

Special Report

On the Front Lines: Primary Care Physicians and Alzheimer's Care in America



82% of primary care physicians say they are on the front lines of providing dementia care.

Alzheimer's and other dementias represent a growing crisis in America. As reported in the Prevalence section (see page 17) of this year's *Alzheimer's Disease Facts and Figures*, there are currently more than 5 million Americans living with Alzheimer's dementia, a number which is projected to increase to nearly 14 million by the year 2050. Meanwhile, there is a shortage of specialty physicians to provide care for the large and increasing number of people with Alzheimer's dementia in the United States. As a result, the responsibility for medical care rests mainly with primary care physicians. This Special Report examines the current gaps and projected future shortages in specialty care for Alzheimer's and other dementias. It also explores the challenges primary care physicians face in caring for those currently living with dementia and in meeting the future care needs of an aging U.S. population. This report concludes with recommendations to address these shortages and challenges so more Americans have access to dementia care.

Who Diagnoses and Provides Medical Care?

Medical care for people with Alzheimer's and other dementias involves a broad array of practitioners, including physicians, nurses, neuropsychologists and allied health care professionals such as occupational and physical therapists and home health aides. In this report, we focus on primary care physicians (family medicine, internal medicine, general practice) and specialists such as geriatricians, neurologists, geriatric psychiatrists and neuropsychologists. Given the complexity of diagnosing and managing treatment for people living with dementia, there is general agreement that having a robust workforce of specialists would be ideal to optimize their care. However, the shortage of such specialists means that the major responsibility for diagnosing and treating people living with dementia lies with primary care physicians.

For example, one recent study⁵⁹⁷ found that the vast majority of older Americans diagnosed with dementia never see a dementia care specialist and are overwhelmingly diagnosed and cared for by non-specialists. Specifically,

the study found that 85% of people first diagnosed with dementia were diagnosed by a non-dementia specialist physician, usually a primary care physician. The same study found that one year after diagnosis, less than a quarter of patients had seen a dementia specialist. After five years, the percentage of patients who had seen a dementia specialist had only increased to 36%. Specialty care follow-up was particularly low for Hispanic and Asian people.

Growing Need, Projected Shortages in Specialists

As noted in the Prevalence section, between 2020 and 2050 the size of America's older population (those 65 and over) is expected to increase dramatically. As the size of the older population grows, the number of individuals living with Alzheimer's dementia will also increase. Today approximately one in 10 people age 65 and older has Alzheimer's dementia. At the same time, however, the workforce to care for the older population is currently, and is likely to continue to be, inadequate.

According to the National Center for Health Workforce Analysis⁵⁹⁸, there was already a shortage of geriatricians in 2013, and although a modest increase in supply was projected by 2025, it was not expected to meet demand. Trends in medical training also point to a growing shortage of geriatricians into the future. For example, geriatrics-related graduate medical education programs grew only 1.1% from the 2001-2002 academic year to the 2017-2018 academic year.⁵⁹⁹ Similarly, a study of the current and future U.S. neurology workforce projected a 19% shortage of neurologists by 2025.⁶⁰⁰

We project large increases in the need for specialists to care for people living with Alzheimer's dementia in 2050. Table 18 shows state-by-state projections for the number of geriatricians needed in 2050. As a nation, we need to triple the number of geriatricians who were practicing in 2019 to have enough geriatricians to care for those 65 and older who are projected to have Alzheimer's dementia in 2050 (approximately 10% of the population age 65 and older). However, the number must increase nine times to have enough geriatricians to care for the 30% of the population age 65 and older estimated by the National Center for Health Workforce Analysis to need geriatrician care. Similar analyses also show large projected needs for neurologists, geriatric psychiatrists and neuropsychologists, specialists who provide critical expertise in dementia diagnosis and care.

These shortages will affect states differently. The gaps are small in some states. For example, New York, Hawaii and Washington, D.C., appear well-positioned to achieve the relatively modest increases they need. In contrast, 14 states need to at least quintuple the number of

TABLE 18

Projected Geriatrician Needs in 2050 by State

State	Number of Geriatricians in 2019	Number of Geriatricians Needed in 2050 to Serve 10% of Those 65 and Older	Number of Geriatricians Needed in 2050 to Serve 30% of Those 65 and Older	State	Number of Geriatricians in 2019	Number of Geriatricians Needed in 2050 to Serve 10% of Those 65 and Older	Number of Geriatricians Needed in 2050 to Serve 30% of Those 65 and Older
Alabama	44	228	684	Montana	8	59	177
Alaska	6	31	92	Nebraska	23	84	253
Arizona	89	363	1,089	Nevada	40	158	474
Arkansas	51	134	402	New Hampshire	30	72	217
California	590	1,676	5,029	New Jersey	205	398	1,193
Colorado	89	289	867	New Mexico	29	93	279
Connecticut	99	166	497	New York	605	818	2,454
Delaware	17	55	165	North Carolina	159	535	1,606
District of Columbia	37	28	83	North Dakota	15	34	103
Florida	348	1,365	4,096	Ohio	163	537	1,611
Georgia	96	492	1,476	Oklahoma	28	171	512
Hawaii	61	64	192	Oregon	62	232	695
Idaho	10	87	261	Pennsylvania	278	601	1,803
Illinois	218	517	1,551	Rhode Island	32	49	147
Indiana	65	299	897	South Carolina	66	288	865
Iowa	24	142	426	South Dakota	10	44	131
Kansas	23	121	364	Tennessee	40	343	1,029
Kentucky	34	207	622	Texas	342	1,255	3,766
Louisiana	31	198	595	Utah	21	114	341
Maine	37	71	213	Vermont	5	32	95
Maryland	150	288	865	Virginia	103	406	1,218
Massachusetts	206	347	1,042	Washington	132	399	1,198
Michigan	169	465	1,394	West Virginia	19	83	250
Minnesota	93	270	811	Wisconsin	84	273	820
Mississippi	25	124	373	Wyoming	4	26	79
Missouri	103	283	849	U.S. Total	5,218	15,417	46,252

The 10% column shows how many geriatricians will be needed to serve only those age 65 and older projected to have Alzheimer's dementia in 2050, assuming the percentage of people age 65 and older with Alzheimer's dementia in that age group remains at 10%. The 30% column shows how many geriatricians will be needed to serve the 30% of people age 65 and older in 2050 who need geriatrician care, regardless of whether they have dementia, according to the National Center for Health Workforce Analysis.⁵⁹⁸ The number of practicing geriatricians in 2019 was provided by IQVIA and includes physicians with geriatrics as either their primary or secondary specialty. Calculations for 2050 assume each geriatrician can care for up to 700 patients.⁵⁹⁸ The underlying state-by-state estimates of the 2050 population age 65 and older were provided by Claritas Pop-Facts 2020.

practicing geriatricians by 2050 to care for those 65 and older projected to have Alzheimer's dementia, or increase the number by 15 times to care for the 30% of the population age 65 and older projected to need geriatrician care. Two states, Tennessee and Idaho, will need to increase the number of geriatricians by nine times just to meet the care needs of those projected to have Alzheimer's dementia, or by 26 times to meet the needs of all those projected to need geriatrician care.

Primary Care Physicians

With a shortage of medical specialists to meet the current and future needs for Alzheimer's dementia care in the United States, primary care physicians (PCPs) will play an increasingly important role in caring for individuals across the disease continuum — from identifying warning signs, to providing competent diagnoses, to meeting the ongoing care and support needs for patients living with a complex, progressive and ultimately fatal disease.

While PCPs are clearly on the front lines, little is known about the extent of PCPs' preparedness to meet the growing demands for dementia care in the clinical setting. To learn more about PCPs' experiences, exposure and attitudes about their medical education and training in dementia care, the Alzheimer's Association commissioned Versta Research to conduct surveys of 1) PCPs,^{A20} 2) recent medical school graduates currently completing a residency in primary care^{A21} and 3) recent primary care residency graduates.^{A22} All surveys were conducted December 11-26, 2019.

The Alzheimer's Association surveys revealed:

- PCPs recognize they are on the front lines of diagnosing and providing care for Alzheimer's and other dementias.
- Half of PCPs believe the medical profession is not prepared to meet the expected increase in demand.
- More than half of PCPs say there are not enough specialists to receive patient referrals.
- Medical school and residency programs in primary care offer very limited coursework and patient contact related to Alzheimer's and other dementias.
- PCPs feel a duty and are committed to staying current on the latest information about the care of patients with Alzheimer's and other dementias, particularly disease management and treatment, screening and testing, and diagnosis.
- Despite this, fewer than half of PCPs have pursued additional training in dementia care since medical school and residency, noting challenges associated with obtaining such training.

Alzheimer's Association Surveys

Physicians included in the Alzheimer's Association Primary Care Physician Dementia Training Survey^{A20} were recruited via WebMD's Medscape Physician Panel, which includes 68% of all practicing primary care physicians (PCPs) in the United States. To qualify for the survey, PCPs had to have been in practice for at least two years, spend at least 50% of their time in direct patient care, and have a practice in which at least 10% of their patients were age 65 or older. A total of 1,000 PCPs, balanced by age, gender, years in practice, type of practice, specialty and region to match the total U.S. population of PCPs, were included in the survey.^{A20}

A total of 202 current PCP residents in general, family or internal medicine who completed their medical school training within the last two years were recruited to participate in the Alzheimer's Association Recent Medical School Graduate Dementia Training Survey^{A21} through WebMD's Medscape Healthcare Professional Panel.

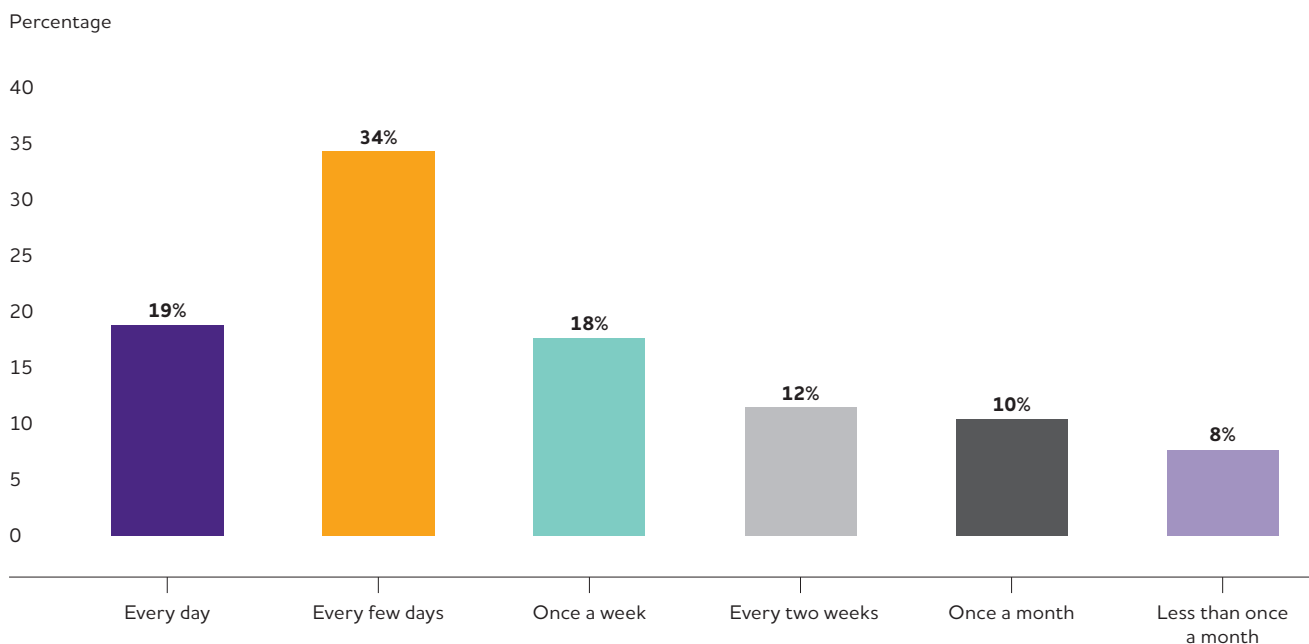
PCPs who had completed their residency within the last two years were recruited to participate in the Alzheimer's Association Recent Primary Care Resident Dementia Training Survey^{A22} through WebMD's Medscape Physician Panel. The sample included 200 PCPs and was matched to the full population of PCPs who are in their first two years of practice based on age, gender, specialty and region.^{A22}

- Nearly two in five PCPs say their own experience in treating patients has been one of the most important teachers, second only to continuing medical education (CME) courses.

Overall, the results of the Alzheimer's Association surveys underscore the important role PCPs play in providing critical dementia care. Findings also highlight the need for additional dementia care training opportunities for PCPs, both during medical school and residency and in subsequent clinical practice.

FIGURE 17

Frequency of Primary Care Physicians Receiving Questions about Alzheimer's or Other Dementias from Patients Age 65 and Older



Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.^{A20}

Survey Results

Patient Population

The Alzheimer's Association Primary Care Physician Dementia Care Training Survey revealed that more than four in five PCPs (82%) believe they are on the front lines of providing critical elements of dementia care for their patients. PCPs reported that, on average, 40% of their patients are age 65 and older and, of these, 13% have been diagnosed with Alzheimer's or other dementias.

The survey also demonstrated that the topic of dementia is one that comes up frequently during patient visits.

The majority (53%) of PCPs receive questions related to Alzheimer's or other dementias from their patients age 65 and older, or their families, every few days or more, with nearly one in five (19%) receiving these questions on a daily basis (Figure 17).

PCPs report the number of patients with Alzheimer's disease is growing. Almost nine in 10 PCPs (87%) expect the number of patients they see with dementia to increase over the next five years, and one-third (33%) expect the number of diagnosed patients to increase "a lot."

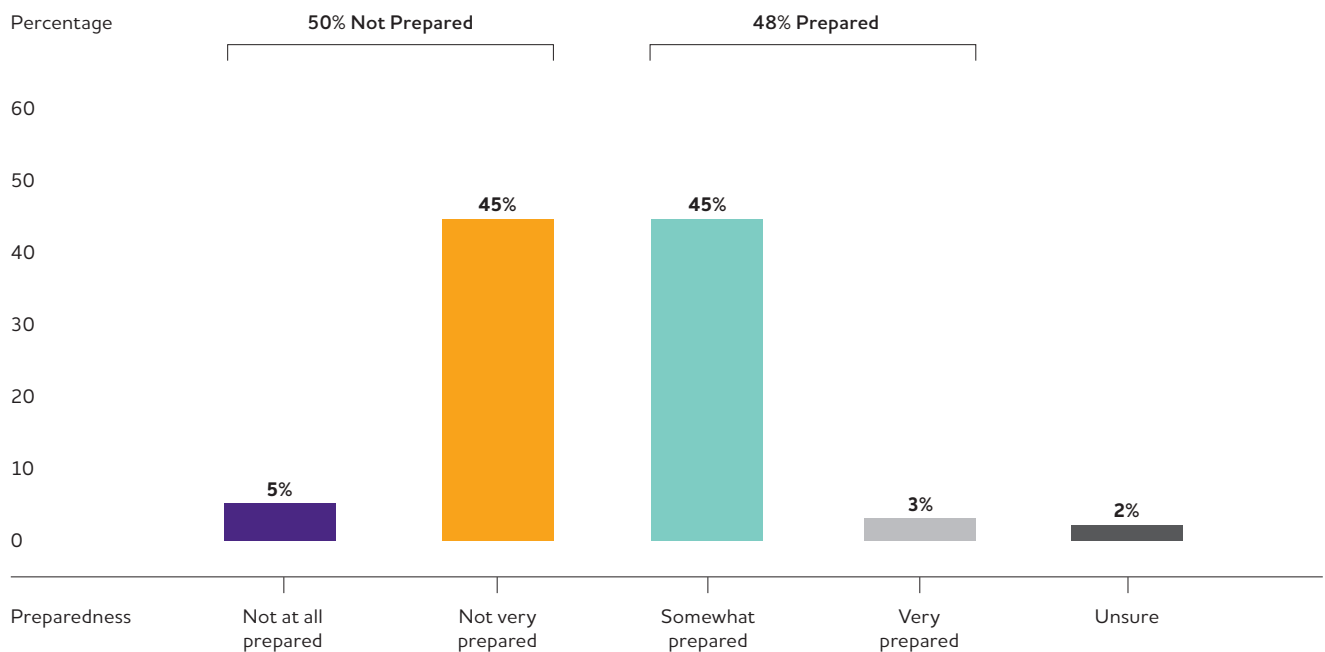
Management of Patients

Despite knowing they are on the front lines of dementia care, a significant number of PCPs surveyed reported that they do not feel adequately prepared to care for patients with Alzheimer's and other dementias. More than one-quarter (27%) report being only sometimes or never comfortable answering patient questions about Alzheimer's or other dementias. Moreover, even though the vast majority of diagnoses are made by PCPs, nearly four in 10 PCPs (39%) report never or only sometimes being comfortable personally making a diagnosis of Alzheimer's or other dementias. In addition, half of PCPs say that the medical profession is either "not very prepared" or "not at all prepared" to care for the growing number of people living with Alzheimer's or other dementias (Figure 18, see page 68).

To care for their patients optimally, nearly one-third (32%) of PCPs make specialist referrals for their dementia patients at least once a month. However, most PCPs (55%) report that there are not enough specialists in their area to meet patient demand (Figure 19, see page 69). There was a substantial difference in PCPs' report of specialist availability depending on whether their practice was located in an urban or rural setting. While 44% of PCPs in a large city and 54% of those

FIGURE 18

Medical Profession's Preparedness to Care for People Living with Alzheimer's and Other Dementias



Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.^{A20}

located in a suburb near a large city reported that there are not enough specialists in their area, 63% of PCPs in a small city or town and 71% of those in a rural area said the same.

