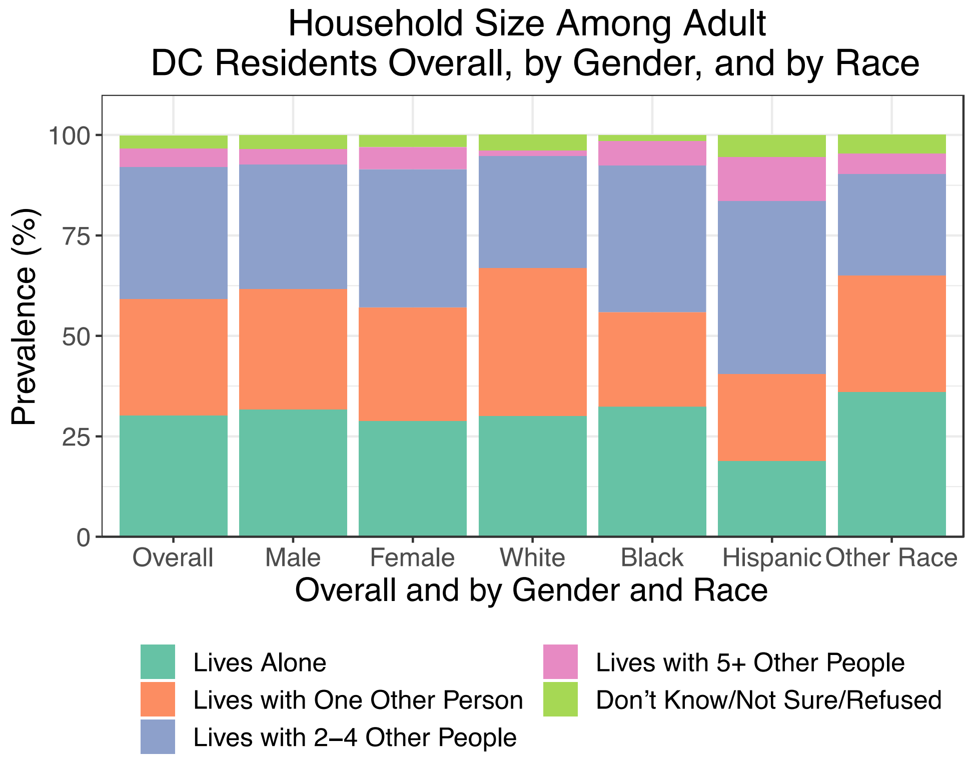
Marital Status Among Adult
DC Residents Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

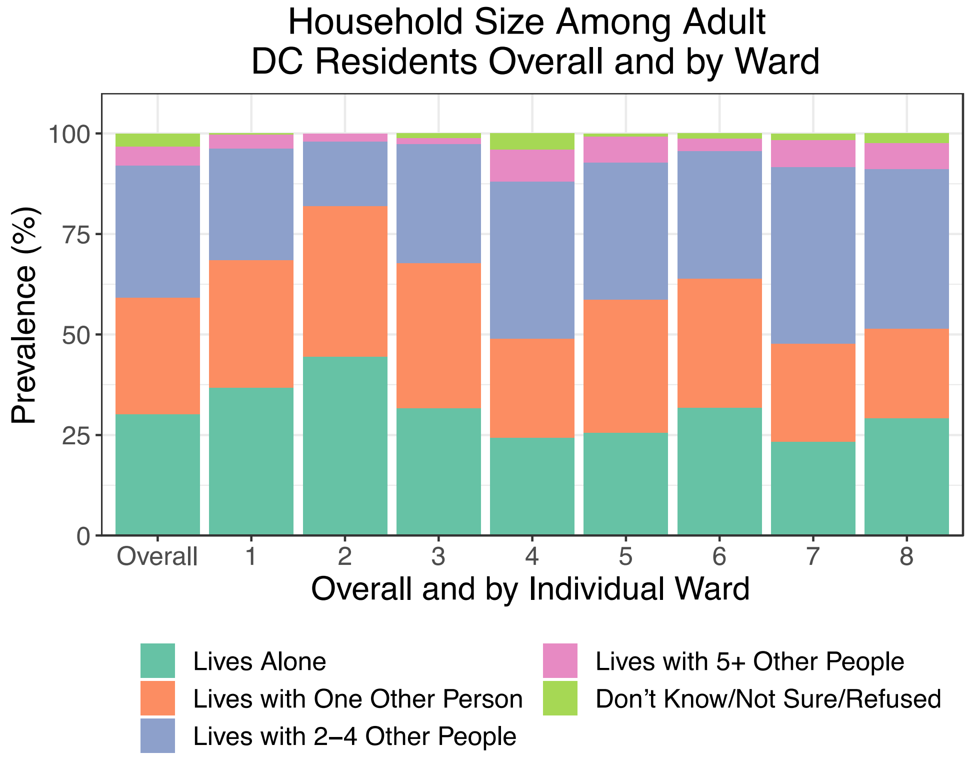


Marital Status Among Adult
DC Residents Overall and by Ward

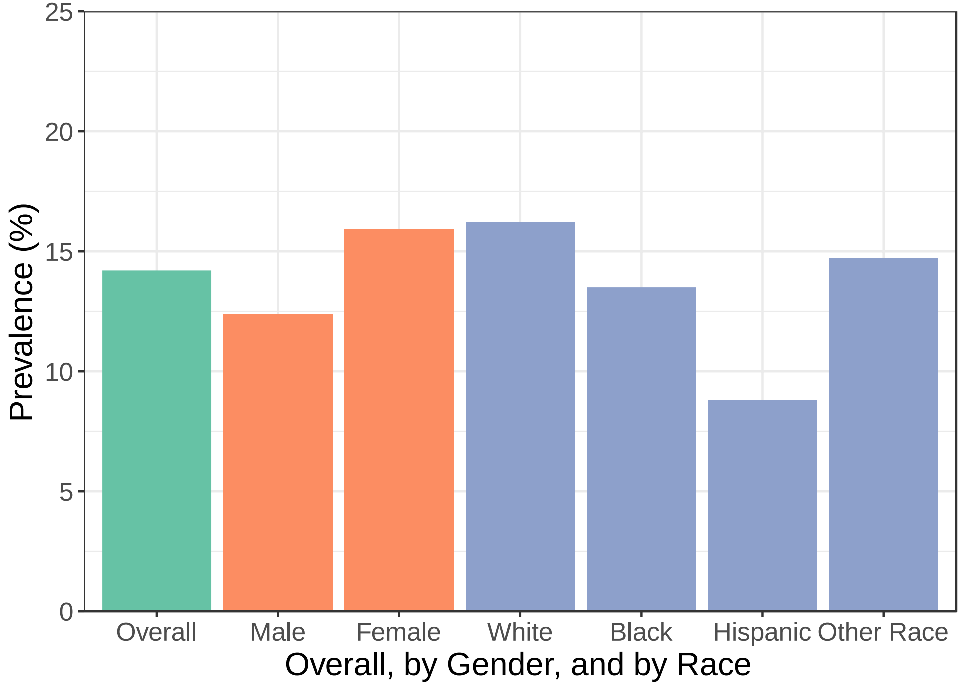
Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

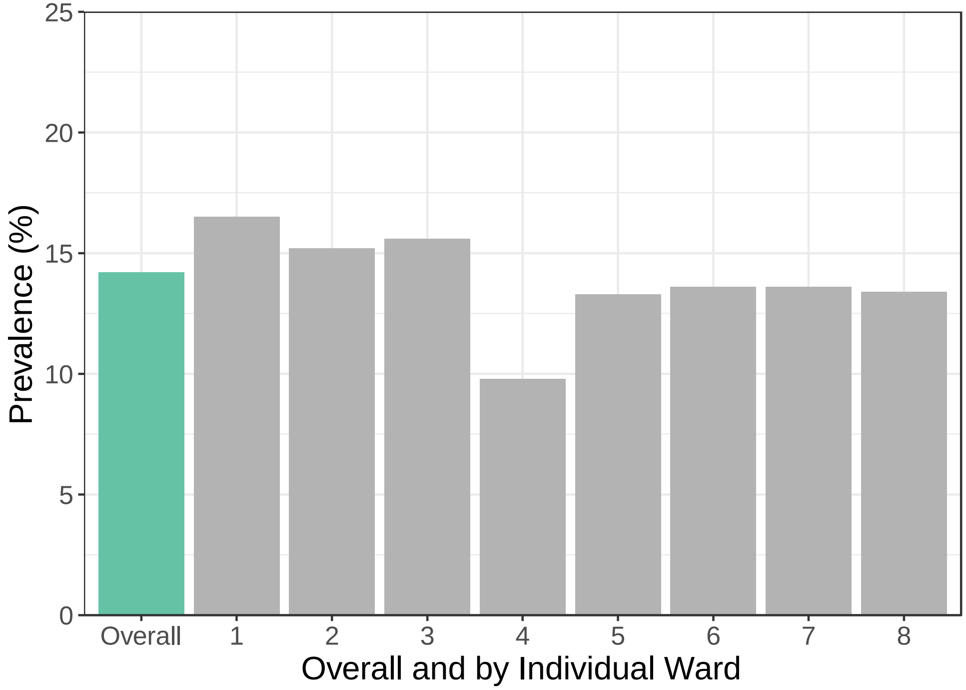


Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



History of Depression Among Adult DC Residents Overall, by Gender, and by Race

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data



History of Depression Among Adult DC Residents Overall and by Ward

Data Source: Behavioral Risk Factor Surveillance System (BRFSS) 2017 Weighted Data