Medical School and Residency Training in Dementia Care

The vast majority of PCPs (91%) had at least some training in the diagnosis and care of people with Alzheimer's and other dementias in medical school, but most of those (66%) describe it as being "very little." Almost one-quarter (22%) of all PCPs had no residency training in dementia diagnosis and care. Of the 78% who did undergo training, 65% reported the amount was "very little."

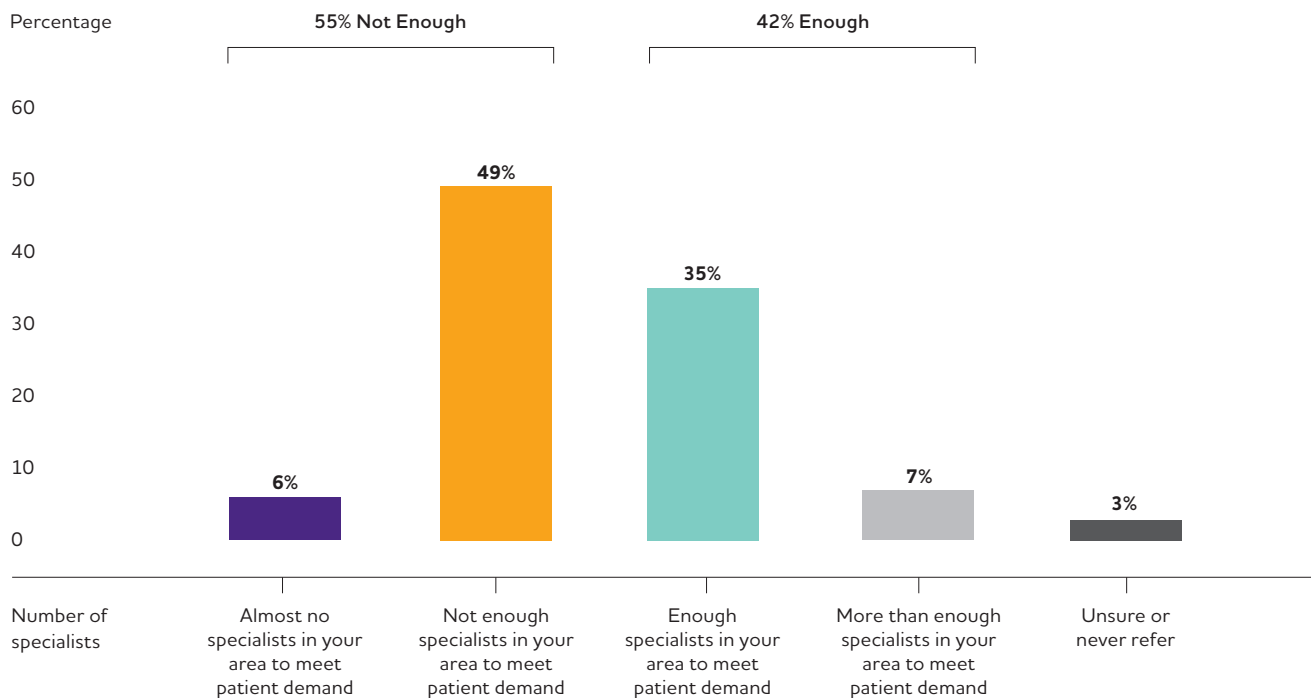
Encouragingly, this trend seems to be changing. A greater proportion of recently trained PCPs report medical school and residency training in dementia care compared with PCPs with a greater number of years in practice. Ninety-eight percent of PCPs in practice for 2-9 years report at least some dementia training in medical school, compared with 81% of those with 30 or more years in practice. Similarly, 85% of PCPs in practice for 2-9 years report receiving dementia training during residency, compared with 65% of PCPs with 30 years or more of practice. However, regardless of how much training they had, most PCPs (78%) said that medical school and residency can never fully prepare a physician for dementia care.

To better understand the dementia training new PCPs undergo, the Alzheimer's Association also surveyed recent medical school and residency graduates. The survey of first- and second-year PCP residents revealed an average of 41 hours of medical school coursework that specifically focused on dementia, including Alzheimer's. However more than one in five (21%) reported having fewer than 20 hours of dementia coursework during medical school. During their clinical training in medical school, they reported seeing an average of just 20 patients with dementia.

The survey of recent residents (currently in their first or second year of practice) revealed that residents had an average of eight hours of formal curricular training focused specifically on Alzheimer's or other dementias, and one-quarter (26%) reported having fewer than two hours. On average, recent residents saw and helped 50 patients with dementia during their residency training. However, they were only involved in diagnostic workup for 10 people with dementia who were undiagnosed when initially seen. Only 18% of recent residents report feeling "very prepared" to provide dementia care in practice, compared with 82% who feel "somewhat," "not very" or "not at all" prepared.

FIGURE 19

Availability of Dementia Specialists for Patient Referral



Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.^{A20}

Keeping Current

Finding New Developments

The Alzheimer's Association surveys revealed that virtually all PCPs (99%) believe it is important to stay current on new developments in dementia care. Similar responses were found among recent medical school graduates (99%) and recent residents (100%). PCPs also expressed the following:

- 93% feel a duty to patients to keep up with new developments in diagnosis and care.
- 92% believe patients and caregivers expect them to know the latest thinking and best practices around dementia care.
- 92% believe dementia care is a rapidly evolving area of medicine that requires ongoing learning and training.

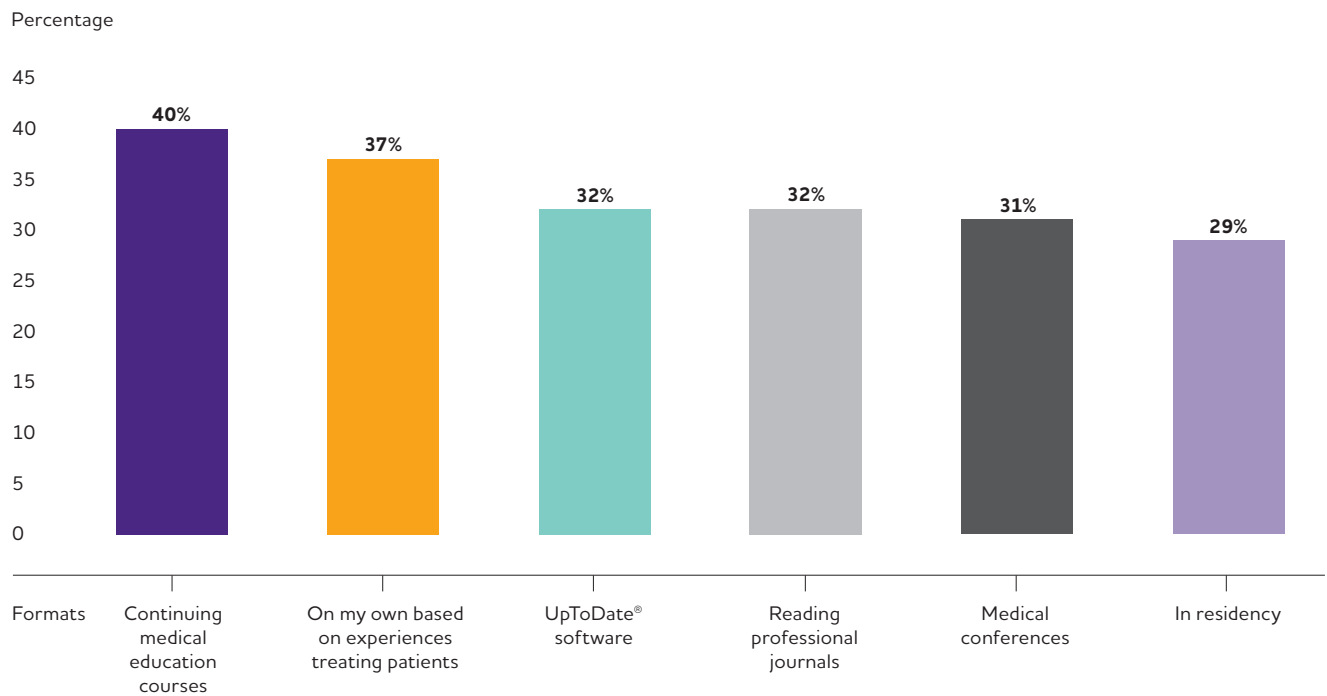
In addition, the surveys found that more than two-thirds of PCPs (69%) say they are always learning about the diagnosis and care of people with Alzheimer's and other dementias, and half (50%) say they put in a lot of time and effort keeping up with new developments. However, more than three in five (63%) feel they don't have enough time to keep up with all of the new developments and half (53%) say the extent to which they are keeping up with the new developments in dementia care is "only a little" or "not at all."

PCPs have enormous demands on their time and energy, across all health-related domains, so ensuring that PCPs have readily accessible, high quality training opportunities is an important challenge for the field.

The most important areas where PCPs want to stay current on Alzheimer's and other dementias include management and treatment (83%), screening and testing (69%), and diagnosis (64%). These same three areas also ranked as most important in the surveys of recent medical school graduates and recent residents. Additional areas where PCPs want to stay current include: prevention (49%), family support (49%), managing dementia alongside other conditions (46%), signs and symptoms (44%), reducing risk (41%), patient support (40%), end-of-life care (31%), palliative care and hospice (28%), coordinating care with other health care providers (24%), quality improvement measures (20%), pathophysiology (19%) and clinical trials (16%).

Additional Training Opportunities

To keep up to date, PCPs are following new developments in dementia care mainly by scanning journals or content summaries for newly published research (77%) or scanning CME offerings for new training opportunities (66%).^{A23} However, only two of five PCPs (42%) have completed

FIGURE 20**Where Primary Care Physicians Learned the Most about Dementia Diagnosis and Care**

Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.^{A20}

additional training specifically on dementia care since their residency. The most common formats for additional training are CME courses (91%), medical conferences (68%), reading professional journals (67%) and UpToDate® software that provides clinical resources to support physician practice (53%).^{A24} The vast majority (89%) of PCPs feel that staying current with dementia diagnosis and care developments requires more than just fulfilling CME requirements, and when learning, the majority (55%) try to go deeper than what most CME offers.

When asked specifically about additional training opportunities, 58% of PCPs feel that the quality of existing training options is either good or excellent, though challenges in obtaining the training were noted. Nearly a third (31%) say the current options are difficult to access, and half (49%) say there are too few options for continuing education and training on dementia care. In fact, 37% reported that they learned the most about dementia care from their own experiences treating patients, second only to the 40% who reported learning the most from CME courses (Figure 20).

This finding highlights a need for better dementia training programs for PCPs. Additional sources where PCPs have learned the most about dementia diagnosis and care include UpToDate® (32%), professional journals (32%), medical conferences (31%) and in residency (29%).^{A25}

The reasons provided by PCPs for pursuing additional dementia care training include general ongoing patient needs given their patient population (70%), specific patient problems or needs they are trying to solve (64%), a professional obligation to stay current (60%), or their own personal or professional interest in the topic (53%). Few PCPs have pursued additional training due to requirements for medical licensing (11%), health insurance companies or other payers (3%), or their employer (1%).

PCPs who haven't pursued additional training say it's because they don't have time (38%) and typically refer patients with Alzheimer's or other dementias to other physicians (35%). Just 19% of those who haven't pursued additional training say it's because they feel confident in how their dementia patients are being managed.^{A26}

Meeting Future Demand

This Alzheimer's Association dementia care analysis and surveys should sound an alarm regarding the future of dementia care in America. This report indicates a shortage of dementia care specialists and a PCP community committed, but not always adequately prepared, to meet the increased demands of an aging population.

One way to address shortages in the workforce is through scholarship and loan forgiveness programs offered by federal and state governments. Studies have found that loan repayment programs are correlated with increasing the number of physicians practicing in rural areas⁶⁰¹ and directly influence the decision of osteopathic medical graduates to become primary care physicians.⁶⁰² A large increase between 2002 and 2009 in the number of young people choosing nursing as a career followed the large increase in federal funding for nursing workforce development, which includes loan repayment and scholarships.⁶⁰³ A report on the geriatric workforce by the Institute of Medicine (now known as the National Academy of Medicine) concluded that "programs that link financial support to service have been effective in increasing the numbers of health care professionals that serve in underserved areas of the country" and that such programs "serve as good models for the development of similar programs to address shortages of geriatric providers."⁴⁷⁶

Another approach that may increase the number of providers available to diagnose and treat those with Alzheimer's and other dementias is through educational funding. For example, federal funding of departments of family medicine at U.S. medical schools is associated with an expansion of the primary care workforce.⁶⁰⁴ In addition, a recent demonstration project by the Centers for Medicare & Medicaid Services (CMS) found that funding for clinical education of Advanced Practice Registered Nurses (APRN) resulted in a 54% increase in APRN student enrollment, with graduations increasing 67%.⁶⁰⁵

In addition to policies that strengthen the specialty workforce, federal and state support is needed for programs that build capacity in primary care. One example is Project ECHO® (Extension for Community Healthcare Outcomes), a highly successful tele-mentoring program for health care providers developed by the University of New Mexico. Project ECHO has been shown to improve primary care for multiple diseases, including hepatitis C⁶⁰⁶ and complex diabetes.⁶⁰⁷ The Alzheimer's Association is launching a global initiative to build primary care capacity for dementia care through expanded use of this model.

Another approach to bridging the gap is to expand collaborative and coordinated care programs, which rely heavily on non-specialists. Pilot programs for individuals

with dementia have reduced hospital and emergency room visits^{502,608} and nursing home placement.⁵⁸⁵ In the UCLA Alzheimer's and Dementia Care Program, dementia care management is provided by a nurse practitioner supervised by a primary care physician. After one year in the program, 58% of people living with dementia and 63% of their caregivers showed clinical benefit on validated instruments,⁵⁰⁸ and the gross savings to Medicare on an annual basis totaled \$2,404 per patient per year.⁵⁸⁵

A similar collaborative care model in Indiana — the Healthy Aging Brain Center (HABC) — resulted in gross savings of \$3,474 per patient per year.⁵⁰² While the HABC included a specialist (either a geriatrician or behavioral neurologist) as part of the care team, the bulk of the team were not physicians, and included a registered nurse, a medical assistant, a technician and a social worker. And among 780 individuals with dementia who participated in the Care Ecosystem — which uses a trained navigator, an advanced practice nurse, a social worker and a pharmacist — there were 120 fewer emergency room visits, 16 fewer ambulance use events, and 13 fewer hospitalizations than would otherwise be expected over a 12-month period.⁶⁰⁸ Individuals in these care models still sometimes received care from specialists, but the improvement in quality care can be attributed to the well-trained, largely primary care teams.

The Alzheimer's Association also offers a variety of resources to support health systems and clinicians throughout the disease continuum, including early detection and diagnosis of Alzheimer's and other dementias, management of these conditions, and care planning and support services following a diagnosis.

For a complete listing of available Alzheimer's Association resources to support health systems and clinicians, visit alz.org/professionals/health-systems-clinicians.

Conclusion

This Special Report underscores the urgent need to develop the medical workforce to meet current and future demands for quality diagnosis and care of people living with Alzheimer's or other dementias. Current and projected future shortages in specialist care — geriatricians, neurologists, geriatric psychiatrists and neuropsychologists — place the burden of the vast majority of patient care on PCPs. However, while PCPs recognize that they are on the front lines of this crisis and feel a duty to provide the highest quality care, they report that the medical profession is not prepared to adequately face the problem, acknowledge that there is a shortage of specialists to receive patient referrals, and note that their training opportunities are lacking or difficult to access. The severity of these needs requires solutions that develop the specialty workforce while also improving capacity in primary care.

End Notes

- A1. Estimated number (prevalence) of Americans age 65 and older with Alzheimer's dementia for 2020 (prevalence of Alzheimer's in 2020): The number 5.8 million is from published prevalence estimates based on incidence data from the Chicago Health and Aging Project (CHAP) and population estimates from the 2010 U.S. Census.⁶²
- A2. Percentage of total Alzheimer's dementia cases by age groups: Percentages for each age group are based on the estimated 200,000 people under 65,⁶² plus the estimated numbers for people age 65 to 74 (1 million), 75 to 84 (2.7 million), and 85+ (2.1 million) based on prevalence estimates for each age group and incidence data from the CHAP study.
- A3. Proportion of Americans age 65 and older with Alzheimer's dementia: The 10% of the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer's dementia (5.8 million) by the U.S. population age 65 and older in 2020, as projected by the U.S. Census Bureau (56.4 million) = approximately 10%.¹⁸⁴
- A4. Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence: ADAMS estimated the prevalence of Alzheimer's dementia to be lower than CHAP, at 2.3 million Americans age 71 and older in 2002,¹⁸⁷ while the CHAP estimate for 2000 was 4.5 million.⁵⁹² At a 2009 conference convened by the National Institute on Aging and the Alzheimer's Association, researchers determined that this discrepancy was mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's.¹⁸⁸ Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,³⁷ the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's dementia in the United States.
- A5. State-by-state prevalence of Alzheimer's dementia: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality.²⁰⁶ Specific prevalence numbers for 2020 were derived from this analysis and provided to the Alzheimer's Association by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.
- A6. Criteria for identifying people with Alzheimer's or other dementias in the Framingham Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.²¹¹ Diagnosis of dementia was made according to the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than 6 months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.
- A7. Number of women and men age 65 and older with Alzheimer's dementia in the United States: The estimates for the number of U.S. women (3.6 million) and men (2.2 million) age 65 and older with Alzheimer's in 2020 is from unpublished data from CHAP. For analytic methods, see Hebert et al.⁶²
- A8. Prevalence of Alzheimer's and other dementias in older whites, blacks/African Americans and Hispanics/Latinos: The statement that blacks/African Americans are twice as likely and Hispanics/Latinos one and one-half times as likely as whites to have Alzheimer's or other dementias is the conclusion of an expert review of a number of multiracial and multiethnic data sources, as reported in detail in the Special Report of the Alzheimer's Association's 2010 *Alzheimer's Disease Facts and Figures*.
- A9. Projected number of people with Alzheimer's dementia: This figure comes from the CHAP study.⁶² Other projections are somewhat lower (see, for example, Brookmeyer et al.⁵⁹³) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.⁴⁴ Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's dementia over the coming decades.
- A10. Projected number of people age 65 and older with Alzheimer's dementia in 2025: The number 7.1 million is based on a linear extrapolation from the projections of prevalence of Alzheimer's for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP.⁶²
- A11. Annual mortality rate due to Alzheimer's disease by state: Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the true burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to Alzheimer's — a burden that appears smaller relative to other states when the rates are adjusted for age.
- A12. Number of family and other unpaid caregivers of people with Alzheimer's or other dementias: To calculate this number, the Alzheimer's Association started with data from the BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2019. Available at: <https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html>. Accessed on January 6, 2020. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP.⁵⁹⁴ The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care. In response, 26% of caregivers said that: (1) Alzheimer's or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26% figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 16.343 million Alzheimer's and dementia caregivers.

A13. The 2014 Alzheimer's Association Women and Alzheimer's Poll:

This poll questioned a nationally-representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics/Latinos, selected from U.S. Census tracts with higher than an 8% concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

A14. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's or other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. The number of family and other unpaid caregivers (16.343 million)^{A12} was multiplied by the average hours of care per year, which totals 18.611 billion hours of care. This is slightly lower than the product of multiplying 1,139 by 16.343 million because of rounding.

A15. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Amo and colleagues.⁵⁹⁵ This method uses the average of the federal minimum hourly wage (\$7.25 in 2019) and the mean hourly wage of home health aides (\$18.97 in July 2019).⁵⁹⁶ The average is \$13.11, which was multiplied by the number of hours of unpaid care (18.611 billion) to derive the total value of unpaid care (243.994 billion); this is slightly higher than the product of multiplying \$13.11 by 18.611 billion because 18.611 billion is a rounded number for the hours of unpaid care).

A16. Lewin Model on Alzheimer's and dementia costs: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the

prevalence levels from Hebert and colleagues⁶² and included in this report (5.8 million in 2019),^{A2} rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

A17. All cost estimates were inflated to year 2019 dollars using the Consumer Price Index (CPI): All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

A18. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2011 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health.²⁰⁷ The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2020 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of Alzheimer's disease or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's or other dementias in 2008. The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician, or other health care provider visit. The diagnostic codes used to identify survey participants with Alzheimer's or other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11.

Costs from the MCBS analysis are based on responses from 2011 and reported in 2019 dollars.

A19. Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues⁵²⁰ estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2020 Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS) to be \$50,201. One reason that the per-person costs estimated by Hurd and colleagues are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations

of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that the Hurd et al. estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's and other dementias (those costs attributed only to dementia), while the per-person costs in *2020 Alzheimer's Disease Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

A20. Alzheimer's Association Primary Care Physician Dementia

Training Survey: In sampling from the Medscape physician panel, data from the American Medical Association (AMA) master file of all practicing physicians in the United States were used to stratify sampling and weight final data, ensuring a representative sample based on age, gender, years in practice, type of practice, specialty and region. Of the 1,000 respondents of the survey, 18% spent less than 90% of their professional time in direct patient care, while 82% spent between 90 and 100% of their time in direct patient care. On average, 50% of their patients were age 18-64 and 40% were age 65 and older. Sixty percent of respondents were male and 39% were female. Twenty-nine percent of respondents had been in practice for 10-19 years, 28% for 20-29 years, 24% for 35 years or more, and 19% for fewer than 10 years. Eighty-three percent had office-based practices, and 14% had hospital-based practices. Fifty percent had a primary medical specialty of family medicine, 47% specialized in internal medicine, and three percent were general practitioners. Thirty-four percent of respondents practiced in the South, 25% in the West, 22% in the Midwest and 19% in the Northeast.

A21. Alzheimer's Association Recent Medical School Graduate

Dementia Training Survey: Of the 202 respondents of the survey, 55% were in their first year of residency and 45% were in their second year. Ninety-seven percent of respondents were under age 40 and three percent were age 40-49. Sixty-nine percent of respondents were male and 31% were female. Sixty-eight percent had a primary medical specialty of internal medicine, 31% specialized in family medicine, and less than one percent were general practitioners. Thirty-two percent of respondents were in residency in the South, 25% in the Northeast, 23% in the Midwest and 20% in the West.

In estimating total hours of training from the survey data, 48 work weeks were assumed per year, with 5 hours of formal curriculum training each week, over the course of a three-year PCP residency.

A22. Alzheimer's Association Recent Primary Care Resident Dementia

Training Survey: Data from the AMA master file were used to weight final data to ensure a sample that closely matches the full population of PCPs who are in their first two years of practice based on age, gender, specialty and region. Of the 200 respondents of the survey, 43% spent less than 90% of their professional time in direct patient care, while 57 percent spent between 90 and 100% of their time in direct patient care. Fifty-eight percent had finished residency and begun an independent practice within the last year, and 42% had done so within the last two years. Fifty-two percent of respondents were male and 48% were female. Sixty-one percent had office-based practices, and 34% had hospital-based practices. Fifty-seven percent had a primary medical specialty of family medicine, 42% specialized in internal medicine, and one percent were general practitioners. Thirty-one percent of respondents practiced in the South, 27% in the West, 25% in the Midwest and 16% in the Northeast.

To estimate total hours of training from the survey data, it was assumed that each one-week block of coursework involved 45 hours of classroom and study time.

A23. Other ways PCPs follow new developments in the diagnosis and

care of Alzheimer's and other dementias: Additional responses, ranked by the percentage of participants who selected that choice, are detailed below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Email or social media alerts that track new developments or offerings (31%); listening to podcasts hosted by medical professionals that focus on Alzheimer's and dementia (25%); subscribing to publications focused on disorders of the nervous system (17%); participating in online groups of physicians who discuss Alzheimer's and dementia (13%); subscribing to an online community focused on Alzheimer's and dementia (9%); other ways (12%).

A24. Other formats for additional training in dementia:

Additional responses, ranked by the percentage of participants who selected that choice, are detailed below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Lectures (including grand rounds, noon conferences, etc.) (38%); other online resources (such as AAN, NIH, CDC, etc.) (20%); workshops (11%); YouTube videos or other resources found on social media platforms (4%); geriatric fellowship (2%); another format (4%).

A25. Other sources where PCPs have learned the most about

dementia diagnosis and care: Additional responses, ranked by the percentage of participants who selected that choice, are detailed below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Own research to learn about the topic (17%); in medical school (15%); lectures (including grand rounds, noon conferences, etc.) (13%); professional discussion groups (8%); other online resources (such as AAN, NIH, CDC, etc.) (6%); workshops (5%); YouTube videos or other resources found on social media platforms (1%); another format (1%); geriatric fellowship (less than 1%).

A26. Other reasons for not pursuing additional training in dementia

diagnosis and care: Additional responses, ranked by the percentage of participants who selected that choice, are detailed below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Decided to focus practice on another area of medicine (17%); dementia care is less relevant than other topics (15%); do not have good access to resources for additional training (14%); do not see much Alzheimer's or other dementia among patients (7%); medical school and residency training was sufficient (5%); not much has changed in dementia care so there is no need (5%); other reasons (1%).

References

1. Villemagne VL, Burnham S, Bourgeat P, Brown B, Ellis KA, Salvado O, et al. Amyloid β deposition, neurodegeneration, and cognitive decline in sporadic Alzheimer's disease: A prospective cohort study. *Lancet Neurol* 2013;12(4):357-67.
2. Reiman EM, Quiroz YT, Fleisher AS, Chen K, Velez-Pardos C, Jimenez-Del-Rio M, et al. Brain imaging and fluid biomarker analysis in young adults at genetic risk for autosomal dominant Alzheimer's disease in the presenilin 1 E280A kindred: A case-control study. *Lancet Neurol* 2012;11(2):1048-56.
3. Jack CR, Lowe VJ, Weigand SD, Wiste HJ, Senjem ML, Knopman DS, et al. Serial PiB and MRI in normal, mild cognitive impairment and Alzheimer's disease: Implications for sequence of pathological events in Alzheimer's disease. *Brain* 2009;132:1355-65.
4. Bateman RJ, Xiong C, Benzinger TL, Fagan AM, Goate A, Fox NC, et al. Clinical and biomarker changes in dominantly inherited Alzheimer's disease. *N Engl J Med* 2012;367(9):795-804.
5. Gordon BA, Blazey TM, Su Y, Hari-Raj A, Dincer A, Flores S, et al. Spatial patterns of neuroimaging biomarker change in individuals from families with autosomal dominant Alzheimer's disease: A longitudinal study. *Lancet Neurol* 2018;17(3):241-50.
6. Braak H, Thal DR, Ghebremedhin E, Del Tredici K. Stages of the pathologic process in Alzheimer disease: age categories from 1 to 100 years. *J Neuropathol Exp Neurol* 2011;70(11):960-9.
7. Sato C, Barthélemy NR, Mawuenyega KG, Patterson BW, Gordon BA, Jockel-Balsarotti J, et al. Tau kinetics in neurons and the human central nervous system. *Neuron* 2018;98(4):861-4.
8. Hanseeuw BJ, Betensky RA, Jacobs HIL, Schultz AP, Sepulcre J, Becker JA, et al. Association of amyloid and tau with cognition in preclinical Alzheimer disease. *JAMA Neurol* 2019;76(8):915-24.
9. Kapasi A, DeCarli C, Schneider JA. Impact of multiple pathologies on the threshold for clinically overt dementia. *Acta Neuropathol* 2017;134(2):171-86.
10. Brenowitz WD, Hubbard RA, Keene CD, Hawes SE, Longstreth WT, Woltjer, et al. Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample. *Alzheimers Dement*. 2017;13(6):654-62.
11. National Institute on Aging. What are frontotemporal disorders? Available at: <https://www.nia.nih.gov/health/what-are-frontotemporal-disorders>. Accessed November 17, 2019.
12. Hogan DB, Jette N, Fiest KM, Roberts JI, Pearson D, Smith EE, et al. The prevalence and incidence of frontotemporal dementia: a systematic review. *Can J Neurol Sci* 2016;43(suppl):S96-109.
13. Stojkowska I, Krainc D, Mazzulli JR. Molecular mechanisms of α -synuclein and GBA1 in Parkinson's disease. *Cell Tissue Res* 2018;373(1):51-60.
14. De Reuck J, Maurage CA, Deramecourt V, Pasquier F, Cordonnier C, Leys D, et al. Aging and cerebrovascular lesions in pure and in mixed neurodegenerative and vascular dementia brains: A neuropathological study. *Folia Neuropathol* 2018;56(2):81-7.
15. James BD, Bennett DA, Boyle PA, Leurgans S, Schneider JA. Dementia from Alzheimer disease and mixed pathologies in the oldest old. *JAMA* 2012;307(17):1798-1800.
16. Dilworth-Anderson P, Hendrie HC, Manly JJ, Khachaturian AS, Fazio S. Diagnosis and assessment of Alzheimer's disease in diverse populations. *Alzheimers Dement* 2008;4(4):305-9.
17. Steenland K, Goldstein FC, Levey A, Wharton W. A meta-analysis of Alzheimer's disease incidence and prevalence comparing African-Americans and caucasians. *J Alzheimers Dis* 2015;50(1):71-6.
18. Potter GG, Plassman BL, Burke JR, Kabeto MU, Langa KM, Llewellyn DJ, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and whites. *Alzheimers Dement* 2009;5(6):445-53.
19. Gurland BJ, Wilder DE, Lantigua R, Stern Y, Chen J, Killeffer EH, et al. Rates of dementia in three ethnorracial groups. *Int J Geriatr Psychiatry* 1999;14(6):481-93.
20. Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, 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):280-92.
21. Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox N, et al. The diagnosis of mild cognitive impairment due to 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):270-9.
22. McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, et al. The diagnosis of dementia due to 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):263-9.
23. Jack CR, Albert MS, Knopman DS, McKhann GM, Sperling RA, Carrillo MC, et al. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement* 2011;7(3):257-62.
24. Vermunt L, Sikkes SAM, van den Hout A, Handels R, Bos I, van der Flier WM, et al. Duration of preclinical, prodromal, and dementia stages of Alzheimer's disease in relation to age, sex, and APOE genotype. *Alzheimers Dement* 2019;15:888-98.
25. Bennett DA, Schneider JA, Arvanitakis Z, Kelly JF, Aggarwal NT, Shah RC, et al. Neuropathology of older persons without cognitive impairment from two community-based studies. *Neurology* 2006;66:1837-44.
26. Knopman DS, Parisi JE, Salviati A, Floriach-Robert M, Boeve BF, Ivnik RJ, et al. Neuropathology of cognitively normal elderly. *J Neuropathol Exp Neurol* 2003;62:1087-95.
27. Petersen RC, Lopez O, Armstrong MJ, Getchius TSD, Ganguli M, Gloss D, et al. Practice guideline update summary: Mild cognitive impairment. *Neurology* 2018;90(3):126-35.
28. Ward A, Tardiff S, Dye C, Arrighi HM. Rate of conversion from prodromal Alzheimer's disease to Alzheimer's dementia: A systematic review of the literature. *Dement Geriatr Cogn Disord Extra* 2013;3:320-32.
29. Mitchell AJ, Shiri-Feshki M. Rate of progression of mild cognitive impairment to dementia: Meta-analysis of 41 robust inception cohort studies. *Acta Psychiatr Scand* 2009;119:252-65.
30. Johnson KA, Minoshima S, Bohnen NI, Donohoe KJ, Foster NL, Herscovitch P, et al. Appropriate use criteria for amyloid PET: A report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. *Alzheimers Dement* 2013;9(1):e1-e16.
31. Shaw LM, Arias J, Blennow K, Galasko D, Molinuevo JL, Salloway S, et al. Appropriate use criteria for lumbar puncture and cerebrospinal fluid testing in the diagnosis of Alzheimer's disease. *Alzheimers Dement* 2018;14:1505-21.
32. Wilson RS, Segawa E, Boyle PA, Anagnos SE, Hizez LP, Bennett DA. The natural history of cognitive decline in Alzheimer's disease. *Psychol Aging* 2012;27(4):1008-17.
33. Barker WW, Luis CA, Kashuba A, Luis M, Harwood DG, Loewenstein D, et al. Relative frequencies of Alzheimer's disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank. *Alzheimer Dis Assoc Disord* 2002;16(4):203-12.
34. Viswanathan A, Rocca WA, Tzourio C. Vascular risk factors and dementia: How to move forward? *Neurology* 2009;72:368-74.
35. Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology* 2007;69:2197-204.
36. Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer disease and mild cognitive impairment. *Ann Neurol* 2009;66(2):200-8.