**Appendix E.** Methods used for qualitative research around challenges and unmet needs of primary, unpaid DC caregivers

Recruitment

We targeted primary caregivers of individuals with Alzheimer's disease and related dementias (ADRD) residing in Washington, DC who were between the ages of 18 and 85 with the assistance of community partners. These organizations included the DC Department for Aging and Community Living (DACL) network (i.e., community programs, Senior Centers, care managers, etc.), George Washington University Medical Faculty Associates (MFA), Age-Friendly DC, the Washington DC Area Villages Exchange, faith communities, and other community-based organizations. Potential participants were given fliers about the study which included a contact telephone number and instructions to leave a voicemail indicating interest in participating in the study. A member of the research team then contacted participants to provide them with additional information about the study, and to screen them for eligibility. Those who expressed continued interest and who met eligibility criteria completed an intake form and were scheduled to participate in an upcoming focus group.

Eligibility criteria included: 1) self-reported unpaid primary caregiver for an older adult with ADRD, 2) 18 to 85 years of age, 3) resident of Washington, DC, and 4) ability to provide meaningful dialogue for a focus group. The recruitment process ended when we reached our target number of participants. The intake form was used to collect information on participant sociodemographic characteristics, zip code of residence, care recipient's dementia severity, and the care recipient's relationship and living situation.

Focus groups

Due to the COVID-19 pandemic, the focus groups were held virtually on the WebEx Conference platform. To minimize technical difficulties during each focus group, participants received emailed instructions for using WebEx (including a telephone number for a Research Assistant (RA) to provide technical support during the focus groups, if needed). In addition, within the two days prior to participation, an RA provided telephone support to assist with downloading and installing WebEx and assistance with navigating the instructions for participating in the video conference.

Dr. Lunsford moderated, and Dr. Turner co-moderated the sessions. Informed consent for focus group participation and for audio-recording was obtained at the start of each focus group; participants were reminded to leave the focus group and exit WebEx if they did not consent to either. Sessions were recorded directly via WebEx, as well as via an iPhone or alternate recording application by an RA as a back-up. RAs took notes and assisted in observation of respondents on video. Discussion between participants was encouraged to promote sharing of knowledge and experiences. Each focus group lasted approximately 90 minutes. Participants each received $100 as a token of appreciation for their participation.

Data Analysis

Audio recorded files from each focus group session were uploaded to *rev.com*, a web-based transcription service. The verbatim transcripts received from *rev.com* were then uploaded to *Dedoose*, a software application designed for qualitative and mixed methods data analysis. The data were analyzed by three coders using a combined inductive-deductive thematic analysis approach. The first coder developed an initial coding scheme based on the focus group guide and ideas heard while conducting the focus groups, and subsequent fine-tuning through the process of coding the first focus group transcript. Coders 2 and 3 then coded the same transcript using the initial coding scheme. Each coder independently reviewed the coded transcript and identified any coding discrepancies across coders. The three coders then met to discuss coding discrepancies and establish inter-coder agreement, to review themes and codes, and to make additional adjustments to the coding scheme. Inter-coder reliability was confirmed, and a finalized set of codes was established. The four remaining transcripts were then coded by two separate coders each.

**Appendix F.** Narrative summary of findings about current use of resources and services in DC by focus group participants

*Overview*

Below, we provide detailed descriptions of the use of specific resources that were discussed in the focus groups, as well as challenges and unmet needs associated with these resources. Where relevant, we note specific resources discussed by participants. Finally, we note any COVID-19 related disruptions or challenges discussed that were specific to a given resource. We include supporting quotes in footnotes throughout. Please note that quotes have been edited for clarity, flow, and participant privacy.

*Use of Specific Services and Resources, and Associated Challenges or Unmet Needs*

*DC Department of Aging and Community Living (DACL) and the DC Caregivers Institute (DCCI)*
Most participants had engaged with DACL in some capacity, although DACL was best known to the participants as the DC Office on Aging (DCOA); only one person noted that it had been renamed but could not recall the new name. DACL is frequently reported as one of the first places that participants sought for help. Many participants found DACL to be helpful in providing useful information and referrals to other resources and services, including senior centers and adult daycares, home modification agencies, home health aides, grants for financial support, and legal services, as well as specialized physicians.

There were a few participants who noted challenges with DACL. One caregiver was frustrated by the fact that they were unable to receive in-home support from DACL, while another caregiver was disappointed that DACL failed to refer them to the DC Caregiver Institute. Additionally, one participant suggested that DACL should be actively tracking and monitoring community-dwelling seniors for dementia to ensure that they are receiving care.[i] This suggestion was well-received by other participants from the same focus group.

DCCI (funded by DACL) was discussed frequently as a source for education, financial assistance, and in-home support services. Participants generally reported learning a lot from DCCI's educational programs, which were described as comprising a mandatory orientation, ongoing caregiver support programs, as well as caregiver certification classes. A number of participants referred to a 'grant' from the DCCI that they find to be particularly helpful. This grant program provides a monthly allocation based on each individual's eligibility, and it reimburses caregivers for caregiving-related expenses. Participants similarly recommended DCCI's financial support program for respite care by a family member or friend.[ii] At least one participant reported

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[i] *There needs to be somebody out there checking on some of these senior people in their homes. There are a lot of other seniors that I've run into or met that have early dementia, and their family doesn't recognize it and some of them do, but they're pulling away from them because they don't want to be the caregiver.*

[ii] It can be a family member or a friend, and they will pay them anywhere from a hundred to $200 a month to come in to give you a break […] I think that program will be good for you, and also [*name redacted*].

receiving in-home support services through DCCI. Finally, one participant was particularly grateful to the DCCI social worker who helped them arrange for a house call physician.

With regard to challenges, one participant expressed frustration with the difficulties in receiving timely assistance from DCCI due to the high demand for their services, apparent lack of coordination between DCCI and other agencies, as well as lack of information about other agencies.[iii] Another participant described feeling overwhelmed with the amount of information that they were receiving from various agencies, and that they lacked the time to parse through the information or to make the requisite phone calls to identify and apply for what they need. For this participant, the most pressing need is a system whereby the city automatically assigns each caregiver with one or two caseworkers to distill the information and navigate them through the processes of applying to various services.[iv]

*Senior Centers and Adult Daycare Services*

A number of senior centers across DC were discussed in the focus groups, including Hattie Holmes, the Washington Seniors Wellness Center (WSWC; known to participants as the Family Collaborate or East of the River), TERRIFIC Inc.'s senior services, Iona senior services, as well as a senior center through a Baptist church. Participants generally reported senior centers to be a helpful resource that serve many useful functions, with few complaints.[v] Many were satisfied with the adult daycare services and daily activities (including exercise, trips, dancing, Club Memory) that provided their care recipients with opportunities for exercise, and social and mental engagement. A number of participants also received helpful information, as well as referrals to and arrangements for other resources (including in-home support, home modification or renovation services, and transportation services) from the senior centers and the centers' social workers. One participant was especially grateful to TERRIFIC Inc., which helped them make the necessary arrangements to transition the care for their spouse from a nursing home back to their home. One participant mentioned using the lunch services at the senior centers while another receives meal deliveries through their senior center. WSWC was noted to assist with SNAP applications and tax filing, and the Baptist church senior center was noted to provide various supplies (e.g. adult diapers).

A few participants noted that their senior centers require care recipients to be accompanied by someone while attending daycare or participating in center activities; this may pose a barrier to

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[iii] What I need is, is right now. I don't need to wait till somebody comes back off of a maternity leave or somebody comes back from lunch. What do you have available now? And if it's not you, who is it? Can you give me another number? Who is your sister agency? Like people work together, agencies work together, and I just don't see that that information is out there.