37. Jellinger KA, Attems J. Neuropathological evaluation of mixed dementia. *J Neurol Sci* 2007;257(1-2):80-7.
38. Jellinger KA. The enigma of mixed dementia. *Alzheimers Dement* 2007;3(1):40-53.
39. Boustani M, Peterson B, Hanson L, Harris R, Lohr KN. Screening for dementia in primary care: A summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med* 2003;138(11):927-37.
40. Bradford A, Kunik ME, Schultz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alz Dis Assoc Disord* 2009;23(4):306-14.
41. Kotagal V, Langa KM, Plassman BL, Fisher GG, Giordani BJ, Wallace RB, et al. Factors associated with cognitive evaluations in the United States. *Neurology* 2015;84(1):64-71.
42. 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):807-15.
43. Barrett AM, Orange W, Keller M, Damgaard P, Swerdlow RH. Short-term effect of dementia disclosure: How patients and families describe the diagnosis. *J Am Geriatr Soc* 2006;54(12):1968-70.
44. Zaleta AK, Carpenter BD, Porensky EK, Xiong C, Morris JC. Agreement on diagnosis among patients, companions, and professionals after a dementia evaluation. *Alzheimer Dis Assoc Disord* 2012;26(3):232-7.
45. Amjad H, Roth DL, Samus QM, Yasar S, Wolff JL. Potentially unsafe activities and living conditions of older adults with dementia. *J Am Geriatr Soc* 2016;64(6):1223-32.
46. Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures. *Alzheimer Dement* 2015;11(3):332-84.
47. Ralph SJ, Espinet AJ. Increased all-cause mortality by antipsychotic drugs: Updated review and meta-analysis in dementia and general mental health care. *J Alzheimers Dis Rep* 2018;2:1-26.
48. Maust DT, Kim HM, Seyfried LS, Chiang C, Kavanagh J, Schneider LS, et al. Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. *JAMA Psychiatry* 2015;72:438-45.
49. McKhann GM, Albert MS, Sperling RA. Changing diagnostic concepts of Alzheimer's disease. In: Hampel H, Carrillo MC, eds. *Alzheimer's disease — Modernizing concept, biological diagnosis and therapy*. Basel, Switzerland: Karger; 2012: p. 115-21.
50. Bloudek LM, Spackman ED, Blankenburg M, Sullivan SD. Review and meta-analysis of biomarkers and diagnostic imaging in Alzheimer's disease. *J Alzheimers Dis* 2011;26:627-45.
51. Watt JA, Goodarzi Z, Veroniki AA, Nincic V, Khan PA, Ghassemi M, et al. Comparative efficacy of interventions for aggressive and agitated behaviors in dementia. *Ann Internal Med* October 2019. doi:10.7326/M19-0993.
52. Groot C, Hooghiemstra AM, Raijmakers PG, van Berckel BN, Scheltens P, Scherder E, et al. The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. *Ageing Res Rev* 2016;25:13-23.
53. Farina N, Rusted J, Tabet N. The effect of exercise interventions on cognitive outcome in Alzheimer's disease: A systematic review. *Int Psychogeriatr* 2014;26(1):9-18.
54. Aguirre E, Woods RT, Spector A, Orrell M. Cognitive stimulation for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing Res Rev* 2013;12(1):253-62.
55. Fukushima RLM, do Carmo EG, do Valle Pedroso R, Micali PN, Donadelli PS, Fuzaro G, et al. Effects of cognitive stimulation on neuropsychiatric symptoms in elderly with Alzheimer's disease: A systematic review. *Dement Neuropsychol* 2016;10(3):178-84.
56. Bahar-Fuchs A, Martyr A, Goh AMY, Sabates J, Clare L. Cognitive training for people with mild to moderate dementia. *Cochrane Database of Systematic Reviews* 2019, Issue 3. Art. No.: CD013069. doi: 10.1002/14651858.CD013069.pub2.
57. Kishita N, Backhouse T, Mioshi E. Nonpharmacological interventions to improve depression, anxiety, and quality of life (QoL) in people with dementia: An overview of systematic reviews. *J Geriatr Psychiatry Neurol*. 2020;33(1):28-41.
58. Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. The effect of a disease management intervention on quality and outcomes of dementia care: A randomized, controlled trial. *Ann Intern Med* 2006;145(10):713-26.
59. Voisin T, Vellas B. Diagnosis and treatment of patients with severe Alzheimer's disease. *Drugs Aging* 2009;26(2):135-44.
60. Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ. The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: Recommendations of an expert consensus panel. *Prim Care Companion J Clin Psychiatry* 2010;12(1):PCC.09cs00833.
61. Hebert LE, Bienias JL, Aggarwal NT, Wilson RS, Bennett DA, Shah RC, et al. Change in risk of Alzheimer disease over time. *Neurology* 2010;75:786-91.
62. 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):1778-83.
63. Saunders AM, Strittmatter WJ, Schmechel D, George-Hyslop PH, Pericak-Vance MA, Joo SH, et al. Association of apolipoprotein E allele epsilon 4 with late-onset familial and sporadic Alzheimer's disease. *Neurology* 1993;43:1467-72.
64. Farrer LA, Cupples LA, Haines JL, Hyman B, Kukull WA, Mayeux R, et al. Effects of age, sex, and ethnicity on the association between apolipoprotein E genotype and Alzheimer disease: A meta-analysis. *JAMA* 1997;278:1349-56.
65. Green RC, Cupples LA, Go R, Benke KS, Edeki T, Griffith PA, et al. Risk of dementia among white and African American relatives of patients with Alzheimer disease. *JAMA* 2002;287(3):329-36.
66. Fratiglioni L, Ahlbom A, Viitanen M, Winblad B. Risk factors for late-onset Alzheimer's disease: A population-based, case-control study. *Ann Neurol* 1993;33(3):258-66.
67. Mayeux R, Sano M, Chen J, Tatemichi T, Stern Y. Risk of dementia in first-degree relatives of patients with Alzheimer's disease and related disorders. *Arch Neurol* 1991;48(3):269-73.
68. Lautenschlager NT, Cupples LA, Rao VS, Auerbach SA, Becker R, Burke J, 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):641-50.
69. Nelson PT, Head E, Schmitt FA, Davis PR, Neltner JH, Jicha GA, et al. Alzheimer's disease is not "brain aging": Neuropathological, genetic, and epidemiological human studies. *Acta Neuropathol* 2011;121:571-87.
70. Rajan KB, Barnes LL, Wilson RS, McAninch EA, Weuve J, Singhoko D, et al. Racial differences in the association between apolipoprotein E risk alleles and overall and total cardiovascular mortality over 18 years. *JAGS* 2017;65:2425-30.
71. Evans DA, Bennett DA, Wilson RS, Bienias JL, Morris MC, Scherr PA, et al. Incidence of Alzheimer disease in a biracial urban community: Relation to apolipoprotein E allele status. *Arch Neurol* 2003;60(2):185-9.
72. Tang M, Stern Y, Marder K, Bell K, Gurland B, Lantigua R, et al. The APOE-e4 allele and the risk of Alzheimer disease among African Americans, whites, and Hispanics. *JAMA* 1998;279:751-5.
73. Loy CT, Schofield PR, Turner AM, Kwok JBJ. Genetics of dementia. *Lancet* 2014;383:828-40.
74. Holtzman DM, Herz J, Bu G. Apolipoprotein E and apolipoprotein E receptors: Normal biology and roles in Alzheimer disease. *Cold Spring Harb Perspect Med* 2012;2(3):a006312.
75. Michaelson DM. APOE ε4: The most prevalent yet understudied risk factor for Alzheimer's disease. *Alzheimers Dement* 2014;10:861-8.
76. Jansen WJ, Ossenkoppele R, Knol KL, Tijms BM, Scheltens P, Verhey FRJ, et al. Prevalence of cerebral amyloid pathology in persons without dementia. *JAMA* 2015;313(19):1924-38.

77. Spinney L. Alzheimer's disease: The forgetting gene. *Nature* 2014;510(7503):26-8.
78. Ward A, Crean S, Mercaldi CJ, Collins JM, Boyd D, Cook MN, et al. Prevalence of apolipoprotein e4 genotype and homozygotes (APOE ε4/ε4) among patients diagnosed with Alzheimer's disease: A systematic review and meta-analysis. *Neuroepidemiology* 2012;38:1-17.
79. Mayeux R, Saunders AM, Shea S, Mirra S, Evans D, Roses AD, et al. Utility of the apolipoprotein E genotype in the diagnosis of Alzheimer's disease. *N Engl J Med* 1998;338:506-11.
80. Weuve J, Barnes LL, Mendes de Leon CF, Rajan KB, Beck T, Aggarwal NT, et al. Cognitive aging in black and white Americans: Cognition, cognitive decline, and incidence of Alzheimer disease dementia. *Epidemiology* 2018;29(1):151-9.
81. Hendrie HC, Murrell J, Baiyewu O, Lane KA, Purnell C, Ogunniyi A, et al. APOE ε4 and the risk for Alzheimer disease and cognitive decline in African Americans and Yoruba. *Int Psychogeriatr* 2014;26(6):977-85.
82. Reitz C, Jun G, Naj A, Rajbhandary R, Vardarajan BN, Wang LS, et al. Variants in the ATP-binding cassette transporter (ABCA7), apolipoprotein E epsilon 4, and the risk of late-onset Alzheimer disease in African Americans. *JAMA* 2013;309(14):1483-92.
83. Wolters FJ, van der Lee SJ, Koudstaal PJ, van Duijn CM, Hofman A, Ikam MK, et al. Parental family history of dementia in relation to subclinical brain disease and dementia risk. *Neurology* 2017;88:1642-9.
84. World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines. https://www.who.int/mental_health/neurology/dementia/guidelines_risk_reduction/en/. Accessed September 13, 2019.
85. 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):718-26.
86. Institute of Medicine. *Cognitive Aging: Progress in Understanding and Opportunity for Action*. Washington, D.C.: The National Academies Press; 2015.
87. Mergenthaler P, Lindauer U, GA Dienel, Meisel A. Sugar for the brain: The role of glucose in physiological and pathological brain function. *Trends Neurosci* 2013;36(10):587-97.
88. Samieri C, Perier MC, Gaye B, Proust-Lima C Helmer C, Dartigues JF, et al. Association of cardiovascular health level in older age with cognitive decline and incident dementia. *JAMA* 2018;320(7):657-64.
89. Anstey KJ, von Sanden C, Salim A, O'Kearney R. Smoking as a risk factor for dementia and cognitive decline: A meta-analysis of prospective studies. *Am J Epidemiol* 2007;166(4):367-78.
90. Rusanen M, Kivipelto M, Quesenberry CP, Zhou J, Whitmer RA. Heavy smoking in midlife and long-term risk of Alzheimer disease and vascular dementia. *Arch Intern Med* 2011;171(4):333-9.
91. Beydoun MA, Beydoun HA, Gamaldo AA, Teel A, Zonderman AB, Wang Y. Epidemiologic studies of modifiable factors associated with cognition and dementia: Systematic review and meta-analysis. *BMC Public Health* 2014;14:643.
92. Ohara T, Ninomiya T, Hata J, Ozawa M, Yoshida D, Mukai N, et al. Midlife and late-life smoking and risk of dementia in the community: The Hisayama Study. *J Am Geriatr Soc* 2015;63(11):2332-9.
93. Choi D, Choi S, Park SM. Effect of smoking cessation on the risk of dementia: A longitudinal study. *Ann Clin Transl Neurol* 2018;5(10):1192-9.
94. Wu W, Brickman AM, Luchsinger J, Ferrazzano P, Pichiale P, Yoshita M, et al. The brain in the age of old: The hippocampal formation is targeted differentially by diseases of late life. *Ann Neurol* 2008;64:698-706.
95. Gudala K, Bansal D, Schifano F, Bhansali A. Diabetes mellitus and risk of dementia: A meta-analysis of prospective observational studies. *Diabetes Investig* 2013;4(6):640-50.
96. Vagelatos NT, Eslick GD. Type 2 diabetes as a risk factor for Alzheimer's disease: The confounders, interactions, and neuropathology associated with this relationship. *Epidemiol Rev* 2013;35(1):152-60.
97. Reitz C, Brayne C, Mayeux R. Epidemiology of Alzheimer disease. *Nat Rev Neurol* 2011;7(3):137-52.
98. Rönnemaa E, Zethelius B, Lannfelt L, Kilander L. Vascular risk factors and dementia: 40-year follow-up of a population-based cohort. *Dement Geriatr Cogn Disord* 2011;31(6):460-6.
99. Crane PK, Walker R, Hubbard RA, Li G, Nathan DM, Zheng H, et al. Glucose levels and risk of dementia. *N Engl J Med* 2013;369(6):540-8.
100. Sajeev G, Weuve J, McQueen MB, Blacker D. Diabetes. The AlzRisk Database. Alzheimer Research Forum. Available at: <http://www.alzrisk.org>. Accessed November 17, 2019.
101. Kivimaki M, Luukkonen R, Batty GD, Ferrie JE, Pentti J, Nyberg ST, et al. Body mass index and risk of dementia: Analysis of individual-level data from 1.3 million individuals. *Alzheimers Dement* 2018;14:601-9.
102. Loef M, Walach H. Midlife obesity and dementia: Meta-analysis and adjusted forecast of dementia prevalence in the United States and China. *Obesity (Silver Spring)* 2013;21(1):E51-5.
103. Anstey KJ, Cherbuin N, Budge M, Young J. Body mass index in midlife and late-life as a risk factor for dementia: A meta-analysis of prospective studies. *Obes Rev* 2011;12(5):E426-37.
104. Gottesman RF, Schneider AL, Zhou Y, Coresh J, Green E, Gupta N, et al. Association between midlife vascular risk factors and estimated brain amyloid deposition. *JAMA* 2017;17(14):1443-50.
105. Abell JG, Kivimäki M, Dugravot A, Tabak AG, Fayosse A, Shipley M, et al. Association between systolic blood pressure and dementia in the Whitehall II cohort study: Role of age, duration, and threshold used to define hypertension. *Eur Heart J* 2018;39(33):3119-25.
106. Ninomiya T, Ohara T, Hiraoka Y, Yoshida D, Doi Y, Hata J, et al. Midlife and late-life blood pressure and dementia in Japanese elderly: The Hisayama Study. *Hypertension* 2011;58(1):22-8.
107. Debette S, Seshadri S, Beiser A, Au R, Himali JJ, Palumbo C, et al. Midlife vascular risk factor exposure accelerates structural brain aging and cognitive decline. *Neurology* 2011;77:461-8.
108. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley H, Ames D, et al. Dementia prevention, intervention, and care. *Lancet* 2017;390:2673-734.
109. Gottesman RF, Albert MS, Alonso A, Coker LH, Coresh J, Davis SM, et al. Associations between midlife vascular risk factors and 25-year incident dementia in the Atherosclerosis Risk in Communities (ARIC) cohort. *JAMA Neurol* 2017;74(10):1246-54.
110. Solomon A, Kivipelto M, Wolozin B, Zhou J, Whitmer, RA. Midlife serum cholesterol and increased risk of Alzheimer's and vascular dementia three decades later. *Dement and Geriatr Disord* 2009;28:75-80.
111. Meng XF, Yu JT, Wang HF, Tan MS, Wang C, Tan CC, et al. Midlife vascular risk factors and the risk of Alzheimer's disease: A systematic review and meta-analysis. *J Alzheimers Dis* 2014;42(4):1295-310.
112. Fitzpatrick A, Kuller LH, Lopez OL, Diehr P, O'Meara ES, Longstreth WT, et al. Mid- and late-life obesity: Risk of dementia in the Cardiovascular Health Cognition Study. *Arch Neurol* 2009;66:336-42.
113. Corrada MM, Hayden KM, Paganini-Hill A, Bullain SS, DeMoss J, Aguirre C, et al. Age of onset of hypertension and risk of dementia in the oldest-old: The 90+ Study. *Alzheimer Dement* 2017;(13):103-10.
114. The SPRINT MIND Investigators for the SPRINT Research Group. Effect of intensive vs standard blood pressure control on probable dementia: A randomized clinical trial. *JAMA* 2019;321(6):553-61.
115. Ogino E, Manly JJ, Schupf N, Mayeux R, Gu Y. Current and past leisure time physical activity in relation to risk of Alzheimer's disease in older adults. *Alzheimers Dement* 2019;15(12):1603-11.

116. Najjar J, Ostling S, Gudmundsson P, Sundh V, Johansson L, Kern S, et al. Cognitive and physical activity and dementia: A 44-year longitudinal population study of women. *Neurology* 2019;92(12):e1322-e1330.
117. Buchman AS, Yu L, Wilson RS, Lim A, Dawe RJ, Gaiteri C, et al. Physical activity, common brain pathologies, and cognition in community-dwelling older adults. *Neurology* 2019;92(8):e811-e822.
118. Harrington M, Weuve J, Jackson JW, Blacker D. Physical Activity. The AlzRisk Database. Alzheimer Research Forum. Available at: <http://www.alzrisk.org>. Accessed November 17, 2019.
119. Tan ZS, Spartano NL, Beiser AS, DeCarli C, Auerbach SH, Vasan RS, et al. Physical activity, brain volume, and dementia risk: The Framingham Study. *J Gerontol A Biol Sci Med Sci* 2017;72:789-95.
120. Willey JZ, Gardener H, Caunca MR, Moon YP, Dong C, Cheung YK, et al. Leisure-time physical activity associates with cognitive decline: The Northern Manhattan Study. *Neurology* 2016;86(20):1897-903.
121. Stephen R, Hongisto K, Solomon A, Lonnroos E. Physical Activity and Alzheimer's Disease: A systematic review. *J Gerontol A Biol Sci Med Sci* 2017;72(6):733-9.
122. 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.
123. Koscak TB. Physical activity improves cognition: Possible explanations. *Biogerontology* 2017;18(4):477-83.
124. Guure CB, Ibrahim NA, Adam MB, Said SM. Impact of physical activity on cognitive decline, dementia, and its subtypes: Meta-analysis of prospective studies. *Biomed Res Int* 2017;2017:9016924.
125. Soni M, Orrell M, Bandelow S, Steptoe A, Rafnsson S, d'Orsi E, et al. Physical activity pre- and post-dementia: English Longitudinal Study of Ageing. *Aging Ment Health* 2017;17:1-7.
126. Barberger-Gateau P, Raffaitin C, Letenneur L, Berr C, Tzourio C, Dartigues JF, et al. Dietary patterns and risk of dementia: The Three-City Cohort Study. *Neurology* 2007;69(20):1921-30.
127. 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.
128. Lourida I, Soni M, Thompson-Coon J, Purandare N, Lang IA, Ukoumunne OC, et al. Mediterranean diet, cognitive function, and dementia: A systematic review. *Epidemiology* 2013;24:479-89.
129. Morris MC, Tangney CC, Wang Y, Sacks FM, Barnes LL, Bennett DA, et al. MIND diet slows cognitive decline with aging. *Alzheimers Dement* 2015;11(9):1015-22.
130. Morris MC, Tangney CC, Wang Y, Sacks FM, Bennett DA, Aggarwal NT. MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimers Dement* 2015;11:1007-14.
131. Butler M, Nelson VA, Davila H, Ratner E, Fink HA, Hemmy LS, et al. Over-the-counter supplement interventions to prevent cognitive decline, mild cognitive impairment, and clinical Alzheimer-type dementia. *Ann Intern Med* 2018;168:52-62.
132. Rosenberg A, Ngandu T, Rusanen M, Antikainen R, Bäckman L, Havulinna S, et al. Multidomain lifestyle intervention benefits a large elderly population at risk for cognitive decline and dementia regardless of baseline characteristics: The FINGER trial. *Alzheimers Dement* 2018;14(3):263-70.
133. Kulmala J, Ngandu T, Kivipelto M. Prevention matters: Time for global action and effective implementation. *J Alzheimers Dis* 2018;64(s1):S191-8.
134. Fitzpatrick AL, Kuller LH, Ives DG, Lopez OL, Jagust W, Breitner JC, et al. Incidence and prevalence of dementia in the Cardiovascular Health Study. *J Am Geriatr Soc* 2004;52(2):195-204.
135. Kukull WA, Higdon R, Bowen JD, McCormick WC, Teri L, Schellenberg GD, et al. Dementia and Alzheimer disease incidence: A prospective cohort study. *Arch Neurol* 2002;59(11):1737-46.
136. Stern Y. Cognitive reserve in ageing and Alzheimer's disease. *Lancet Neurol* 2012;11(11):1006-12.
137. Sando SB, Melquist S, Cannon A, Hutton M, Sletvold O, Saltvedt I, et al. Risk-reducing effect of education in Alzheimer's disease. *Int J Geriatr Psychiatry* 2008;23(11):1156-62.
138. Hendrie HC, Smith-Gamble V, Lane KA, Purnell C, Clark DO, Gao S. The Association of early life factors and declining incidence rates of dementia in an elderly population of African Americans. *J Gerontol B Psychol Sci Soc Sci* 2018;16(73, suppl 1):S82-9.
139. Stern Y. What is cognitive reserve? Theory and research application of the reserve concept. *J Int Neuropsychol Soc* 2002;8:448-60.
140. Stern Y, Arenaza-Urquijo EM, Bartres-Faz D, Belleville S, Cantilon M, Chetelat G, et al. Whitepaper: Defining and investigating cognitive reserve, brain reserve, and brain maintenance. *Alzheimers Dement* 2018;pii:S1552-5260(18)33491-5.
141. Grzywacz JG, Segel-Karpas D, Lachman ME. Workplace exposures and cognitive function during adulthood: Evidence from National Survey of Midlife Development and the O*NET. *J Occup Environ Med* 2016;58(6):535-41.
142. Pool LR, Weuve J, Wilson RS, Bültmann U, Evans DA, Mendes de Leon CF. Occupational cognitive requirements and late-life cognitive aging. *Neurology* 2016;86(15):1386-92.
143. Then FS, Luck T, Luppa M, Arelin K, Schroeter ML, Engel C, et al. Association between mental demands at work and cognitive functioning in the general population: Results of the health study of the Leipzig Research Center for Civilization Diseases. *J Occup Med Toxicol* 2014;9:23.
144. Fisher GG, Stachowski A, Infurna FJ, Faul JD, Grosch J, Tetrack LE. Mental work demands, retirement, and longitudinal trajectories of cognitive functioning. *J Occup Health Psychol* 2014;19(2):231-42.
145. Dekhtyar S, Marseglia A, Xu W, Darin-Mattsson A, Wang H, Fratiglioni L. Genetic risk of dementia mitigated by cognitive reserve: A cohort study. *Ann Neurol* 2019;86(1):68-78.
146. McDowell I, Xi G, Lindsay J, Tierney M. Mapping the connections between education and dementia. *J Clin Exp Neuropsychol* 2007;29(2):127-41.
147. Ihab M, Benson AF, Lubin TJ, Sacks JD, Richmond-Bryant J. Disparities in distribution of particulate matter emission sources by race and poverty status. *Am J Public Health* 2018;108:480-5.
148. Bernard SM, McGeehin MA. Prevalence of blood lead levels ≥ 5 micro g/dL among US children 1 to 5 years of age and socioeconomic and demographic factors associated with blood of lead levels of 5 to 10 micro g/dL, Third National Health and Nutrition Examination Survey, 1988-1994. *Pediatrics* 2003;112(6 Pt 1):1308-13.
149. Griffith M, Tajik M, Wing S. Patterns of agricultural pesticide use in relation to socioeconomic characteristics of the population in the rural U.S. South. *Int J Health Serv* 2007;37(2):259-77.
150. Harris CD, Watson KB, Carlson SA, Fulton JE, Dorn JM, Elam-Evans L. Adult participation in aerobic and muscle-strengthening physical activities — United States, 2011. *Morb Mortal Wkly Rep* 2013;62(17):326-30.
151. Menke A, Casagrande S, Geiss L, Cowie CC. Prevalence of and trends in diabetes among adults in the United States, 1988-2012. *JAMA* 2015;314(10):1021-9.
152. Sims M, Diez Roux AV, Boykin S, Sarpong D, Gebreab SY, Wyatt SB, et al. The socioeconomic gradient of diabetes prevalence, awareness, treatment, and control among African Americans in the Jackson Heart Study. *Ann Epidemiol* 2011;21(12):892-8.
153. Lee TC, Glynn RJ, Peña JM, Paynter NP, Conen D, Ridker PM, et al. Socioeconomic status and incident type 2 diabetes mellitus: Data from the Women's Health Study. *PLoS One* 2011;6(12):E27670.
154. Gillespie CD, Hurvitz KA. Prevalence of hypertension and controlled hypertension — United States, 2007-2010. *MMWR Suppl* 2013 Nov 22;62(3):144-8.