[iv] You've got a lot of agencies who offer information, information just across the internet and they could send you all this information, but I need people to walk me through it. I don't want to read a 10-page brochure because I asked one question, […] It would be nice if in addition to that information, they provided people to help out with this information […] with our schedules, it's almost impossible to sit down and read all that and make all the phone calls and be on hold.

[v] They have been an amazing source of resources, of information, of referrals, of things to do, people to be in touch with, they are very, very thorough and my mother was going to them twice a week.

caregivers who do not have access to an aide. Caregivers also need to arrange for travel to and from the senior centers, which may be challenging; one participant noted that their senior center (WSWC) provides limited and unreliable transportation for travel to and from the center.[vi]

The closing of the daycare programs resulting from the COVID-19 pandemic has been very difficult for caregivers due to disruption of routines and loss of activities for their loved ones experiencing dementia. One participant noted that their loved one became more challenging to care for as a result of the loss of routine.[vii]

*In-Home Support*

In-home care was reported to be a priority service by focus group participants, who discussed the need for general caregiving support as well as for caregiver respite or relief. Specifically, given the time and efforts that are demanded by, as well as the mental and physical challenges of caregiving, many reported in-home support as crucial for allowing them to take regular breaks and to attend to their own self-care,[viii] as well as to attend to other responsibilities.[ix] Based on the experience of one of our participants, in-home support may be especially important for supporting caregivers who are still employed while providing care for their loved one at home; as noted by another participant, they were “forced into unplanned retirement” by the demands of caregiving.

Home health aides were the most commonly used or desired form of in-home support. The need for home health aides was high across participants, particularly among those caring for persons with high dependencies and/or require round-the-clock care.[x] For caregivers without family support, home health aides are crucial for providing support in general, and for providing coverage when the caregivers cannot be available. Even for caregivers with good social support systems, home health aides are helpful because they allow for an alternating schedule between aides and family members/friends to facilitate round-the-clock care and allow for needed breaks for the primary caregiver.

Participants reported a number of organizations through which they found home health aides. DC Home Care Partners appeared to be the most commonly used agency by our group of

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[vi] The wellness centers have limited transportation, so it all depends on what kind of bus or van they have, [which] will determine whether or not they'll pick you up.

[vii] She doesn't want the aides to dress her. She was when my mother used to go to a senior daycare Monday to Friday. When it closed in March, she got out of the routine of getting up at 7:30. [now] only wants me to get her dressed.

[viii] Respite is important, it's very important so that the caregiver can really have the time to rest, and re-up, and start all over again, because we don't get that, we don't get that chance to take care of ourselves

[ix] I also take care of my dad who lives out of town, but I do that remotely and try to visit when I can get respite care for my mom.

[x] Health aides come in. You know, there's been a time where I have not had it and like the others have said, it is a full-time job. And even with the home health aides, there's still a 24/7 because you have to be responsible for others, in addition to yourself […] it never stops.

participants; one participant noted that DCCI appears to send referrals to DC Home Care Partners. Other agencies through which participants found home health aides include DC Caregiver Institute, DC Office on Aging, Caring Givers, Consumers Direct – Service My Way, as well as Health Management Inc. (HMI).

Challenges to receiving adequate home health services were commonly discussed and elicited frustration across focus groups. The pathways to finding care were varied, and for many, were burdensome and time-consuming. For example, one participant described a process that took approximately 18 months and required legal assistance. During that time, they paid for a private aide out-of-pocket until it became unaffordable and subsequently relied on family support. Another participant similarly required legal assistance from AARP to become qualified for Medicaid and receive covered home health support. Relatedly, two participants also expressed frustration at the lack of appropriate coverage for services under Medicaid/United Healthcare and Medicare. Even among participants who succeeded in obtaining home health aide services, the number of hours received was generally reported to be insufficient. A common sentiment shared by many participants was that those who have worked all their life and become sick in late life should automatically receive covered home health aide support. Similarly, one participant lamented the lack of home health coverage for persons with dementia who have significant cognitive decline, but who are still relatively physically independent. They noted the need for and benefits of having aides provide cognitive/emotional stimulation and supervise activities, urging the city to recognize the broader range of dementia symptoms, and to address this critical gap in need.[xi] Finally, some participants also had challenges with regard to the quality of home health aide services, including aides who were unreliable or unhelpful,[xii] improperly trained to care for persons with dementia,[xiii] or were difficult for the care recipient to understand due to language barriers.[xiv]

Participants also used other forms of in-home support. Participants noted two organizations,

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[xi] As much as DC talks about person centered programming, one of the things is if your parent doesn't fall into certain […] categories, it's really hard to get help. […] It's hard to get a level of care for somebody who isn't totally dependent and it ignores the fact that people who have dementia have mental health needs as well, and that isolation among people with dementia hastens their cognitive decline and, certainly, does nothing for their emotional wellbeing [...] I can't get an aide at home because of that barrier […] it's to keep people in the community versus being institutionalized, but it's, kind of narrow in the focus in a way because it doesn't acknowledge the range of how dementia looks like […] it would be lovely if somebody could sit and listen to music with her and sing. […] that really helps somebody intellectually and emotionally and is needed. So my plea is a broader range of understanding the nature of dementia and what each person really needs.

[xii] The agency aides, they'll sit on their phone, they just, "I'm here to give him his food and help him bathe," and they don't have to talk to him. So they sit on their phones the majority of the time they're here.

[xiii] And so it falls to me […] we have a PCA and that person was absolutely worthless because I asked the young guy, “Have you ever handled dementia?” And man, he said, “No.” I said, “Nobody told you anything about working with dementia patients.” And he said, “No.”

[xiv] My mother couldn't understand the language if they have like broken English, so it was very important that I found somebody that could speak clear English […] it's kind of hard trying to find places that you can get somebody that's caring and can speak clear English.

the DC Caregiver Institute and Consumer Direct – Service My Way, that pay for family members or friends to provide in-home assistance, which participants found to be very helpful. This service may be particularly helpful to those caring for loved ones who are resistant to being taken care of by non-family members or strangers. A few participants whose loved ones were more restricted in mobility or had transportation issues used in-home medical/nursing care.[xv] The avenues through which in-home medical/nursing care are provided include: VITAS hospice, DC Caregivers Institute, the DC Medicaid Elderly and Persons with Physical Disabilities (EPD) Waiver program, and the Washington Hospital Center/Medstar House Calls Program.

Limited use of other forms of in-home support appears to be due, at least in part, to lack of awareness of these services. Of note, hospice was only mentioned by one participant; while it is a very useful program for accessing holistic in-home support, eligibility under Medicare requires a 6-month prognosis certification. Thus, while hospice is inaccessible during the earlier stages of disease, awareness of hospice services should be improved to facilitate end-of-life care. Finally, in-home support for supervising and guiding physical activity appears to be an unmet need, one that home health aides are not able to reliably provide. One participant suggested physical therapy students as a potential avenue that the city could explore for providing these services.

*Caseworkers / Social Workers / Counselors*

Many participants received support from a case worker, social worker, or counselor through a senior center, Sibley, or the MedStar House Calls Program. Most commonly, participants described their caseworker/social worker/counselor as very helpful in working with them to learn about and navigate resources and services. Some were also impressed by their attention and care. In one case, the caseworker was checking in regularly to ensure that their care recipients are stocked on essentials. In a second case, the caseworker spent social time with the care recipient. One participant also described an instance where their caseworker advocated for them when their insurance denied them a service.

Some participants also had challenges. One participant was frustrated with their social worker's lack of responsiveness.[xvi] A few participants also noted difficulties with communication in cases where the caseworkers/social workers only interacted with the care recipients rather than with the caregivers. Two participants were very frustrated by this, noting that the care recipients are cognitively impaired and are unable to communicate clearly or effectively. Another participant explained that because they are engaging with the care recipient daily, they are most attuned to their needs, and wished that they were able to directly

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[xv] Especially if you can't get your parent in and out, or your loved one in and out of the hospital on your own. I used to call Metro Access but that kind of got a little rough so I would take the Uber. And then it kind of got rough on me after a while because my father stopped walking. Now I just have them, I still use hospice […] I'm pretty satisfied for having them come in the house instead of me having to take him to the doctor.

[xvi] I don't have time to keep running behind them. I ask them to check something that I know that the people not going to talk to me about, then I don't hear, and I got to call back again. I'm not doing all that, that's just too much.

communicate with the social worker to best coordinate care. Similarly, one participant explained that their mother had not even been aware of having a social worker due to her cognitive impairment.

*Nursing Homes*

The need for nursing homes was not frequently discussed, potentially a result of the participant pool, as need for nursing home is greatly dependent on the health and extent of functional limitations of the care recipient. The few participants who spoke about nursing homes were concerned about the availability of nursing home beds in quality facilities in DC. One participant who was no longer able to continue providing care at home noted that they had difficulties placing their spouse in a nursing home due to lack of availability; their efforts were furthermore interrupted due to the COVID-19 pandemic. Similarly, there was little discussion of assisted living facilities or residential memory care facilities.

*Home Modification / Renovation*

Many participants indicated using services that provide home modifications and renovations to improve the safety and livability of the home. Safe at Home was the most commonly used service for home modifications (e.g. installation of handrails and chairlifts) among our focus group participants, a number of whom were referred to by the DC Office of Aging. One participant also received home repair services from Single Family Restoration, which is covered by Medicaid for eligible beneficiaries. Another participant noted that the VA covered various home modifications for their father, who is a veteran. Those who were eligible for covered services from these agencies reported positive experiences. Relatedly, one participant found Community Forklift, referred to them by Iona, to be helpful. It is an organization that collects donations of appliances, furniture, and a range of building materials. Donated goods are refurbished, and then sold or re-distributed to qualifying residents who need them.

Multiple participants noted challenges to accessing necessary services related to home modifications and renovation.[xvii] For Safe at Home specifically, participants expressed frustration with eligibility challenges, as eligibility is determined by not just the income of the person being cared for, but also that of the caregiver.[xviii] While some caregivers were able to pay for the services out of pocket, this was not an affordable option for others. Another challenge to making home modifications is rental regulations. For example, one participant was unable to make needed modifications to their mother's rented condominium because the regulations stipulate that any changes to the space must be reversed at the end of the lease; this posed an added financial burden that was prohibitive to this participant.

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[xvii] When I came here, his house had paper at the wall, at the windows. It was cold. Furnace was broke. It was just a lot of things that should have been taken care of that weren't. I've been fighting for the new windows and a new roof and a new heating system, and just the basic things for us to be comfortable in the house.

[xviii] Instead of looking at my mother's income, they were looking at my income so I didn't qualify because they had to have my income and everything. So I just went ahead and did what I needed to do and thankfully was able to do what I needed to do.

Finally, as one participant noted, all the home modification agencies were closed at the time the focus groups were conducted due to the COVID-19 pandemic, further restricting access to these services.

Due to unmet home modifications needs, caregivers may face additional care dependencies and burdens; for example, one participant who was deemed ineligible for a chairlift installation explained that they need to help walk their loved one down the stairs.  Others also noted a need for assistance with installation for security panels and in-home cameras to facilitate supervision of persons with dementia.  Finally, Community Forklift did not appear to be a well-known organization among our participants, despite a number of whom expressed a need for new appliances or home repairs.

### *Meals and Food Services*

Several participants used resources related to meals or food access.  Participants reported using Mom's Meals, Seabury, and Meals on Wheels for meals delivered to the home.  One participant uses a program known as a Brown Bag Service, which they described as a program available to Medicaid beneficiaries that provides vouchers to use at the Eastern Market farmer's market. They appreciated that the service allowed them to provide healthy fresh vegetables for their loved one.  The Supplemental Nutrition Assistance Program (SNAP) did not appear to be a commonly used service among our participants.  Only one participant noted being enrolled in SNAP in the past, but suggested that they are no longer enrolled due to a decline in the level of services available.  One participant noted that WSWC facilitates SNAP applications, which is a convenient option for those in Ward 7, while another referenced the SNAP eligibility criteria as a model for senior services because it is based on individual, rather than household level income.  However, it was unclear whether these participants or their loved ones were enrolled in SNAP.

Based on the experiences of our participants using meals services, there is a need for healthier and better tasting food.  For example, one participant who uses Mom's Meals reported that the food does not contain sufficient fiber, while another noted that it contains too much sodium. One participant also described the food from Mom's Meals as being too bland.  Similarly, the one participant who discussed the quality of Meals on Wheels food was unsatisfied with the nutritional content, and they suggested that the city consider contracting with a different company that is more equipped to provide better meals.

### *Transportation Services*

A handful of different services were mentioned by focus group participants, including $5 transportation vouchers for non-emergency yellow cab rides to doctor appointments, Seabury services for pick-up/drop-off or funds to cover a cab or Lyft ride, Metro Access, services through United Health Care, and pick-up/drop-off services through a senior center.

In general, based on the experiences of those who used transportation services, they appear to be insufficient and unreliable. For example, one participant using Metro Access described instances where they provided the wrong type of vehicle that could not accommodate their needs, or did not show up to pick up their mother from the senior center. As noted previously, senior center transportation services tend to be limited in availability. Another challenge with transportation services is awareness and understanding of what is available. For example, there appeared to be confusion with the yellow cab ride services, and most were unaware of whether they had transportation services through their insurance. Many participants reported driving their loved ones to senior centers or doctor appointments themselves, and some identified improved transportation services as a priority need.

*Education Services*

A number of participants noted that they tried to attend any event that offered education on caregiving. Some participants reported classes hosted by DC Care Partners and DCCI to be helpful for learning how to respond to and better address behavioral problems.[xix] Some participants also reported good experiences with the Club Memory program, which offers classes and counseling for caregivers, as well as activities for care recipients. One participant noted Club Memory to be a good resource for themselves, but not for their care recipient. Finally, one caregiver has been relying on in-home care personnel and phone support through hospice to obtain the information they need.[xx]

A few caregivers indicated feeling unprepared for the role of caregiving, though it was unclear whether they were unable to use any educational services, or whether educational services they had used were unhelpful. Notably, participants discussed the need for educating the community and family members of persons with dementia. For example, several caregivers were hesitant to accept offers of help from friends, citing the concern that friends may not have the requisite knowledge on the needs and behaviors of someone experiencing dementia. One participant also described the frustrating experience of family members not willing to recognize that their loved one has dementia.[xxi] As suggested by one participant, one solution to educate

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[xix] So I’ve attended a [program at an organization] for six months, and I learnt a lot, how to tolerate […] people with dementia, they say something, they get agitated, they do this, how to accommodate them, how to be patient. Those are things I want to learn. Any word, any training on managing [a dementia] patient, I'm ready to attend.

[xx] So one of the nurses that he sent suggested that I get hospice, and I thought "Hospice?" I wasn't really ready to accept the end stage yet, but once they [Vitas] came in and they were such good people, and they actually took good care of her. So that kind of swayed me into, I felt a little bit better with them being in the house. I could always call them, they even sent out a preacher to come out and talk to you. They left a lot of literature and we had the greatest nurses, they also provided a nurse aide during that time.

[xxi] It's so amazing about family, because as much as I tell my husband's family that he has dementia, they say, "Oh no, he's all right." But when they come to visit, if they come to visit, he says, "Hi baby, how ya doin'?" So they assume that means he recognized them. No, he just doesn't know your name. So now it's, sort of, a fight. It's, like, you're gonna tell me he doesn't have dementia and I'm tellin' you that if I go in a bathroom here, and I'm not sitting there, or the aide is not sitting here, he's gonna walk out the door. They say, "Oh no, he wouldn't do that." Yes, he would do that. He has done it. And then they ask, "Who are you, what's your name?" "I don't

friends and family members is by broadcasting public service announcements on television and/or radio to educate people in the community on dementia-related topics, including how to interact with persons with dementia, and the responsibilities of caregiving.[xxii] This suggestion was well-received by other participants from the same focus group session, one of whom emphasized that educating the public on dementia and supporting resources may help prevent unnecessary abuse of persons with dementia.[xxiii] Finally, participants also reported a need for improved training for home health aides and healthcare professionals who interact with dementia patients. As noted previously, some participants had challenges with home health aides who had not been trained to work with persons with dementia. With regard to physicians, one participant noted the importance of training them to diagnose dementia in a timely manner, explaining that their mother's physicians did not diagnose her dementia until it was very advanced, delaying their own ability to provide proper care. [xxiv]

*Legal services*

Several participants needed legal assistance services. One participant recommended the AARP Legal Counsel for the Elderly and the DC DACL, which they noted would refer caregivers to university law centers for legal resources. Four participants sought out legal support from AARP to gain eligibility for services. In each case, AARP provided legal counsel and/or accompanied caregivers to court to help their loved ones obtain appropriate coverage for services, including re-enrollment in the Medicaid Waiver Program, enrollment in Medicaid, [xxv] home health aide coverage, and additional medical assistance through the VA. These

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know." I can't get through to the family, so I can't even share. That's where the isolation piece come, because I can't share anything with them because they are doubtful. They're in denial.