155. Centers for Disease Control and Prevention. Current Cigarette Smoking Among Adults in the United States. Available at: https://www.cdc.gov/tobacco/data_statistics/fact_sheets/adult_data/cig_smoking/index.htm. Accessed November 4, 2019.
156. Staf RT, Hogan MJ, Williams DS, Whalley LJ. Intellectual engagement and cognitive ability in later life (the "use it or lose it" conjecture): Longitudinal, prospective study. *BMJ* 2018;363:k4925.
157. Wang H-X, Xu W, Pei J-J. Leisure activities, cognition and dementia. *BBA-Mol Basis Dis* 2012;1822(3):482-91.
158. Wang H-X, Karp A, Winblad B, Fratiglioni L. Late-life engagement in social and leisure activities is associated with a decreased risk of dementia: A longitudinal study from the Kungsholmen Project. *Am J Epidemiol* 2002;155(12):1081-7.
159. Saczynski JS, Pfeifer LA, Masaki K, Korf ES, Laurin D, White L, et al. The effect of social engagement on incident dementia: The Honolulu-Asia Aging Study. *Am J Epidemiol* 2006;163(5):433-40.
160. Karp A, Paillard-Borg S, Wang H-X, Silverstein M, Winblad B, Fratiglioni L. Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. *Dement Geriatr Cogn Disord* 2005;21(2):65-73.
161. Di Marco LY, Marzo A, Muñoz-Ruiz M, Ikram MA, Kivipelto M, Ruefenacht D, et al. Modifiable lifestyle factors in dementia: A systematic review of longitudinal observational cohort studies. *J Alzheimers Dis* 2014;42(1):119-35.
162. 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.
163. 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;9:1-16.
164. Ball K, Berch DB, Helmers KF, Jobe JB, Leveck MD, Marsiske M, et al. Effects of cognitive training interventions with older adults: A randomized controlled trial. *JAMA* 2002;288(18):2271-81.
165. Hall CB, Lipton RB, Sliwinski M, Katz MJ, Derby CA, Verghese J. Cognitive activities delay onset of memory decline in persons who develop dementia. *Neurology* 2009;73:356-61.
166. Sanjeev G, Weuve J, Jackson JW, VanderWeele TJ, Bennett DA, Grodstein F, et al. Late-life cognitive activity and dementia. *Epidemiology* 2016;27(5):732-42.
167. Wilson RS, Bennett DA, Bienias JL, Aggarwal NT, Mendes De Leon CF, Morris MC, et al. Cognitive activity and incident AD in a population-based sample of older persons. *Neurology* 2002;59(12):1910-4.
168. Fann JR, Ribe AR, Pedersen HS, Fenger-Grøn M, Christensen J, Benros ME, et al. Long-term risk of dementia among people with traumatic brain injury in Denmark: A population-based observational cohort study. *Lancet Psychiatry* 2018;5(5):424-31.
169. Centers for Disease Control and Prevention. Surveillance Report of Traumatic Brain Injury-related Emergency Department Visits, Hospitalizations, and Deaths: United States, 2014. Available at https://www.cdc.gov/traumaticbraininjury/pdf/TBI-Surveillance-Report-FINAL_508.pdf. Accessed February 10, 2020.
170. Plassman BL, Havlik RJ, Steffens DC, Helms MJ, Newman TN, Drosdick D, et al. Documented head injury in early adulthood and risk of Alzheimer's disease and other dementias. *Neurology* 2000;55(8):1158-66.
171. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: A practical scale. *Lancet* 1974;2(7872):81-4.
172. Centers for Disease Control and Prevention. Traumatic Brain Injury & Concussion. Potential Effects. Available at: <https://www.cdc.gov/traumaticbraininjury/outcomes.html>. Accessed December 5, 2019.
173. Barnes DE, Byers AL, Gardner RC Seal KH, Boscardin WJ, Yaffe K. Association of mild traumatic brain injury with and without loss of consciousness with dementia in U.S. military veterans. *JAMA Neurol* 2018;75(9):1055-61.
174. LoBue C, Wadsworth H, Wilmoth K, Clem M, Hart J Jr, Womack KB. Traumatic brain injury history is associated with earlier age of onset of Alzheimer disease. *Clin Neuropsychol* 2017;31(1):85-98.
175. Mez J, Daneshvar DH, Abdolmohammadi B, Chua AS, Alosco ML, Kiernan PT, et al. Duration of American football play and chronic traumatic encephalopathy. *Ann Neurol* 2019.doi:10.1002/ana.25611.
176. Asken BM, Sullan MJ, DeKosky ST, Jaffee MS, Bauer RM. Research gaps and controversies in chronic traumatic encephalopathy: A review. *JAMA Neurol* 2017;74(10):1255-62.
177. McKee AC, Stein TD, Kiernan PT, Alvarez VE. The neuropathology of chronic traumatic encephalopathy. *Brain Pathol* 2015;25(3):350-64.
178. McKee AC, Cairns NJ, Dickson DW, Folkerth RD, Keene CD, Litvan I, et al. The first NINDS/NIBIB consensus meeting to define neuropathological criteria for the diagnosis of chronic traumatic encephalopathy. *ACTA Neuropathol* 2016;131(1):75-86.
179. Bekris LM, Yu CE, Bird TD. Genetics of Alzheimer disease. *J Geriatr Psychiatry Neurol* 2010;23(4):213-27.
180. Goldman JS, Hahn SE, Bird T. Genetic counseling and testing for Alzheimer disease: Joint practice guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors. *Genet Med* 2011;13:597-605.
181. Lott IT, Dierssen M. Cognitive deficits and associated neurological complications in individuals with Down's syndrome. *Lancet Neurol* 2010;9(6):623-33.
182. National Down Syndrome Society. Alzheimer's Disease and Down Syndrome. Available at: <https://www.ndss.org/resources/alzheimers/>. Accessed September 26, 2019.
183. He W, Goodkind D, Kowal P. U.S. Census Bureau, International Population Reports, P95/16-1, An Aging World: 2015, U.S. Government Publishing Office, Washington, D.C., 2016. Available at: <http://www.census.gov/content/dam/Census/library/publications/2016/demo/p95-16-1.pdf>. Accessed December 4, 2019.
184. U.S. Census Bureau. 2014 National Population Projections: Downloadable Files. Available at: <https://www.census.gov/data/datasets/2014/demo/popproj/2014-popproj.html>. Accessed December 4, 2019.
185. Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. A Profile of Older Americans: 2016. Available at: <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2016-Profile.pdf>. Accessed February 4, 2020.
186. Guerreiro R, Bras J. The age factor in Alzheimer's disease. *Genome Med* 2015;7:106. doi: 10.1186/s13073-015-0232-5.
187. Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(1-2):125-32.
188. Wilson RS, Weir DR, Leurgans SE, Evans DA, Hebert LE, Langa KM, et al. Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States. *Alzheimers Dement* 2011;7(1):74-9.
189. Brookmeyer R, Abdalla N, Kawas CH, Corrada MM. Forecasting the prevalence of preclinical and clinical Alzheimer's disease in the United States. *Alzheimers Dement* 2018;14(2):121-9.
190. Jack CR Jr, Therneau TM, Weigand SD, Wiste HJ, Knopman DS, Vemuri P, et al. Prevalence of biologically vs clinically defined Alzheimer spectrum entities using the National Institute on Aging-Alzheimer's Association Research Framework. *JAMA Neurol* 2019;76(10):1174-83.
191. James BD, Wilson RS, Boyle PA, Trojanowski JQ, Bennett DA, Schneider JA. TDP-43 stage, mixed pathologies, and clinical Alzheimer's-type dementia. *Brain* 2016;139(11):2983-93.
192. Serrano-Pozo A, Qian J, Monsell SE, Blacker D, Gomez-Isla T, Betensky RA, et al. Mild to moderate Alzheimer dementia with insufficient neuropathological changes. *Ann Neurol* 2014;75:597-601.

193. Barnes LL, Leurgans S, Aggarwal NT, Shah RC, Arvanitakis Z, James BD, et al. Mixed pathology is more likely in black than white decedents with Alzheimer dementia. *Neurology* 2015;85:528-34.
194. Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. *Alzheimer Dement* 2019;15:321-87.
195. Reisberg B, Gauthier S. Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. *Int Psychogeriatr* 2008;20(1):1-16.
196. Jessen F, Wolfgruber S, Wiese B, Bickel H, Mösch E, Kaduszkiewicz H, et al. AD dementia risk in late MCI, in early MCI, and in subjective memory impairment. *Alzheimers Dement* 2014;10(1):76-83.
197. Jessen F, Amariglio RE, van Boxtel M, Breteler M, Ceccaldi M, Chételat G, et al. A conceptual framework for research on subjective cognitive decline in preclinical Alzheimer's disease. *Alzheimers Dement* 2014;10(6):844-52.
198. Buckley RF, Maruff P, Ames D, Bourgeat P, Martins RN, Masters CL, et al. Subjective memory decline predicts greater rates of clinical progression in preclinical Alzheimer's disease. *Alzheimers Dement* 2016;12(7):796-804.
199. Gifford KA, Liu D, Lu Z, Tripodis Y, Cantwell NG, Palmisano J, et al. The source of cognitive complaints predicts diagnostic conversion differentially among nondemented older adults. *Alzheimers Dement* 2014;10(3):319-27.
200. Brody DJ, Kramarow EA, Taylor CA, McGuire LC. Cognitive performance in adults aged 60 and over: National Health and Nutrition Examination Survey, 2011-2014. National Health Statistics Reports; no 126. Hyattsville, MD: National Center for Health Statistics. 2019.
201. Kaup AR, Nettiksimmons J, LeBlanc ES, Yaffe K. Memory complaints and risk of cognitive impairment after nearly 2 decades among older women. *Neurology* 2015;85(21):1852-8.
202. Reisberg B, Shulman MB, Torossian C, Leng L, Zhu W. Outcome over seven years of healthy adults with and without subjective cognitive impairment. *Alzheimers Dement* 2010;6(1):11-24.
203. Fernandez-Blazquez MA, Avila-Villanueva M, Maestu F, Medina M. Specific features of subjective cognitive decline predict faster conversion to mild cognitive impairment. *J Alzheimers Dis* 2016;52(1):271-81.
204. Wolfgruber S, Kleinedam L, Wagner M, Mösch E, Bickel H, Lühmann D, et al. Differential risk of incident Alzheimer's disease dementia in stable versus unstable patterns of subjective cognitive decline. *J Alzheimers Dis* 2016;54(3):1135-46.
205. Unpublished data from the 2015-2018 Behavioral Risk Factor Surveillance System survey, analyzed and provided to the Alzheimer's Association by the Alzheimer's Disease and Healthy Aging Program, Centers for Disease Control and Prevention.
206. Weuve J, Hebert LE, Scherr PA, Evans DA. Prevalence of Alzheimer disease in U.S. states. *Epidemiology* 2015;26(1):E4-6.
207. Unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2011. Prepared under contract by Avalere Health, March 2016.
208. Hebert LE, Beckett LA, Scherr PA, Evans DA. Annual incidence of Alzheimer disease in the United States projected to the years 2000 through 2050. *Alzheimer Dis Assoc Disord* 2001;15(4):169-73.
209. 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. doi:10.1016/j.jalz.2018.07.216 1.
210. Tom SE, Hubbard RA, Crane PK, Haneuse SJ, Bowen J, McCormick WC, et al. Characterization of dementia and Alzheimer's disease in an older population: Updated incidence and life expectancy with and without dementia. *Am J Public Health* 2015;105(2):408-13.
211. Chene G, Beiser A, Au R, Preis SR, Wolf PA, Dufouil C, et al. Gender and incidence of dementia in the Framingham Heart Study from mid-adult life. *Alzheimers Dement* 2015;11(3):310-20.
212. Seshadri S, Wolf PA, Beiser A, Au R, McNulty K, White R, et al. Lifetime risk of dementia and Alzheimer's disease. The impact of mortality on risk estimates in the Framingham Study. *Neurology* 1997;49(6):1498-504.
213. 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):132-6.
214. Zahodne LB, Schofield PW, Farrell MT, Stern Y, Manly JJ. Bilingualism does not alter cognitive decline or dementia risk among Spanish-speaking immigrants. *Neuropsychology* 2014;28(2):238-46.
215. Kawas C, Gray S, Brookmeyer R, Fozard J, Zonderman A. Age-specific incidence rates of Alzheimer's disease: The Baltimore Longitudinal Study of Aging. *Neurology* 2000;54(11):2072-7.
216. Fratiglioni L, Viitanen M, von Strauss E, Tontodonati V, Herlitz A, Winblad B. Very old women at highest risk of dementia and Alzheimer's disease: Incidence data from the Kungsholmen Project, Stockholm. *Neurology* 1997;48:132-8.
217. Letenneur L, Gilleron V, Commenges D, Helmer C, Orgogozo JM, Dartigues JF. Are sex and educational level independent predictors of dementia and Alzheimer's disease? Incidence data from the PAQUID project. *J Neurol Neurosurg Psychiatry* 1999;66:177-83.
218. Matthews FE, Stephan BC, Robinson L, Jagger C, Barnes LE, Arthur A, et al. A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. *Nat Commun* 2016;7:11398.
219. Mielke MM, Ferretti MT, Iulita MF, Hayden K, Khachaturian AS. Sex and gender in Alzheimer's disease — Does it matter? *Alzheimers Dement* 2018;14(9):1101-3.
220. Rocca WA. Time, Sex, gender, history, and dementia. *Alzheimer Dis Assoc Disord* 2017;31(1):76-9.
221. Mielke MM, Vemuri P, Rocca WA. Clinical epidemiology of Alzheimer's disease: Assessing sex and gender differences. *Clin Epidemiol* 2014;6:37-48.
222. Rocca WA, Mielke MM, Vemuri P, Miller VM. Sex and gender differences in the causes of dementia: A narrative review. *Maturitas* 2014;79(2):196-201.
223. Langa KM, Larson EB, Crimmins EM, Faul JD, Levine DA, Kabeto MU, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Intern Med* 2017;177(1):51-8.
224. Launer LJ, Andersen K, Dewey ME, Letenneur L, Ott A, Amaducci LA, 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.
225. Russ TC, Stamatakis E, Hamer M, Starr JM, Kivimaki M, Batty GD. Socioeconomic status as a risk factor for dementia death: individual participant meta-analysis of 86 508 men and women from the UK. *Br J Psychiatry* 2013;203(1):10-17.
226. Carter CL, Resnick EM, Mallampalli M, Kalbarczyk A. Sex and gender differences in Alzheimer's disease: Recommendations for future research. *J Womens Health* 2012;21(10):1018-23.
227. Altmann A, Tian L, Henderson VW, Greicius MD, Alzheimer's Disease Neuroimaging Initiative Investigators. Sex modifies the APOE-related risk of developing Alzheimer disease. *Ann Neurol* 2014;75(4):563-73.
228. Ungar L, Altmann A, Greicius MD. Apolipoprotein E, gender, and Alzheimer's disease: An overlooked, but potent and promising interaction. *Brain Imaging Behav* 2014;8(2):262-73.
229. Hohman TJ, Dumitrescu L, Barnes LL, Thambisetty M, Beecham G, Kunkle B, et al. Sex-specific association of apolipoprotein E with cerebrospinal fluid levels of tau. *JAMA Neurol* 2018;75(8):989-98.
230. Neu SC, Pa J, Kukull W, Beekly D, Kuzma A, Gangadharan P, et al. Apolipoprotein E genotype and sex risk factors for Alzheimer disease: A meta-analysis. *JAMA Neurol* 2017;74(10):1178-89.

231. Yaffe K, Haan M, Byers A, Tangen C, Kuller L. Estrogen use, APOE, and cognitive decline: Evidence of gene-environment interaction. *Neurology* 2000;54(10):1949-54.
232. Kang JH, Grodstein F. Postmenopausal hormone therapy, timing of initiation, APOE and cognitive decline. *Neurobiol Aging* 2012;33(7):1129-37.
233. Barnes LL, Wilson RS, Bienias JL, Schneider JA, Evans DA, Bennett DA. Sex differences in the clinical manifestations of Alzheimer disease pathology. *Arch Gen Psychiatry* 2005;62(6):685-91.
234. Koran MEI, Wagener M, Hohman TJ. Alzheimer's Neuroimaging Initiative. Sex differences in the association between AD biomarkers and cognitive decline. *Brain Imaging Behav* 2017;11(1):205-13.
235. Buckley RF, Mormino EC, Amariglio RE, Properzi MJ, Rabin JS, Lim YY, et al. Sex, amyloid, and APOE epsilon4 and risk of cognitive decline in preclinical Alzheimer's disease: Findings from three well-characterized cohorts. *Alzheimers Dement* 2018;14(9):1193-203.
236. Manly JJ, Mayeux R. Ethnic differences in dementia and Alzheimer's disease. In: Anderson N, Bulatao R, Cohen B, eds. *Critical perspectives on racial and ethnic differentials in health in late life*. Washington, D.C.: National Academies Press; 2004: p. 95-141.
237. Demirovic J, Prineas R, Loewenstein D, Bean J, Duara R, Sevush S, et al. Prevalence of dementia in three ethnic groups: The South Florida Program on Aging and Health. *Ann Epidemiol* 2003;13(6):472-78.
238. Harwood DG, Ownby RL. Ethnicity and dementia. *Curr Psychol Rep* 2000;2(1):40-5.
239. 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.
240. Haan MN, Mungas DM, Gonzalez HM, Ortiz TA, Acharya A, Jagust WJ. Prevalence of dementia in older Latinos: The influence of type 2 diabetes mellitus, stroke and genetic factors. *J Am Geriatr Soc* 2003;51:169-77.
241. Samper-Ternent R, Kuo YF, Ray LA, Ottenbacher KJ, Markides KS, Al Snih S. Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and non-Hispanic whites. *J Am Med Dir Assn* 2012;13(3):254-9.
242. González HM, Tarraf W, Schneiderman N, Fornage M, Vásquez PM, Zeng D, et al. Prevalence and correlates of mild cognitive impairment among diverse Hispanics/Latinos: Study of Latinos-Investigation of Neurocognitive Aging results. *Alzheimers Dement* 2019;pii:S1552-5260(19)35376-2. doi:10.1016/j.jalz.2019.08.202. [Epub ahead of print].
243. Mehta KM, Yeo GW. Systematic review of dementia prevalence and incidence in United States race/ethnic populations. *Alzheimers Dement* 2017;13(1):72-83.
244. Yaffe K, Falvey C, Harris TB, Newman A, Satterfield S, Koster A, et al. Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study. *BMJ* 2013;347:f7051.
245. Froehlich TE, Bogardus Jr. ST, Inouye SK. Dementia and race: Are there differences between African Americans and Caucasians? *J Am Geriatr Soc* 2001;49(4):477-84.
246. Chin AL, Negash S, Hamilton R. Diversity and disparity in dementia: The impact of ethnoracial differences in Alzheimer disease. *Alzheimer Dis Assoc Disord* 2011;25(3):187-95.
247. Lines LM, Sherif NA, Wiener JM. Racial and ethnic disparities among individuals with Alzheimer's disease in the United States: A literature review. Research Triangle Park, NC: RTI Press; 2014.
248. Glymour MM, Manly JJ. Lifecourse social conditions and racial and ethnic patterns of cognitive aging. *Neuropsychol Rev* 2008;18(3):223-54.
249. Zhang Z, Hayward MD, Yu YL. Life course pathways to racial disparities in cognitive impairment among older Americans. *J Health Soc Behav* 2016;57(2):184-99.
250. Clark PC, Kutner NG, Goldstein FC, Peterson-Hazen S, Garner V, Zhang R, et al. Impediments to timely diagnosis of Alzheimer's disease in African Americans. *J Am Geriatr Soc* 2005;53(11):2012-7.
251. Fitten LJ, Ortiz F, Ponton M. Frequency of Alzheimer's disease and other dementias in a community outreach sample of Hispanics. *J Am Geriatr Soc* 2001;49(10):1301-8.
252. Matthews KA, Xu W, Gaglioti AH, Holt JB, Croft JB, Mack D, 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.
253. 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):216-24.
254. Mayeda ER, Glymour MM, Quesenberry CP, Jr., Whitmer RA. Heterogeneity in 14-year dementia incidence between Asian American subgroups. *Alzheimer Dis Assoc Disord* 2017;31(3):181-6.
255. Sheffield KM, Peek MK. Changes in the prevalence of cognitive impairment among older Americans, 1993-2004: Overall trends and differences by race/ethnicity. *Am J Epidemiol* 2011;174(3):274-83.
256. Hudomiet P, Hurd M, Rohwedder S. Dementia prevalence in the United States in 2000 and 2012: Estimates based on a nationally representative study. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S10-19.
257. Freedman VA, Kasper JD, Spillman BC, Plassman BL. Short-term changes in the prevalence of probable dementia: An analysis of the 2011-2015 National Health and Aging Trends Study. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S48-56.
258. Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II. *Lancet* 2013;382(9902):1405-12.
259. Rocca WA, Petersen RC, Knopman DS, Hebert LE, Evans DA, Hall KS, 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.
260. Wiberg P, Waern M, Billstedt E, Östling S, Skoog I. Secular trends in the prevalence of dementia and depression in Swedish septuagenarians 1976-2006. *Psychol Med* 2013;43:2627-34.
261. Wimo A, Sjölund BM, Sköldunger A, Qiu C, Klarin I, Nordberg G, et al. Cohort effects in the prevalence and survival of people with dementia in a rural area in Northern Sweden. *J Alzheimers Dis* 2016;50:387-96.
262. Hall KS, Gao S, Baiyewu O, Lane KA, Gureje O, Shen J, et al. Prevalence rates for dementia and Alzheimer's disease in African Americans: 1992 versus 2000. *Alzheimers Dement* 2009;5(3):227-33.
263. Wu YT, Beiser AS, Breteler MMB, Fratiglioni L, Helmer C, Hendrie HC, et al. The changing prevalence and incidence of dementia over time: Current evidence. *Nat Rev Neurol* 2017;13(6):327-39.
264. Schrijvers EM, Verhaaren BF, Koudstaal PJ, Hofman A, Ikram MA, Breteler MM. Is dementia incidence declining? Trends in dementia incidence since 1990 in the Rotterdam Study. *Neurology* 2012;78(19):1456-63.
265. Qiu C, von Strauss E, Backman L, Winblad B, Fratiglioni L. Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden. *Neurology* 2013;80(20):1888-94.
266. Satizabal CL, Beiser AS, Chouraki V, Chene G, Dufouil C, Seshadri S. Incidence of dementia over three decades in the Framingham Heart Study. *N Engl J Med* 2016;374:523-32.
267. Cerasuolo JO, Cipriano LE, Sposato LA, Kapral MK, Fang J, Gill SS, et al. Population-based stroke and dementia incidence trends: Age and sex variations. *Alzheimers Dement* 2017;13(10):1081-8.

268. Derby CA, Katz MJ, Lipton RB, Hall CB. Trends in dementia incidence in a birth cohort analysis of the Einstein Aging Study. *JAMA Neurol* 2017;74(11):1345-51.
269. Ahmadi-Abhari S, Guzman-Castillo M, Bandosz P, Shipley MJ, Muniz-Terrera G, Singh-Manoux A, et al. Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: Modelling study. *BMJ* 2017;358:j2856.
270. Sullivan KJ, Dodge HH, Hughes TF, Chang CH, Zhu X, Liu A, et al. Declining incident dementia rates across four population-based birth cohorts. *J Gerontol A Biol Sci Med Sci* 2018. doi: 10.1093/gerona/gly236. [Epub ahead of print].
271. van den Kommer TN, Deeg DJH, van der Flier WM, and Comijs HC. Time trend in persistent cognitive decline: Results from the longitudinal aging study Amsterdam. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S57-64.
272. Sekita A, Ninomiya T, Tanizaki Y, Doi Y, Hata J, Yonemoto K, et al. Trends in prevalence of Alzheimer's disease and vascular dementia in a Japanese community: The Hisayama Study. *Acta Psychiatr Scand* 2010;122(4):319-25.
273. Crimmins EM, Saito Y, Kim JK, Zhang Y, Sasson I, Hayward MD. Educational differences in the prevalence of dementia and life expectancy with dementia in the United States: Changes from 2000 to 2010. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S20-28.
274. Choi H, Schoeni RF, Martin LG, Langa K M. Trends in the prevalence and disparity in cognitive limitations of Americans 55-69 years old. *J Gerontol B Psychol Sci Soc Sci* 2018;73 (Suppl 1):S29-37.
275. Langa KM. Is the risk of Alzheimer's disease and dementia declining? *Alzheimers Res Ther* 2015;7(1):34.
276. Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *N Engl J Med* 2013;369(24):2275-7.
277. Weuve J, Rajan KB, Barnes LL, Wilson RS, Evans DA. Secular trends in cognitive performance in older black and white U.S. adults, 1993-2012: Findings from the Chicago Health and Aging Project. *J Gerontol B Psychol Sci Soc Sci* 2018;73 (Suppl 1):S73-81.
278. Prince MJ, Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina M. *World Alzheimer Report 2015: The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*; 2015.
279. U.S. Census Bureau. *2017 National Population Projections Tables*. Available at: <https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html>. Accessed December 4, 2019.
280. Xu JQ, Murphy SL, Kochanek KD, Arias E. *Mortality in the United States, 2018*. NCHS Data Brief; No. 355. Hyattsville, MD: National Center for Health Statistics. 2020.
281. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. *CDC WONDER online database: About Underlying Cause of Death, 1999-2018*. Available at: <https://wonder.cdc.gov/ucd-icd10.html>. Accessed February 14, 2020.
282. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems*. 10th revision. 2nd edition. WHO Press: Geneva, Switzerland; 2004.
283. Kramarow EA, Tejada-Vera B. *Dementia mortality in the United States, 2000-2017*. National Vital Statistics Reports; vol 68 no 2. Hyattsville, MD: National Center for Health Statistics. 2019. https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_02-508.pdf.
284. Burns A, Jacoby R, Luthert P, Levy R. Cause of death in Alzheimer's disease. *Age Ageing* 1990;19(5):341-4.
285. Brunnstrom HR, Englund EM. Cause of death in patients with dementia disorders. *Eur J Neurol* 2009;16(4):488-92.
286. Ives DG, Samuel P, Psaty BM, Kuller LH. Agreement between nosologist and Cardiovascular Health Study review of deaths: Implications of coding differences. *J Am Geriatr Soc* 2009;57(1):133-9.
287. Romero JP, Benito-Leon J, Mitchell AJ, Trincado R, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates using data from a population-based study (NEDICES). *J Alzheimers Dis* 2014;39(4):741-8.
288. Romero JP, Benito-Leon J, Louis ED, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates: A systematic review of population-based cohort studies. *J Alzheimers Dis* 2014;41(1):213-21.
289. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: A community study. *J Am Geriatr Soc* 1999;47(7):842-9.
290. James BD, Leurgans SE, Hebert LE, Scherr PA, Yaffe K, Bennett DA. Contribution of Alzheimer disease to mortality in the United States. *Neurology* 2014;82(12):1045-50.
291. Unpublished tabulations based on data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014. Prepared under contract by Avalere Health, January 2016.
292. Weuve J, Hebert LE, Scherr PA, Evans DA. Deaths in the United States among persons with Alzheimer's disease (2010-2050). *Alzheimers Dement* 2014;10(2):E40-6.
293. Arrighi HM, Neumann PJ, Lieberburg IM, Townsend RJ. Lethality of Alzheimer disease and its impact on nursing home placement. *Alzheimer Dis Assoc Disord* 2010;24(1):90-5.
294. Tejada-Vera B. *Mortality from Alzheimer's disease in the United States: Data for 2000 and 2010*. National Center for Health Statistics Data Brief, No. 116. National Center for Health Statistics, Hyattsville, MD; 2013.
295. Taylor C, Greenlund S, McGuire L, Lu H, Croft J. *Deaths from Alzheimer's Disease — United States, 1999-2014*. *MMWR Morb Mortal Wkly Rep* 2017;66:521-6.
296. Ganguli M, Dodge HH, Shen C, Pandav RS, DeKosky ST. Alzheimer disease and mortality: A 15-year epidemiological study. *Arch Neurol* 2005;62(5):779-84.
297. Waring SC, Doody RS, Pavlik VN, Massman PJ, Chan W. Survival among patients with dementia from a large multi-ethnic population. *Alzheimer Dis Assoc Disord* 2005;19(4):178-83.
298. Brookmeyer R, Corrada MM, Curriero FC, Kawas C. Survival following a diagnosis of Alzheimer disease. *Arch Neurol* 2002;59(11):1764-7.
299. Larson EB, Shadlen MF, Wang L, McCormick WC, Bowen JD, Teri L, et al. Survival after initial diagnosis of Alzheimer disease. *Ann Intern Med* 2004;140(7):501-9.
300. Helzner EP, Scarmeas N, Cosentino S, Tang MX, Schupf N, Stern Y. Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. *Neurology* 2008;71(19):1489-95.
301. Xie J, Brayne C, Matthews FE. Survival times in people with dementia: Analysis from a population based cohort study with 14-year follow-up. *BMJ* 2008;336(7638):258-62.
302. Brodaty H, Seeher K, Gibson L. Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *Int Psychogeriatr* 2012;24(7):1034-45.
303. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: A review. *Int J Geriatr Psychiatry* 2013;28(11):1109-24.
304. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53(2):299-305.
305. U.S. Burden of Disease Collaborators, Mokdad AH, Ballestreros K, et al. The state of U.S. health, 1990-2016: Burden of diseases, injuries, and risk factors among U.S. states. *JAMA* 2018;319(14):1444-72.
306. Gaugler JE, Kane RL, Kane RA. Family care for older adults with disabilities: Toward more targeted and interpretable research. *Int J Aging Hum Dev* 2002;54(3):205-31.
307. Schulz R, Quittner AL. Caregiving through the life-span: Overview and future directions. *Health Psychol* 1998;17:107-11.
308. Friedman EM, Shih RA, Langa KM, Hurd MD. U.S. prevalence and predictors of informal caregiving for dementia. *Health Aff* 2015;34(10):1637-41.
309. Spillman B, Wolff J, Freedman VA, Kasper JD. *Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study*. Available at: <https://aspe.hhs.gov/pdf-report/informal-caregiving-older-americans-analysis-2011-national-health-and-aging-trends-study>. Accessed December 4, 2019.