[xxii] Still want to push my idea of public service announcements on what it's like to be a caregiver. To help the general public understand better what it's like to be a caregiver, and to help people understand better how to communicate with people who are in an altered state from the way that they we're accustomed to dealing with them […] how to talk to someone with dementia. That kind of thing would be really good for the general public to understand.

[xxiii] There are a lot of other seniors that I've run into or met that have early dementia, and their family doesn't recognize it, and they're pulling away from them because they […] don't want to be the caregiver […]. I respect them because I don't want you to go in there and abuse anybody, that's not what I'm saying, but they need to be taken care of also. And it's a lot of other people […] we're lucky because we recognize we have resources, and we're looking for resources. But there's a lot of other people. That public service announcement would be a gift.

[xxiv] If I could add one more thing that I think is extremely important […] that is education of healthcare providers, so they can identify dementia earlier on, and so that families can be prepared. My mother probably had her dementia 20 years or more ago, but she was only diagnosed in recent years after it was advanced. And I can't tell you how devastating that was, and how guilty I feel now that I've read up on some of the symptoms and whatnot, I feel terrible that I didn't understand sooner. I would have behaved differently toward her behavior if I had known there was a diagnosis. That is so important. So, education. My mother was seeing multiple doctors every week, you know, and nobody told me.

[xxv] They helped me to go to the hearing, prepared me for the hearing to request additional hours for my husband. They also helped me focus when I went to Human Resources about my husband not getting anything. I took his medical bills, I took everything to welfare and told them these are all the bills, […] two days they called me back and said "Yes, your husband qualifies for Medicaid", and that was really what helped me, cause I'm retired.

participants felt supported by the AARP and spoke highly of their experience.

With regard to unmet needs, a few participants also raised the need for assistance with end-of-life related legal issues, including establishing wills, living trusts and advance directives, appointing powers of attorney for health and financial matters, as well as establishing guardianship or conservatorship.  Some participants offered DACL, AARP, and online resources as possible avenues for assistance, but did not describe any personal experiences with these services, and thus it is unclear whether they are available.

**Appendix G.** Stakeholders interviewed or engaged during the development of the services and resources guide

In support of development of the services and resources guide, we have reached out to and engaged with the following key stakeholders:

Alzheimer’s Association
DC Department of Aging and Community Living (DACL)
DC Health Care Ombudsman at the Department of Health Care Finance (DHCF)
DC Health Care Reform and Innovation Administration at the Department of Health Care Finance (DHCF)
DC Long Term Care Administration at the Department of Health Care Finance (DHCF)
DC Villages
East River Family Strengthening Collaborative
House Calls at Washington Hospital Center
Howard University School of Social Work
Iona
Legal Counsel for the Elderly
Seabury
TERRIFIC Inc.
Veteran Based Services
Whitman Walker Health

## References

1. Jack CR, Jr., Knopman DS, Jagust WJ, et al. Hypothetical model of dynamic biomarkers of the Alzheimer's pathological cascade. *Lancet Neurol.* 2010;9(1):119-128.
2. Power MC, Mormino E, Soldan A, et al. Combined neuropathological pathways account for age-related risk of dementia. *Ann Neurol.* 2018;84(1):10-22.
3. Jack Jr CR, Knopman DS, Jagust WJ, et al. Tracking pathophysiological processes in Alzheimer's disease: an updated hypothetical model of dynamic biomarkers. *The Lancet Neurology.* 2013;12(2):207-216.
4. Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology.* 2007;69(24):2197-2204.
5. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V).* Arlington, VA: American Psychiatric Association; 2013.
6. Sperling RA, Aisen PS, Beckett LA, et al. Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement.* 2011;7(3):280-292.
7. Gianattasio KZ, Prather C, Glymour MM, Ciarleglio A, Power MC. Racial disparities and temporal trends in dementia misdiagnosis risk in the United States. *Alzheimers Dement (N Y).* 2019;5:891-898.
8. Taylor DH, Jr., Ostbye T, Langa KM, Weir D, Plassman BL. The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited. *J Alzheimers Dis.* 2009;17(4):807-815.
9. Lang L, Clifford A, Wei L, et al. Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. *BMJ Open.* 2017;7(2):e011146.
10. Power MC GK, Ciarleglio AC. Implications of the use of algorithmic diagnoses or Medicare claims to ascertain dementia. *Neuroepidemiology.* In Press.
11. Zissimopoulos JM, Tysinger BC, St Clair PA, Crimmins EM. The Impact of Changes in Population Health and Mortality on Future Prevalence of Alzheimer's Disease and Other Dementias in the United States. *J Gerontol B Psychol Sci Soc Sci.* 2018;73(suppl_1):S38-S47.
12. Matthews KA, Xu W, Gaglioti AH, et al. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged >/=65 years. *Alzheimers Dement.* 2019;15(1):17-24.
13. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology.* 2013;80(19):1778-1783.
14. U.S. Environmental Protection Agency. About Risk Assessment. https://www.epa.gov/risk/about-risk-assessment. Accessed September 7, 2020.
15. U.S. Census Bureau. Explore Census Data. https://data.census.gov/cedsci/. Accessed September 24, 2020.

16. Moore JT, Ricaldi JN, Rose CE, et al. Disparities in Incidence of COVID-19 Among Underrepresented Racial/Ethnic Groups in Counties Identified as Hotspots During June 5-18, 2020 - 22 States, February-June 2020. *MMWR Morb Mortal Wkly Rep.* 2020;69(33):1122-1126.
17. Dorn AV, Cooney RE, Sabin ML. COVID-19 exacerbating inequalities in the US. *Lancet.* 2020;395(10232):1243-1244.
18. Yancy CW. COVID-19 and African Americans. *JAMA.* 2020;323(19):1891-1892.
19. Apicella M, Campopiano MC, Mantuano M, Mazoni L, Coppelli A, Del Prato S. COVID-19 in people with diabetes: understanding the reasons for worse outcomes. *Lancet Diabetes Endocrinol.* 2020;8(9):782-792.
20. Wortham JM, Lee JT, Althomsons S, et al. Characteristics of Persons Who Died with COVID-19 - United States, February 12-May 18, 2020. *MMWR Morb Mortal Wkly Rep.* 2020;69(28):923-929.
21. U.S. Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System. https://www.cdc.gov/brfss/index.html. Accessed September 24, 2020.
22. Reitz C, Jun G, Naj A, et al. Variants in the ATP-binding cassette transporter (ABCA7), apolipoprotein E 4,and the risk of late-onset Alzheimer disease in African Americans. *JAMA.* 2013;309(14):1483-1492.
23. Ward A, Crean S, Mercaldi CJ, et al. Prevalence of apolipoprotein E4 genotype and homozygotes (APOE e4/4) among patients diagnosed with Alzheimer's disease: a systematic review and meta-analysis. *Neuroepidemiology.* 2012;38(1):1-17.
24. Mayeux R, Saunders AM, Shea S, et al. Utility of the apolipoprotein E genotype in the diagnosis of Alzheimer's disease. Alzheimer's Disease Centers Consortium on Apolipoprotein E and Alzheimer's Disease. *N Engl J Med.* 1998;338(8):506-511.
25. Evans DA, Bennett DA, Wilson RS, et al. Incidence of Alzheimer disease in a biracial urban community: relation to apolipoprotein E allele status. *Arch Neurol.* 2003;60(2):185-189.
26. Tang MX, Stern Y, Marder K, et al. The APOE-epsilon4 allele and the risk of Alzheimer disease among African Americans, whites, and Hispanics. *JAMA.* 1998;279(10):751-755.
27. Hendrie HC, Murrell J, Baiyewu O, et al. APOE epsilon4 and the risk for Alzheimer disease and cognitive decline in African Americans and Yoruba. *Int Psychogeriatr.* 2014;26(6):977-985.
28. Katz MJ, Lipton RB, Hall CB, et al. Age-specific and sex-specific prevalence and incidence of mild cognitive impairment, dementia, and Alzheimer dementia in blacks and whites: a report from the Einstein Aging Study. *Alzheimer Dis Assoc Disord.* 2012;26(4):335-343.
29. Riedel-Heller SG, Busse A, Aurich C, Matschinger H, Angermeyer MC. Prevalence of dementia according to DSM-III-R and ICD-10: results of the Leipzig Longitudinal Study of the Aged (LEILA75+) Part 1. *Br J Psychiatry.* 2001;179:250-254.
30. Rocca WA, Petersen RC, Knopman DS, et al. Trends in the incidence and prevalence of Alzheimer's disease, dementia, and cognitive impairment in the United States. *Alzheimers Dement.* 2011;7(1):80-93.