310. Walmart: 2019 Annual Report. Available at: https://s2.q4cdn.com/056532643/files/doc_financials/2019/annual/Walmart-2019-AR-Final.pdf. Accessed December 4, 2019.
311. McDonald's Corporation Report 2018. Available at: https://corporate.mcdonalds.com/content/dam/gwscorp/nfl/investor-relations-content/annual-reports/McDonalds_2018_Annual_Report.pdf. Accessed December 4, 2019.
312. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and family lifetime cost of dementia: Implications for policy. *J Am Geriatr Soc* 2017;65(10):2169-75.
313. Official Data Foundation. CPI inflation calculator. Available at: <http://www.in2013dollars.com/2017-dollars-in-2018?amount=139765>. Accessed December 4, 2019.
314. Deb A, Thornton JD, Sambamoorthi U, Innes K. Direct and indirect cost of managing alzheimer's disease and related dementias in the United States. *Expert Rev Pharmacoecon Outcomes Res* 2017;17(2):189-202.
315. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatr* 2019;19(1):169.
316. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff* 2015;34(10):1642-49.
317. Ornstein KA, Wolff JL, Bollens-Lund E, Rahman OK, Kelley AS. Spousal caregivers are caregiving alone in the last years of life. *Health Aff (Millwood)* 2019;38(6):964-72.
318. Alzheimer's Association. Issues Brief: LGBT and Dementia. Available at: <https://www.alz.org/media/Documents/lgbt-dementia-issues-brief.pdf>. Accessed December 4, 2019.
319. Kasper JD, Freedman VA, Spillman BC. Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. U.S. Department of Health and Human Services; 2014. Available at: <http://aspe.hhs.gov/report/disability-and-care-needs-older-americans-dementia-status-analysis-2011-national-health-and-aging-trends-study>. Accessed December 4, 2019.
320. Rabarison KM, Bouldin ED, Bish CL, McGuire LC, Taylor CA, Greenlund KJ. The economic value of informal caregiving for persons with dementia: Results from 38 states, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS. *Am J Public Health* 2018;108(10):1370-7.
321. Langa KM, Plassman BL, Wallace RB, Herzog AR, Heeringa SG, Ofstedal MB, et al. The Aging, Demographics, and Memory Study: Study design and methods. *Neuroepidemiology* 2005;25(4):181-91.
322. Fisher GG, Franks MM, Plassman BL, Brown SL, Potter GG, Llewellyn D, et al. Caring for individuals with dementia and cognitive impairment, not dementia: Findings from The Aging, Demographics, and Memory Study. *J Am Geriatr Soc* 2011;59(3):488-94.
323. National Alliance for Caregiving in Partnership with the Alzheimer's Association. Dementia Caregiving in the U.S. Bethesda, MD. Available at: http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf. Accessed December 4, 2019.
324. Unpublished data from the 2015, 2016 and 2017 Behavioral Risk Factor Surveillance System survey, analyzed by and provided to the Alzheimer's Association by the Alzheimer's Disease and Healthy Aging Program (AD+HP), Centers for Disease Control and Prevention (CDC).
325. Riffin C, Van Ness PH, Wolff JL, Fried T. Family and other unpaid caregivers and older adults with and without dementia and disability. *J Am Geriatr Soc* 2017;65(8):1821-8.
326. National Poll on Healthy Aging. Dementia Caregivers: Juggling, Delaying and Looking Forward. Available at: http://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf. Accessed December 4, 2019.
327. National Alliance for Caregiving and AARP. Caregiving in the U.S.: Unpublished data analyzed under contract for the Alzheimer's Association; 2009.
328. Alzheimer's Association. 2014 Alzheimer's Disease Facts and Figures. *Alzheimer Dement* 2014;10(2):e47-e92.
329. Pinquart M, Sörensen. Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2006;61(1):P33-45. Available at: <http://psychsocgerontology.oxfordjournals.org/content/61/1/P33.long>. Accessed December 4, 2019.
330. Ma M, Dorstyn D, Ward L, Prentice S. Alzheimer's disease and caregiving: A meta-analytic review comparing the mental health of primary carers to controls. *Aging Ment Health* 2017;5:1-11.
331. National Alliance for Caregiving and AARP. Caregiving in the U.S. (2015). Available at: http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf. Accessed December 4, 2019.
332. Spillman BC, Freedman VA, Kasper JD, Wolff JL. Change over time in caregiving networks for older adults with and without dementia. *J Gerontol B Psychol Sci Soc Sci* 2019 May 18. pii: gbz065. doi: 10.1093/geronb/gbz065. [Epub ahead of print].
333. Garity J. Caring for a family member with Alzheimer's disease: Coping with caregiver burden post-nursing home placement. *J Gerontol Nurs* 2006;32(6):39-48.
334. Port CL, Zimmerman S, Williams CS, Dobbs D, Preisser JS, Williams SW. Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *Gerontologist* 2005;45(Special Issue 1):87-95.
335. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292(8):961-7.
336. Rattinger GB, Schwartz S, Mullins CD, Corcoran C, Zuckerman IH, Sanders C, et al. Dementia severity and the longitudinal costs of informal care in the Cache County population. *Alzheimers Dement* 2015;11(8):946-54.
337. Rattinger GB, Fauth EB, Behrens S, Sanders C, Schwartz S, Norton MC, et al. Closer caregiver and care-recipient relationships predict lower informal costs of dementia care: The Cache County Dementia Progression Study. *Alzheimers Dement* 2016;12(8):917-24.
338. Wolff JL, Mulcahy J, Huang J, Roth DL, Covinsky K, Kasper JD. Family Caregivers of Older Adults, 1999-2015: Trends in characteristics, circumstances, and role-related appraisal. *Gerontologist* 2018;58(6):1021-32.
339. Ornstein K, Gaugler JE. The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *Int Psychogeriatr* 2012;24(10):1536-52.
340. Vaingankar JA, Chong SA, Abidin E, Picco L, Shafie S, Seow E, et al. Psychiatric morbidity and its correlates among informal caregivers of older adults. *Compr Psychiatry* 2016;68:178-85.
341. Feast A, Moniz-Cook E, Stoner C, Charlesworth G, Orrell M. A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *Int Psychogeriatr* 2016;28(11):1761-74.
342. Kiecolt-Glaser JK, Glaser R, Gravenstein S, Malarkey WB, Sheridan J. Chronic stress alters the immune response to influenza virus vaccine in older adults. *Proc Natl Acad Sci* 1996;93:3043-7.
343. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA* 1999;282:2215-60.
344. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129(6):946-72.
345. Liu W, Gallagher-Thompson D. Impact of dementia caregiving: Risks, strains, and growth. In: Qualls SH, Zarit SH, eds. *Aging families and caregiving*. Hoboken, NJ: John Wiley & Sons, Inc.; 2009: p. 85-112.
346. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2003;58(2):112-28.

347. Sörensen S, Duberstein P, Gill D, Pinquart M. Dementia care: Mental health effects, intervention strategies, and clinical implications. *Lancet Neurol* 2006;5(11):961-73.
348. Goren A, Montgomery W, Kahle-Wroblewski K, Nakamura T, Ueda K. Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: Findings from a community based survey in Japan. *BMC Geriatr* 2016;16:122.
349. Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures. *Alzheimer Dement* 2016;12(4):459-509.
350. Jones RW, Lebec J, Kahle-Wroblewski K, Dell'Agnello G, Bruno G, Vellas B, et al. Disease progression in mild dementia due to Alzheimer disease in an 18-month observational study (GERAS): The impact on costs and caregiver outcomes. *Dement Geriatr Cogn Dis Extra* 2017;7(1):87-100.
351. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *Gerontologist* 2018.doi:10.1093/geront/gny168.
352. Zarit SH. Positive aspects of caregiving: More than looking on the bright side. *Aging Ment Health* 2012;16(6):673-74.
353. Cheng ST, Mak EP, Lau RW, Ng NS, Lam LC. Voices of Alzheimer caregivers on positive aspects of caregiving. *Gerontologist* 2016;56(3):451-60.
354. Monin JK, Schulz R, Feeney BC. Compassionate love in individuals with Alzheimer's disease and their spousal caregivers: Associations with caregivers' psychological health. *Gerontologist* 2015;55(6):981-9.
355. Roth DL, Dilworth-Anderson P, Huang J, Gross AL, Gitlin LN. Positive aspects of family caregiving for dementia: Differential item functioning by race. *J Gerontol B Psychol Sci Soc Sci* 2015;70(6):813-9.
356. Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London)* 2016;15(6):1534-61.
357. Yu DSF, Cheng ST, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud* 2018;79:1-26.
358. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist* 1995;35(6):771-91.
359. Baumgarten M, Battista RN, Infante-Rivard C, Hanley JA, Becker R, Gauthier S. The psychological and physical health of family members caring for an elderly person with dementia. *J Clin Epidemiol* 1992;45(1):61-70.
360. Mausbach BT, Chattillion EA, Roepke SK, Patterson TL, Grant I. A comparison of psychosocial outcomes in elderly Alzheimer caregivers and noncaregivers. *Am J Geriatr Psychiatry* 2013;21(1):5-13.
361. Kessler RC, Chiu WT, Demler O, Merikangas KR, Walters EE. Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry* 2005;62:617-27.
362. Sallim AB, Sayampanathan AA, Cuttilan A, Chun-Man Ho R. Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. *J Am Med Dir Assoc* 2015;16(12):1034-41.
363. Atteih S, Mellon L, Hall P, Brewer L, Horgan F, Williams D, et al. Implications of stroke for caregiver outcomes: Findings from the ASPIRE-S Study. *Int J Stroke* 2015;10:918-23.
364. Thunyadee C, Sitthimongkol Y, Sangon S, Chai-Aroon T, Hegadoren KM. Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *J Nurs Health Sci* 2015;17:412-9.
365. Collins RN, Kishita N. Prevalence of depression and burden among informal care-givers of people with dementia: A meta-analysis. *Ageing and Society*, 1-38. doi:10.1017/S0144686X19000527.
366. Vitaliano PP, Ustundag O, Borson S. Objective and subjective cognitive problems among caregivers and matched non-caregivers. *Gerontologist* 2017;57(4):637-47.
367. Dassel KB, Carr DC, Vitaliano P. Does caring for a spouse with dementia accelerate cognitive decline? Findings from the Health and Retirement Study. *Gerontologist* 2017;57(2):319-28.
368. Arthur PB, Gitlin LN, Kairalla JA, Mann WC. Relationship between the number of behavioral symptoms in dementia and caregiver distress: What is the tipping point? *Int Psychogeriatr* 2018;30(8):1099-107.
369. Gillespie R, Mullan J, Harrison L. Managing medications: The role of informal caregivers of older adults and people living with dementia: A review of the literature. *J Clin Nurs* 2014;23(23-24):3296-308.
370. Alsaeed D, Jamieson E, Gul MO, Smith FJ. Challenges to optimal medicines use in people living with dementia and their caregivers: A literature review. *Int J Pharm* 2016;512(2):396-404.
371. Polenick CA, Stanz SD, Leggett AN, Maust DT, Hodgson NA, Kales HC. Stressors and resources related to medication management: Associations with spousal caregivers' role overload. *Gerontologist* 2018.doi:10.1093/geront/gny130. [Epub ahead of print].
372. Aston L, Hilton A, Moutela T, Shaw R, Maidment I. Exploring the evidence base for how people with dementia and their informal carers manage their medication in the community: A mixed studies review. *BMC Geriatr* 2017;17(1):242.
373. Badana ANS, Marino V, Haley WE. Racial differences in caregiving: Variation by relationship type and dementia care status. *J Aging Health* 2019;31(6):925-46.
374. Gaugler JE, Mittelman MS, Hepburn K, Newcomer R. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine* 2010;8:85.
375. Mausbach BT, Chattillion EA, Ho J, Flynn LM, Tiznado D, von Känel R, et al. Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychol Aging* 2014;29(4):776-86.
376. Peacock SC. The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review. *Palliat Support Care* 2013;11(2):155-68.
377. Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med* 2003;349(20):1936-42.
378. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *Int Psychogeriatr* 2014;26(5):725-47.
379. von Känel R, Mausbach BT, Ancoli-Israel S, Mills PJ, Dimsdale JE, Patterson TL, et al. Positive affect and sleep in spousal Alzheimer caregivers: A longitudinal study. *Behav Sleep Med* 2014;12(5):358-72.
380. Peng H-L, Chang Y-P. Sleep disturbance in family caregivers of individuals with dementia: A review of the literature. *Perspect Psychiatr C* 2012;49(2):135-46.
381. Gao C, Chapagain NY, Scullin MK. Sleep Duration and Sleep Quality in caregivers of patients with dementia: A systematic review and meta-analysis. *JAMA Netw Open* 2019;2(8):e199891.
382. Välimäki TH, Martikainen JA, Hongisto K, Väättäinen S, Sintonen H, Koivisto AM. Impact of Alzheimer's disease on the family caregiver's long-term quality of life: Results from an ALSOVA follow-up study. *Qual Life Res* 2016;25(3):687-97.
383. Bremer P, Cabrera E, Leino-Kilpi H, Lethin C, Saks K, Sutcliffe C. Informal dementia care: Consequences for caregivers' health and health care use in 8 European countries. *Health Policy* 2015;119(11):1459-71.
384. MetLife Mature Market Institute. The MetLife Study of Alzheimer's Disease: The Caregiving Experience; August 2006. Available at: <http://docplayer.net/20982840-The-metlife-study-of-alzheimer-s-disease-the-caregiving-experience.html>. Accessed December 4, 2019.
385. Dassel KB, Carr DC. Does dementia caregiving accelerate frailty? Findings from the Health and Retirement Study. *Gerontologist* 2016;56(3):444-50.

386. Fredman L, Bertrand RM, Martire LM, Hochberg M, Harris EL. Leisure-time exercise and overall physical activity in older women caregivers and non-caregivers from the Caregiver-SOF Study. *Prev Med* 2006;43:226-9.
387. Rote SM, Angel JL, Moon H, Markides K. Caregiving Across Diverse Populations: New Evidence From the National Study of Caregiving and Hispanic EPESE. *Innov Aging* 2019;3(2):igz033.
388. von Kanel R, Dimsdale JE, Mills PJ, Ancoli-Israel S, Patterson TL, Mausbach BT, et al. Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. *J Gerontol A Biol Sci Med Sci* 2006;61(9):963-9.
389. Kiecolt-Glaser JK, Dura JR, Speicher CE, Trask OJ, Glaser R. Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosom Med* 1991;53:345-62.
390. Kiecolt-Glaser JK, Marucha PT, Mercado AM, Malarkey WB, Glaser R. Slowing of wound healing by psychological stress. *Lancet* 1995;346(8984):1194-6.
391. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler I. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosom Med* 2002;64:418-35.
392. Mausbach BT, Romero-Moreno R, Bos T, von Kanel R, Ziegler MG, Allison MA, et al. Engagement in pleasant leisure activities and blood pressure: A 5-year longitudinal study in Alzheimer caregivers. *Psychosom Med* 2017;79(7):735-41.
393. Shaw WS, Patterson TL, Ziegler MG, Dimsdale JE, Semple SJ, Grant I. Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. *J Psychosom Res* 1999;46(3):215-27.
394. Mausbach BT, Roepke SK, Ziegler MG, Milic M, Von Kanel R, Dimsdale JE, et al. Association between chronic caregiving stress and impaired endothelial function in the elderly. *J Am Coll Cardiol* 2010;55(23):2599-606.
395. Allen AP, Curran EA, Duggan Á, Cryan JF, Chorcoráin AN, Dinan TG, et al. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neurosci Biobehav Rev* 2017;73:123-64.
396. Roth DL, Sheehan OC, Haley WE, Jenny NS, Cushman M, Walston JD. Is family caregiving associated with inflammation or compromised immunity? A meta-analysis. *Gerontologist* 2019;59(5):e521-e534.
397. Schubert CC, Boustani M, Callahan CM, Perkins AJ, Hui S, Hendrie HC. Acute care utilization by dementia caregivers within urban primary care practices. *J Gen Intern Med* 2008;23(11):1736-40.
398. Zhu CW, Scarmeas N, Ornstein K, Albert M, Brandt J, Blacker D, et al. Health-care use and cost in dementia caregivers: Longitudinal results from the Predictors Caregiver Study. *Alzheimers Dement* 2015;11(4):444-54.
399. Leggett AN, Sonnega AJ, Lohman MC. Till death do us part: Intersecting health and spousal dementia caregiving on caregiver mortality. *J Aging Health* 2019. doi: 10.1177/0898264319860975. [Epub ahead of print].
400. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist* 2015;55(2):309-19.
401. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719-30.
402. Perkins M, Howard VJ, Wadley VG, Crowe M, Safford MM, Haley WE, et al. Caregiving strain and all-cause mortality: Evidence from the REGARDS Study. *J Gerontol B Psychol Sci Soc Sci* 2013;68(4):504-12.
403. Gaugler JE, Jutkowitz E, Peterson CM, Zmora R. Caregivers dying before care recipients with dementia. *Alzheimers Dement (NY)* 2018;4:688-93.
404. National Academies of Sciences, Engineering, and Medicine. Families Caring for an Aging America. Washington, D.C.: The National Academies Press; 2016.
405. Albert SM, Schulz R. The MetLife Study of working caregivers and employer health care costs. New York, N.Y.: MetLife Mature Market Institute; 2010.
406. Gaugler JE, Pestka DL, Davila H, Sales R, Owen G, Baumgartner SA, et al. The complexities of family caregiving at work: A mixed-methods study. *Int J Aging Hum Dev* 2018;87(4):347-76.
407. AARP. Family Caregiving and Out-of-Pocket Costs: 2016 Report. Available at: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/lrc/2016/family-caregiving-costs-fact-sheet.doi.10.26419%252Fres.00138.002.pdf. Accessed December 4, 2019.
408. Stall NM, Kim SJ, Hardacre KA, Shah PS, Straus SE, Bronskill SE, et al. Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *J Am Geriatr Soc* 2019;67(3):609-17.
409. Gaugler JE, Jutkowitz E, Shippee TP, Brasure M. Consistency of dementia caregiver intervention classification: An evidence-based synthesis. *Int Psychogeriatr* 2017;29(1):19-30.
410. Gitlin LN, Hodgson N. Caregivers as therapeutic agents in dementia care: The evidence-base for interventions supporting their role. In: Gaugler JE, Kane RL, eds. *Family caregiving in the new normal*. Philadelphia, Pa.: Elsevier, Inc.; 2015: p. 305-56.
411. Williams F, Moghaddam N, Ramsden S, De Boos D. Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of randomised controlled trials. *Aging Ment Health* 2019;23(12):1629-42.
412. Kaddour L, Kishita N, Schaller A. A meta-analysis of low-intensity cognitive behavioral therapy-based interventions for dementia caregivers. *Int Psychogeriatr* 2018:1-16.
413. Nguyen H, Terry D, Phan H, Vickers J, McInerney F. Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *J Clin Nurs* 2019;28(7-8):1050-69.
414. Jütten LH, Mark RE, Wicherts JM, Sitskoorn MM. The effectiveness of psychosocial and behavioral interventions for informal dementia caregivers: Meta-analyses and meta-regressions. *J Alzheimers Dis* 2018;66(1):149-72.
415. Maslow K. *Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's Disease and their Caregiver at Home and in the Community*. Washington, D.C.: Administration on Aging; 2012. Available at: https://nadr.acl.gov/sites/default/files/uploads/docs/TranslatingInnovationtoImpactAlzheimersDisease_0.pdf. Accessed December 4, 2019.
416. Rosalynn Carter Institute for Caregiving. Caregiver Intervention Database. Available at: <https://www.rosalynncarter.org/research/caregiver-intervention-database/>. Accessed December 4, 2019.
417. Liew TM, Lee CS. Reappraising the efficacy and acceptability of multicomponent interventions for caregiver depression in dementia: The utility of network meta-analysis. *Gerontologist* 2019;59(4):e380-e392.
418. Teri L, Logsdon RG, McCurry SM, Pike KC, McGough EL. Translating an evidence-based multicomponent intervention for older adults with dementia and caregivers. *Gerontologist* 2018;Oct 9. doi: 10.1093/geront/gny122. [Epub ahead of print].
419. Menne HL, Bass DM, Johnson JD, Primitica B, Kearney KR, Bollin S, et al. Statewide implementation of "reducing disability in Alzheimer's disease": Impact on family caregiver outcomes. *J Gerontol Soc Work* 2014;57(6-7):626-39.
420. Teri L, McKenzie G, Logsdon RG, McCurry SM, Bollin S, Mead J, et al. Translation of two evidence-based programs for training families to improve care of persons with dementia. *Gerontologist* 2012;52(4):452-9.
421. Gitlin LN, Jacobs M, Earland TV. Translation of a dementia caregiver intervention for delivery in homecare as a reimbursable Medicare service: Outcomes and lessons learned. *Gerontologist* 2010;50(6):847-54.
422. Burgio LD, Collins IB, Schmid B, Wharton T, McCallum D, Decoster J. Translating the REACH caregiver intervention for use by area agency on aging personnel: The REACH OUT program. *Gerontologist* 2009;49(1):103-16.