31. Wolters FJ, Chibnik LB, Waziry R, et al. Twenty-seven-year time trends in dementia incidence in Europe and the United States. *The Alzheimer Cohorts Consortium.* 2020;95(5):e519-e531.
32. Hebert LE, Scherr PA, McCann JJ, Beckett LA, Evans DA. Is the risk of developing Alzheimer's disease greater for women than for men? *Am J Epidemiol.* 2001;153(2):132-136.
33. Lautenschlager NT, Cupples LA, Rao VS, et al. Risk of dementia among relatives of Alzheimer's disease patients in the MIRAGE study: What is in store for the oldest old? *Neurology.* 1996;46(3):641-650.
34. Rajan KB, Weuve J, Barnes LL, Wilson RS, Evans DA. Prevalence and incidence of clinically diagnosed Alzheimer's disease dementia from 1994 to 2012 in a population study. *Alzheimers Dement.* 2019;15(1):1-7.
35. Knopman DS, Gottesman RF, Sharrett AR, et al. Mild Cognitive Impairment and Dementia Prevalence: The Atherosclerosis Risk in Communities Neurocognitive Study (ARIC-NCS). *Alzheimers Dement (Amst).* 2016;2:1-11.
36. Tang MX, Cross P, Andrews H, et al. Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology.* 2001;56(1):49-56.
37. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement.* 2016;12(3):216-224.
38. Moon H, Badana ANS, Hwang SY, Sears JS, Haley WE. Dementia Prevalence in Older Adults: Variation by Race/Ethnicity and Immigrant Status. *Am J Geriatr Psychiatry.* 2019;27(3):241-250.
39. Mehta KM, Yeo GW. Systematic review of dementia prevalence and incidence in United States race/ethnic populations. *Alzheimers Dement.* 2017;13(1):72-83.
40. Perkins P, Annegers JF, Doody RS, Cooke N, Aday L, Vernon SW. Incidence and prevalence of dementia in a multiethnic cohort of municipal retirees. *Neurology.* 1997;49(1):44-50.
41. Barnes LL, Bennett DA. Alzheimer's disease in African Americans: risk factors and challenges for the future. *Health Aff (Millwood).* 2014;33(4):580-586.
42. The National Institute on Aging. Causes of Alzheimer’s Disease: Assessing Risk for Alzheimer’s Disease. https://www.nia.nih.gov/health/assessing-risk-alzheimers-disease. Accessed September 24, 2020.
43. Korf ES, White LR, Scheltens P, Launer LJ. Brain aging in very old men with type 2 diabetes: the Honolulu-Asia Aging Study. *Diabetes Care.* 2006;29(10):2268-2274.
44. Areosa Sastre A, Vernooij RW, Gonzalez-Colaco Harmand M, Martinez G. Effect of the treatment of Type 2 diabetes mellitus on the development of cognitive impairment and dementia. *Cochrane Database Syst Rev.* 2017;6:CD003804.
45. Gorelick PB, Sacco RL, Smith DB, et al. Prevention of a first stroke: a review of guidelines and a multidisciplinary consensus statement from the National Stroke Association. *JAMA.* 1999;281(12):1112-1120.

46. Skrobot OA, Black SE, Chen C, et al. Progress toward standardized diagnosis of vascular cognitive impairment: Guidelines from the Vascular Impairment of Cognition Classification Consensus Study. *Alzheimers Dement.* 2018;14(3):280-292.
47. American Heart Association. Stroke Risk Factors You Can Control, Treat and Improve. https://www.stroke.org/en/about-stroke/stroke-risk-factors/stroke-risk-factors-you-can-control-treat-and-improve. Accessed September 24, 2020.
48. Global Council on Brain Health. The Brain Health Connection: GCBH Recommendations to Manage Cardiovascular Risks to Brain Health. 2020; Available at www.GlobalCouncilOnBrainHealth.org.
49. Power MC, Weuve J, Gagne JJ, McQueen MB, Viswanathan A, Blacker D. The association between blood pressure and incident Alzheimer disease: a systematic review and meta-analysis. *Epidemiology.* 2011;22(5):646-659.
50. Qiu C, Winblad B, Fratiglioni L. The age-dependent relation of blood pressure to cognitive function and dementia. *Lancet Neurol.* 2005;4(8):487-499.
51. Barnes DE, Yaffe K. The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol.* 2011;10(9):819-828.
52. Kloppenborg RP, van den Berg E, Kappelle LJ, Biessels GJ. Diabetes and other vascular risk factors for dementia: which factor matters most? A systematic review. *Eur J Pharmacol.* 2008;585(1):97-108.
53. Silva MVF, Loures CMG, Alves LCV, de Souza LC, Borges KBG, Carvalho MDG. Alzheimer's disease: risk factors and potentially protective measures. *J Biomed Sci.* 2019;26(1):33.
54. Rouch L, Cestac P, Hanon O, et al. Antihypertensive drugs, prevention of cognitive decline and dementia: a systematic review of observational studies, randomized controlled trials and meta-analyses, with discussion of potential mechanisms. *CNS Drugs.* 2015;29(2):113-130.
55. Tzourio C, Laurent S, Debette S. Is hypertension associated with an accelerated aging of the brain? *Hypertension.* 2014;63(5):894-903.
56. Kennelly SP, Lawlor BA, Kenny RA. Blood pressure and the risk for dementia: a double edged sword. *Ageing Res Rev.* 2009;8(2):61-70.
57. Kane RL, Butler M, Fink HA, et al. In: *Interventions to Prevent Age-Related Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer's-Type Dementia.* Rockville (MD)2017.
58. Sprint Mind Investigators for the SPRINT Research Group, Williamson JD, Pajewski NM, et al. Effect of Intensive vs Standard Blood Pressure Control on Probable Dementia: A Randomized Clinical Trial. *JAMA.* 2019;321(6):553-561.
59. U.S. Centers for Disease Control and Prevention. What is Dementia? . https://www.cdc.gov/aging/dementia/index.html. Updated April 5, 2019. Accessed September 2, 2020.
60. World Health Organization. Dementia. https://www.who.int/news-room/fact-sheets/detail/dementia Accessed September 24, 2020.
61. Anstey KJ, Lipnicki DM, Low LF. Cholesterol as a risk factor for dementia and cognitive decline: a systematic review of prospective studies with meta-analysis. *Am J Geriatr Psychiatry.* 2008;16(5):343-354.

62. Stewart R, White LR, Xue QL, Launer LJ. Twenty-six-year change in total cholesterol levels and incident dementia: the Honolulu-Asia Aging Study. *Arch Neurol.* 2007;64(1):103-107.
63. Mielke MM, Zandi PP, Shao H, et al. The 32-year relationship between cholesterol and dementia from midlife to late life. *Neurology.* 2010;75(21):1888-1895.
64. Beckett N, Nunes M, Bulpitt C. Is it advantageous to lower cholesterol in the elderly hypertensive? *Cardiovasc Drugs Ther.* 2000;14(4):397-405.
65. McGuinness B, Cardwell CR, Passmore P. Statin withdrawal in people with dementia. *Cochrane Database Syst Rev.* 2016;9:CD012050.
66. Power MC, Weuve J, Sharrett AR, Blacker D, Gottesman RF. Statins, cognition, and dementia-systematic review and methodological commentary. *Nat Rev Neurol.* 2015;11(4):220-229.
67. Beydoun MA, Beydoun HA, Wang Y. Obesity and central obesity as risk factors for incident dementia and its subtypes: a systematic review and meta-analysis. *Obes Rev.* 2008;9(3):204-218.
68. Sellbom KS, Gunstad J. Cognitive function and decline in obesity. *J Alzheimers Dis.* 2012;30 Suppl 2:S89-95.
69. Tolppanen AM, Ngandu T, Kareholt I, et al. Midlife and late-life body mass index and late-life dementia: results from a prospective population-based cohort. *J Alzheimers Dis.* 2014;38(1):201-209.
70. Kiliaan AJ, Arnoldussen IA, Gustafson DR. Adipokines: a link between obesity and dementia? *Lancet Neurol.* 2014;13(9):913-923.
71. Anjum I, Fayyaz M, Wajid A, Sohail W, Ali A. Does Obesity Increase the Risk of Dementia: A Literature Review. *Cureus.* 2018;10(5):e2660.
72. Fitzpatrick AL, Kuller LH, Lopez OL, et al. Midlife and late-life obesity and the risk of dementia: cardiovascular health study. *Arch Neurol.* 2009;66(3):336-342.
73. Gustafson D. A life course of adiposity and dementia. *Eur J Pharmacol.* 2008;585(1):163-175.
74. The National Institute on Aging. Causes of Alzheimer’s Disease: What Causes Alzheimer’s Disease? https://www.nia.nih.gov/health/what-causes-alzheimers-disease Accessed September 24, 2020.
75. American Heart Association. Vascular Dementia. https://www.stroke.org/en/about-stroke/effects-of-stroke/cognitive-and-communication-effects-of-stroke/vascular-dementia. Accessed September 29, 2020.
76. U.S. Centers for Disease Control and Prevention. About Heart Disease. https://www.cdc.gov/heartdisease/about.htm. Accessed September 24, 2020.
77. Mayo Clinic. Heart disease. https://www.mayoclinic.org/diseases-conditions/heart-disease/symptoms-causes/syc-20353118. Accessed September 24, 2020.
78. Durazzo TC, Mattsson N, Weiner MW, Alzheimer's Disease Neuroimaging I. Smoking and increased Alzheimer's disease risk: a review of potential mechanisms. *Alzheimers Dement.* 2014;10(3 Suppl):S122-145.

79. Blondell SJ, Hammersley-Mather R, Veerman JL. Does physical activity prevent cognitive decline and dementia?: A systematic review and meta-analysis of longitudinal studies. *BMC Public Health.* 2014;14:510.
80. Young J, Angevaren M, Rusted J, Tabet N. Aerobic exercise to improve cognitive function in older people without known cognitive impairment. *Cochrane Database Syst Rev.* 2015(4):CD005381.
81. Hafdi M, Hoevenaar-Blom MP, Richard E. Multi-domain interventions for the prevention of dementia and cognitive decline. *Cochrane Database of Systematic Reviews.* 2020(4).
82. Phillips C, Baktir MA, Srivatsan M, Salehi A. Neuroprotective effects of physical activity on the brain: a closer look at trophic factor signaling. *Front Cell Neurosci.* 2014;8:170.
83. Leckie RL, Oberlin LE, Voss MW, et al. BDNF mediates improvements in executive function following a 1-year exercise intervention. *Front Hum Neurosci.* 2014;8:985.
84. Diaz KM, Shimbo D. Physical activity and the prevention of hypertension. *Curr Hypertens Rep.* 2013;15(6):659-668.
85. Hardman RJ, Kennedy G, Macpherson H, Scholey AB, Pipingas A. Adherence to a Mediterranean-Style Diet and Effects on Cognition in Adults: A Qualitative Evaluation and Systematic Review of Longitudinal and Prospective Trials. *Front Nutr.* 2016;3:22.
86. Lourida I, Soni M, Thompson-Coon J, et al. Mediterranean diet, cognitive function, and dementia: a systematic review. *Epidemiology.* 2013;24(4):479-489.
87. Valls-Pedret C, Sala-Vila A, Serra-Mir M, et al. Mediterranean Diet and Age-Related Cognitive Decline: A Randomized Clinical Trial. *JAMA Intern Med.* 2015;175(7):1094-1103.
88. Frisardi V, Panza F, Seripa D, et al. Nutraceutical properties of Mediterranean diet and cognitive decline: possible underlying mechanisms. *J Alzheimers Dis.* 2010;22(3):715-740.
89. Dai J, Jones DP, Goldberg J, et al. Association between adherence to the Mediterranean diet and oxidative stress. *Am J Clin Nutr.* 2008;88(5):1364-1370.
90. Koyama A WJ, Jackson JW, Blacker D. Dietary Pattern. The AlzRisk Database. Alzheimer Research Forum. http://www.alzrisk.org/riskfactordoc.aspx?rfid=19. Accessed September 24, 2020.
91. Morris MC. Nutrition and risk of dementia: overview and methodological issues. *Ann N Y Acad Sci.* 2016;1367(1):31-37.
92. Canevelli M, Lucchini F, Quarata F, Bruno G, Cesari M. Nutrition and Dementia: Evidence for Preventive Approaches? *Nutrients.* 2016;8(3):144.
93. Butler M, Nelson VA, Davila H, et al. Over-the-Counter Supplement Interventions to Prevent Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer-Type Dementia: A Systematic Review. *Ann Intern Med.* 2018;168(1):52-62.
94. Gillette-Guyonnet S, Secher M, Vellas B. Nutrition and neurodegeneration: epidemiological evidence and challenges for future research. *Br J Clin Pharmacol.* 2013;75(3):738-755.
95. Ruitenberg A, van Swieten JC, Witteman JC, et al. Alcohol consumption and risk of dementia: the Rotterdam Study. *Lancet.* 2002;359(9303):281-286.

96. Weyerer S, Schaufele M, Wiese B, et al. Current alcohol consumption and its relationship to incident dementia: results from a 3-year follow-up study among primary care attenders aged 75 years and older. *Age Ageing.* 2011;40(4):456-463.
97. Sabia S, Fayosse A, Dumurgier J, et al. Alcohol consumption and risk of dementia: 23 year follow-up of Whitehall II cohort study. *BMJ.* 2018;362:k2927.
98. Anstey KJ, Mack HA, Cherbuin N. Alcohol consumption as a risk factor for dementia and cognitive decline: meta-analysis of prospective studies. *Am J Geriatr Psychiatry.* 2009;17(7):542-555.
99. Collins MA, Neafsey EJ, Mukamal KJ, et al. Alcohol in moderation, cardioprotection, and neuroprotection: epidemiological considerations and mechanistic studies. *Alcohol Clin Exp Res.* 2009;33(2):206-219.
100. Ridley NJ, Draper B, Withall A. Alcohol-related dementia: an update of the evidence. *Alzheimers Res Ther.* 2013;5(1):3.
101. Shi L, Chen SJ, Ma MY, et al. Sleep disturbances increase the risk of dementia: A systematic review and meta-analysis. *Sleep Med Rev.* 2018;40:4-16.
102. Bubu OM, Brannick M, Mortimer J, et al. Sleep, Cognitive impairment, and Alzheimer's disease: A Systematic Review and Meta-Analysis. *Sleep.* 2017;40(1).
103. Kukull WA, Higdon R, Bowen JD, et al. Dementia and Alzheimer disease incidence: a prospective cohort study. *Arch Neurol.* 2002;59(11):1737-1746.
104. Jefferson AL, Gibbons LE, Rentz DM, et al. A life course model of cognitive activities, socioeconomic status, education, reading ability, and cognition. *J Am Geriatr Soc.* 2011;59(8):1403-1411.
105. Evans DA, Hebert LE, Beckett LA, et al. Education and other measures of socioeconomic status and risk of incident Alzheimer disease in a defined population of older persons. *Arch Neurol.* 1997;54(11):1399-1405.
106. Sharp ES, Gatz M. Relationship between education and dementia: an updated systematic review. *Alzheimer Dis Assoc Disord.* 2011;25(4):289-304.
107. Stern Y, Gurland B, Tatemichi TK, Tang MX, Wilder D, Mayeux R. Influence of education and occupation on the incidence of Alzheimer's disease. *JAMA.* 1994;271(13):1004-1010.
108. McDowell I, Xi G, Lindsay J, Tierney M. Mapping the connections between education and dementia. *J Clin Exp Neuropsychol.* 2007;29(2):127-141.
109. Ngandu T, von Strauss E, Helkala EL, et al. Education and dementia: what lies behind the association? *Neurology.* 2007;69(14):1442-1450.
110. Stern Y. Cognitive reserve in ageing and Alzheimer's disease. *Lancet Neurol.* 2012;11(11):1006-1012.
111. Fratiglioni L, Paillard-Borg S, Winblad B. An active and socially integrated lifestyle in late life might protect against dementia. *Lancet Neurol.* 2004;3(6):343-353.
112. Ertel KA, Glymour MM, Berkman LF. Effects of social integration on preserving memory function in a nationally representative US elderly population. *Am J Public Health.* 2008;98(7):1215-1220.
113. James BD, Wilson RS, Barnes LL, Bennett DA. Late-life social activity and cognitive decline in old age. *J Int Neuropsychol Soc.* 2011;17(6):998-1005.

114. Barnes LL, Mendes de Leon CF, Wilson RS, Bienias JL, Evans DA. Social resources and cognitive decline in a population of older African Americans and whites. *Neurology.* 2004;63(12):2322-2326.
115. Seeman TE, Miller-Martinez DM, Stein Merkin S, Lachman ME, Tun PA, Karlamangla AS. Histories of social engagement and adult cognition: midlife in the U.S. study. *J Gerontol B Psychol Sci Soc Sci.* 2011;66 Suppl 1:i141-152.
116. O'Connor ML, Edwards JD, Wadley VG, Crowe M. Changes in mobility among older adults with psychometrically defined mild cognitive impairment. *J Gerontol B Psychol Sci Soc Sci.* 2010;65B(3):306-316.
117. Kotwal AA, Kim J, Waite L, Dale W. Social Function and Cognitive Status: Results from a US Nationally Representative Survey of Older Adults. *J Gen Intern Med.* 2016;31(8):854-862.
118. Hsiung GY, Alipour S, Jacova C, et al. Transition from cognitively impaired not demented to Alzheimer's disease: an analysis of changes in functional abilities in a dementia clinic cohort. *Dement Geriatr Cogn Disord.* 2008;25(6):483-490.
119. Ownby RL, Crocco E, Acevedo A, John V, Loewenstein D. Depression and risk for Alzheimer disease: systematic review, meta-analysis, and metaregression analysis. *Arch Gen Psychiatry.* 2006;63(5):530-538.
120. Barnes DE, Yaffe K, Byers AL, McCormick M, Schaefer C, Whitmer RA. Midlife vs late-life depressive symptoms and risk of dementia: differential effects for Alzheimer disease and vascular dementia. *Arch Gen Psychiatry.* 2012;69(5):493-498.
121. Baumgart M, Snyder HM, Carrillo MC, Fazio S, Kim H, Johns H. Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimers Dement.* 2015;11(6):718-726.
122. Shively S, Scher AI, Perl DP, Diaz-Arrastia R. Dementia resulting from traumatic brain injury: what is the pathology? *Arch Neurol.* 2012;69(10):1245-1251.
123. Plassman BL, Havlik RJ, Steffens DC, et al. Documented head injury in early adulthood and risk of Alzheimer's disease and other dementias. *Neurology.* 2000;55(8):1158-1166.
124. Barnes DE, Kaup A, Kirby KA, Byers AL, Diaz-Arrastia R, Yaffe K. Traumatic brain injury and risk of dementia in older veterans. *Neurology.* 2014;83(4):312-319.
125. Fleminger S, Oliver DL, Lovestone S, Rabe-Hesketh S, Giora A. Head injury as a risk factor for Alzheimer's disease: the evidence 10 years on; a partial replication. *J Neurol Neurosurg Psychiatry.* 2003;74(7):857-862.
126. Crane PK, Gibbons LE, Dams-O'Connor K, et al. Association of Traumatic Brain Injury With Late-Life Neurodegenerative Conditions and Neuropathologic Findings. *JAMA Neurol.* 2016;73(9):1062-1069.
127. Chosy EJ, Gross N, Meyer M, et al. Brain Injury and Later-Life Cognitive Impairment and Neuropathology: The Honolulu-Asia Aging Study. *J Alzheimers Dis.* 2020;73(1):317-325.
128. Dams-O'Connor K, Guetta G, Hahn-Ketter AE, Fedor A. Traumatic brain injury as a risk factor for Alzheimer's disease: current knowledge and future directions. *Neurodegener Dis Manag.* 2016;6(5):417-429.
129. Mehta KM, Ott A, Kalmijn S, et al. Head trauma and risk of dementia and Alzheimer's disease: The Rotterdam Study. *Neurology.* 1999;53(9):1959-1962.

130. Helmes E, Ostbye T, Steenhuis RE. Incremental contribution of reported previous head injury to the prediction of diagnosis and cognitive functioning in older adults. *Brain Inj.* 2011;25(4):338-347.
131. Launer LJ, Andersen K, Dewey ME, et al. Rates and risk factors for dementia and Alzheimer's disease: results from EURODEM pooled analyses. EURODEM Incidence Research Group and Work Groups. European Studies of Dementia. *Neurology.* 1999;52(1):78-84.
132. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet.* 2020;396(10248):413-446.
133. Loughrey DG, Kelly ME, Kelley GA, Brennan S, Lawlor BA. Association of Age-Related Hearing Loss With Cognitive Function, Cognitive Impairment, and Dementia: A Systematic Review and Meta-analysis. *JAMA Otolaryngol Head Neck Surg.* 2018;144(2):115-126.
134. Wayne RV, Johnsrude IS. A review of causal mechanisms underlying the link between age-related hearing loss and cognitive decline. *Ageing Res Rev.* 2015;23(Pt B):154-166.
135. Gates GA, Gibbons LE, McCurry SM, Crane PK, Feeney MP, Larson EB. Executive dysfunction and presbycusis in older persons with and without memory loss and dementia. *Cogn Behav Neurol.* 2010;23(4):218-223.
136. Thomson RS, Auduong P, Miller AT, Gurgel RK. Hearing loss as a risk factor for dementia: A systematic review. *Laryngoscope Investig Otolaryngol.* 2017;2(2):69-79.
137. Search of: Hearing loss - List Results. (n.d.). Retrieved from https://clinicaltrials.gov/ct2/results?cond=hearing+loss
138. Power MC, Adar SD, Yanosky JD, Weuve J. Exposure to air pollution as a potential contributor to cognitive function, cognitive decline, brain imaging, and dementia: A systematic review of epidemiologic research. *Neurotoxicology.* 2016;56:235-253.
139. Paul KC, Haan M, Mayeda ER, Ritz BR. Ambient Air Pollution, Noise, and Late-Life Cognitive Decline and Dementia Risk. *Annu Rev Public Health.* 2019;40:203-220.
140. Brook RD, Rajagopalan S, Pope CA, 3rd, et al. Particulate matter air pollution and cardiovascular disease: An update to the scientific statement from the American Heart Association. *Circulation.* 2010;121(21):2331-2378.
141. Block ML, Calderon-Garciduenas L. Air pollution: mechanisms of neuroinflammation and CNS disease. *Trends Neurosci.* 2009;32(9):506-516.
142. Yates LA, Ziser S, Spector A, Orrell M. Cognitive leisure activities and future risk of cognitive impairment and dementia: systematic review and meta-analysis. *Int Psychogeriatr.* 2016;28(11):1791-1806.
143. Sajeev G, Weuve J, Jackson JW, et al. Late-life Cognitive Activity and Dementia: A Systematic Review and Bias Analysis. *Epidemiology.* 2016;27(5):732-742.
144. Martin M, Clare L, Altgassen AM, Cameron MH, Zehnder F. Cognition-based interventions for healthy older people and people with mild cognitive impairment. *Cochrane Database Syst Rev.* 2011(1):CD006220.
145. Valenzuela M, Sachdev P. Can cognitive exercise prevent the onset of dementia? Systematic review of randomized clinical trials with longitudinal follow-up. *Am J Geriatr Psychiatry.* 2009;17(3):179-187.

146. Ball K, Berch DB, Helmers KF, et al. Effects of cognitive training interventions with older adults: a randomized controlled trial. *JAMA.* 2002;288(18):2271-2281.
147. Willis SL, Tennstedt SL, Marsiske M, et al. Long-term effects of cognitive training on everyday functional outcomes in older adults. *JAMA.* 2006;296(23):2805-2814.
148. Rebok GW, Ball K, Guey LT, et al. Ten-year effects of the advanced cognitive training for independent and vital elderly cognitive training trial on cognition and everyday functioning in older adults. *J Am Geriatr Soc.* 2014;62(1):16-24.
149. Unverzagt FW, Guey LT, Jones RN, et al. ACTIVE cognitive training and rates of incident dementia. *J Int Neuropsychol Soc.* 2012;18(4):669-677.
150. González-Salvador MT, Arango C, Lyketsos CG, Barba AC. The stress and psychological morbidity of the Alzheimer patient caregiver. *Int J Geriatr Psychiatry.* 1999;14(9):701-710.
151. Ory MG, Hoffman RR, 3rd, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist.* 1999;39(2):177-185.
152. Bennett DA, Schneider JA, Buchman AS, Barnes LL, Boyle PA, Wilson RS. Overview and findings from the rush Memory and Aging Project. *Curr Alzheimer Res.* 2012;9(6):646-663.
153. Barnes LL, Shah RC, Aggarwal NT, Bennett DA, Schneider JA. The Minority Aging Research Study: ongoing efforts to obtain brain donation in African Americans without dementia. *Curr Alzheimer Res.* 2012;9(6):734-745.
154. Rush Alzheimer’s Disease Center (RADC). RADC Research Resource Sharing Hub. https://www.radc.rush.edu/. Accessed June 11, 2020.
155. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology.* 2007;29(1-2):125-132.
156. U.S. Census Bureau. Understanding and Using ACS Single-Year and Multiyear Estimates. In: *Understanding and Using American Community Survey Data: What All Data Users Need to Know.* Washington, DC: U.S. Government Printing Office; 2018.
157. U.S. Census Bureau. When to Use 1-year, 3-year, or 5-year Estimates. https://www.census.gov/programs-surveys/acs/guidance/estimates.html. Accessed September 24, 2020.