423. Mittelman MS, Bartels SJ. Translating research into practice: Case study of a community-based dementia caregiver intervention. *Health Aff* 2014;33(4):587-95.
424. Cheung KS, Lau BH, Wong PW, Leung AY, Lou VW, Chan GM, et al. Multicomponent intervention on enhancing dementia caregiver well-being and reducing behavioral problems among Hong Kong Chinese: A translational study based on REACH II. *Int J Geriatr Psychiatry* 2015;30(5):460-9.
425. Samia LW, Abouessa AM, Halloran J, Hepburn K. The Maine Savvy Caregiver Project: Translating an evidence-based dementia family caregiver program within the RE-AIM Framework. *J Gerontol Soc Work* 2014;57(6-7):640-61.
426. Lykens K, Moayad N, Biswas S, Reyes-Ortiz C, Singh KP. Impact of a community based implementation of REACH II program for caregivers of Alzheimer's patients. *PLoS One* 2014;9(2):e89290.
427. Menne HL, Bass DM, Johnson JD, Kearney KR, Bollin S, Teri L. Program components and outcomes of individuals with dementia: Results from the replication of an evidence-based program. *J Appl Gerontol* 2017;36(5):537-52.
428. Primitica B, Menne HL, Bollin S, Teri L, Molea M. Evidence-Based Program replication: Translational activities, experiences, and challenges. *J Appl Gerontol* 2015;34(5):652-70.
429. Fortinsky RH, Gitlin LN, Pizzi LT, Piersol CV, Grady J, Robison JT, et al. Translation of the care of persons with dementia in their environments (COPE) intervention in a publicly-funded home care context: Rationale and research design. *Contemp Clin Trials* 2016;49:155-65.
430. Nichols LO, Martindale-Adams J, Burns R, Zuber J, Graney MJ. REACH VA: Moving from translation to system implementation. *Gerontologist* 2016;56(1):135-44.
431. McCurry SM, Logsdon RG, Pike KC, LaFazia DM, Teri L. Training Area Agencies on Aging case managers to improve physical function, mood, and behavior in persons with dementia and caregivers: Examples from the RDAD-Northwest Study. *J Gerontol Soc Work* 2018;61(1):45-60.
432. Czaja SJ, Lee CC, Perdomo D, Loewenstein D, Bravo M, Moxley JH, et al. Community REACH: An implementation of an evidence-based caregiver program. *Gerontologist* 2018;58(2):e130-7.
433. Fauth EB, Jackson MA, Walberg DK, Lee NE, Easom LR, Alston G, et al. External validity of the New York University Caregiver Intervention: Key caregiver outcomes across multiple demonstration projects. *J Appl Gerontol* 2019;38(9):1253-81.
434. Boustani M, Alder CA, Solid CA. Agile implementation: A blueprint for implementing evidence-based healthcare solutions. *J Am Geriatr Soc* 2018;66(7):1372-6.
435. Boots LM, de Vugt ME, van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psych* 2015;29(4):331-44.
436. Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial intervention for dementia caregivers. *Am J Geriatr Psychiatry* 2013;21(11):1071-81.
437. Griffiths PC, Whitney MK, Kovaleva M, Hepburn K. Development and implementation of tele-savvy for dementia caregivers: A Department of Veterans Affairs Clinical Demonstration Project. *Gerontologist* 2016;56(1):145-54.
438. Brown EL, Ruggiano N, Li J, Clarke PJ, Kay ES, Hristidis V. Smartphone-based health technologies for dementia care: Opportunities, challenges, and current practices. *J Appl Gerontol* 2019;38(1):73-91.
439. Grossman MR, Zak DK, Zelinski EM. Mobile Apps for caregivers of older adults: Quantitative content analysis. *JMIR mHealth and uHealth* 2018;6(7):e162.
440. Gaugler JE, Zmora R, Mitchell LL, Finlay JM, Peterson CM, McCarron H, et al. Six-month effectiveness of remote activity monitoring for persons living with dementia and their family caregivers: An experimental mixed methods study. *Gerontologist* 2019;59(1):78-89.
441. Waller A, Dilworth S, Mansfield E, Sanson-Fisher R. Computer and telephone delivered interventions to support caregivers of people with dementia: A systematic review of research output and quality. *BMC Geriatr* 2017;17(1):265.
442. Hopwood J, Walker N, McDonagh L, Rait G, Walters K, Iliffe S, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: Systematic review. *J Med Internet Res* 2018;20(6):e216.
443. Gitlin LN, Marx K, Scerpella D, Dabelko-Schoeny H, Anderson KA, Huang J, et al. Embedding caregiver support in community-based services for older adults: A multi-site randomized trial to test the Adult Day Service Plus Program (ADS Plus). *Contemp Clin Trials* 2019;83:97-108.
444. Gaugler JE, Potter T, Pruinelli L. Partnering with caregivers. *Clin Geriatr Med* 2014;30(3):493-515.
445. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: State-of-the-science and next steps. *Gerontologist* 2015;55(2):210-26.
446. Wethington E, Burgio LD. Translational research on caregiving: Missing links in the translation process. In: Gaugler JE, Kane RL, eds. *Family caregiving in the new normal*. Philadelphia, Pa.: Elsevier, Inc; 2015: p. 193-210.
447. Zarit SH. Past is prologue: How to advance caregiver interventions. *Aging Ment Health* 2017;16:1-6.
448. Kishita N, Hammond L, Dietrich CM, Mioshi E. Which interventions work for dementia family carers?: an updated systematic review of randomized controlled trials of carer interventions. *Int Psychogeriatr* 2018;30(11):1679-96.
449. Zarit SH. Empirically supported treatment for family caregivers. In: Qualls SH, Zarit SH, eds. *Aging families and caregiving*. Hoboken, N.J.: John Wiley & Sons, Inc.; 2009: p. 131-54.
450. Zarit SH, Lee JE, Barrineau MJ, Whitlatch CJ, Femia EE. Fidelity and acceptability of an adaptive intervention for caregivers: An exploratory study. *Aging Ment Health* 2013;17(2):197-206.
451. Van Mierlo LD, Meiland FJ, Van Hout HP, Dröes RM. Toward an evidence-based implementation model and checklist for personalized dementia care in the community. *Int Psychogeriatr* 2016;28(5):801-13.
452. Gaugler JE, Reese M, Tanler R. Care to Plan: An online tool that offers tailored support to dementia caregivers. *Gerontologist* 2016;56(6):1161-74.
453. Jennings LA, Ramirez KD, Hays RD, Wenger NS, Reuben DB. Personalized goal attainment in dementia care: Measuring what persons with dementia and their caregivers want. *J Am Geriatr Soc* 2018;66(11):2120-7.
454. Whitlatch CJ, Orsulic-Jeras S. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *Gerontologist* 2018;18:58(Suppl 1):S58-73.
455. Akarsu NE, Prince MJ, Lawrence VC, Das-Munshi J. Depression in carers of people with dementia from a minority ethnic background: Systematic review and meta-analysis of randomised controlled trials of psychosocial interventions. *Int J Geriatr Psychiatry* 2019;34(6):790-806.
456. Gonyea JG, López LM, Velásquez EH. The effectiveness of a culturally sensitive cognitive behavioral group intervention for Latino Alzheimer's caregivers. *Gerontologist* 2016;56(2):292-302.
457. Llanque SM, Enriquez M. Interventions for Hispanic caregivers of patients with dementia: A review of the literature. *Am J Alzheimers Dis Other Demen* 2012;27(1):23-32.
458. Kally Z, Cote SD, Gonzalez J, Villarruel M, Cherry DL, Howland S, et al. The Savvy Caregiver Program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. *J Gerontol Soc Work* 2014;57(6-7):681-93.
459. Kally Z, Cherry DL, Howland S, Villarruel M. Asian Pacific Islander dementia care network: A model of care for underserved communities. *J Gerontol Soc Work* 2014;57(6-7):710-27.

460. Napoles AM, Chadiha L, Eversley R, Moreno-John G. Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? *Am J Alzheimers Dis Other Dement* 2010;25:389-406.
461. Hicken BL, Daniel C, Luptak M, Grant M, Kilian S, Rupper RW. Supporting caregivers of rural veterans electronically (SCORE). *J Rural Health* 2017;33(3):305-13.
462. Graham-Phillips A, Roth DL, Huang J, Dilworth-Anderson P, Gitlin LN. Racial and ethnic differences in the delivery of the resources for enhancing Alzheimer's Caregiver Health II Intervention. *J Am Geriatr Soc* 2016;64(8):1662-7.
463. Martindale-Adams J, Tah T, Finke B, LaCounte C, Higgins BJ, Nichols LO. Implementation of the REACH model of dementia caregiver support in American Indian and Alaska Native communities. *Transl Behav Med* 2017;7(3):427-34.
464. Meyer OL, Liu XL, Tancredi D, Ramirez AS, Schulz R, Hinton L. Acculturation level and caregiver outcomes from a randomized intervention trial to enhance caregivers' health: Evidence from REACH II. *Aging Ment Health* 2017;24:1-8.
465. Fields NL, Xu L, Richardson VE, Parekh R, Ivey D, Feinhals G. The Senior Companion Program Plus: A culturally tailored psychoeducational training program (innovative practice). *Dementia (London)*. 2016 Jan 1:1471301216685626. doi: 10.1177/1471301216685626. [Epub ahead of print]
466. Luchsinger JA, Burgio L, Mittelman M, Dunner I, Levine JA, Hoyos C, et al. Comparative effectiveness of 2 interventions for Hispanic caregivers of persons with dementia. *J Am Geriatr Soc* 2018;66(9):1708-15.
467. Gilmore-Bykovskiy A, Johnson R, Walljasper L, Block L, Werner N. Underreporting of gender and race/ethnicity differences in NIH-funded dementia caregiver support interventions. *Am J Alzheimers Dis Other Dement* 2018;33(3):145-52.
468. Fredriksen-Goldsen KI, Jen S, Bryan AEB, Goldsen J. Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *J Appl Gerontol* 2018;37(5):545-69.
469. U.S. Department of Health and Human Services. National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers. Available at: <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>. Accessed December 4, 2019.
470. Khatutsky G, Wiener J, Anderson W, Akhmerova V, Jessup EA, Squillace MR. Understanding direct care workers: A snapshot of two of America's most important jobs: Certified nursing assistants and home health aides. Washington, D.C.: U.S. Department of Health and Human Services; 2011.
471. Stone R. The Long-Term Care Workforce: From Accidental to Valued Profession. In: Wolf D, Folbre N, eds. *Universal Coverage of Long-Term Care in the United States: Can We Get There from Here?* New York, NY: Russell Sage Foundation; 2012: 155-78.
472. Jones AL, Dwyer LL, Bercovitz AR, Strahan GW. The National Nursing Home Survey: 2004 Overview. *Vital Health Stat* 13 2009;(167):1-155.
473. Kramer NA, Smith MC. Training nursing assistants to care for nursing home residents with dementia. In: Molinari V, editor. *Professional psychology in long-term care*. New York, N.Y.: Hatherleigh Press; 2000: p. 227-56.
474. McCabe MP, Davison TE, George K. Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging Ment Health* 2007;11(5):505-19.
475. Beck C, Ortigara A, Mercer S, Shue V. Enabling and empowering certified nursing assistants for quality dementia care. *Int J Geriatr Psychiatry* 1999;14(3):197-211.
476. Institute of Medicine. *Retooling for an Aging America: Building the Health Care Workforce*. Washington, D.C.: The National Academies Press 2008. Available at: <http://www.nationalacademies.org/hmd/reports/2008/retooling-for-an-aging-america-building-the-health-care-workforce.aspx>. Accessed December 4, 2019.
477. Warshaw GA, Bragg EJ. Preparing the health care workforce to care for adults with Alzheimer's disease and related dementias. *Health Aff* 2014;33(4):633-41.
478. American Health Care Association. (2011). *Staffing Survey Report*.
479. Stone RI. Factors affecting the future of family caregiving in the United States. In: JE Gaugler, RL Kane, eds. *Family Caregiving in the New Normal*. San Diego, CA: Elsevier, Inc; 2015: p. 57-77.
480. Elvish R, Burrow S, Cawley R, Harney K, Pilling M, Gregory J, et al. 'Getting to know me': The second phase roll-out of a staff training programme for supporting people with dementia in general hospitals. *Dementia (London)* 2016;pii:1471301216634926 [epub ahead of print].
481. Spector A, Orrell M, Goyder J. A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia. *Ageing Res Rev* 2013;12(1):354-64.
482. Bray J, Evans S, Bruce M, Carter C, Brooker D, Milosevic S, et al. Enabling hospital staff to care for people with dementia. *Nurs Older People* 2015;27(10):29-32.
483. Palmer JL, Lach HW, McGillick J, Murphy-White M, Carroll MB, Armstrong JL. The Dementia Friendly Hospital Initiative education program for acute care nurses and staff. *J Contin Educ Nurs* 2014;45(9):416-24.
484. Surr CA, Smith SJ, Crossland J, Robins J. Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: A repeated measures study. *Int J Nurs Stud* 2016;53:144-51.
485. Eldercare Workforce Alliance. *Geriatrics Workforce Shortage: A Looming Crisis for our Families*. Washington, D.C.: Eldercare Workforce Alliance; 2012.
486. The American Geriatrics Society. *Current Geriatrician Shortfall*. Available at: https://www.americangeriatrics.org/sites/default/files/inline-files/Current-Geriatrician-Shortfall_0.pdf. Accessed December 4, 2019.
487. The American Geriatrics Society. *Projected Future Need for Geriatricians*. Available at: <https://www.americangeriatrics.org/sites/default/files/inline-files/Projected-Future-Need-for-Geriatricians.pdf>. Accessed December 4, 2019.
488. American Association of Nurse Practitioners. *NP Fact Sheet*. Available at: <https://www.aanp.org/all-about-nps/np-fact-sheet>. Accessed December 4, 2019.
489. Hoffman D, Zucker H. A call to preventive action by health care providers and policy makers to support caregivers. *Prev Chronic Dis* 2016;13:E96.
490. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. *JAMA* 2014;311(10):1052-60.
491. Riedel O, Klotsche J, Wittchen HU. Overlooking informal dementia caregivers' burden. *Res Gerontol Nurs* 2016;9(4):167-74.
492. Alzheimer's Association National Plan Care and Support Milestone Workgroup, Borson S, Boustani MA, Buckwalter KC, Burgio LD, Chodosh J, et al. Report on milestones for care and support under the U.S. National Plan to Address Alzheimer's Disease. *Alzheimer's & Dementia* 2016;12(3):334-69.
493. Cross AJ, Garip G, Sheffield D. The psychosocial impact of caregiving in dementia and quality of life: A systematic review and meta-synthesis of qualitative research. *Psychol Health* 2018;27:1-22.
494. Gaugler JE, Westra BL, Kane RL. Professional discipline and support recommendations for family caregivers of persons with dementia. *Int Psychogeriatr* 2016;28(6):1029-40.
495. Austrom MG, Carvell CA, Alder CA, Gao S, Boustani M, LaMantia M. Workforce development to provide person-centered care. *Aging Ment Health* 2016;20(8):781-92.
496. Werner P. Reflections on quality of care for persons with dementia: moving toward an integrated, comprehensive approach. *Int Psychogeriatr*. 2019 Mar;31(3):307-8.
497. Leggett A, Connell C, Dubin L, Dunkle R, Langa KM, Maust DT, et al. Dementia care across a tertiary care health system: What exists now and what needs to change. *J Am Med Dir Assoc* 2019;20(10):1307-12.e1.

498. Noel MA, Kaluzynski TS, Templeton VH. Quality dementia care. *J Appl Gerontol* 2017;36(2):195-212.
499. Bott NT, Shekter CC, Yang D, Peters S, Brady B, Plowman S, et al. Systems Delivery Innovation for Alzheimer Disease. *Am J Geriatr Psychiatry* 2019;27(2):149-61.
500. Tan ZS, Jennings L, Reuben D. Coordinated care management for dementia in a large academic health system. *Health Aff* 2014;33(4):619-25.
501. Callahan CM, Sachs GA, Lamantia MA, Unroe KT, Arling G, Boustani MA. Redesigning systems of care for older adults with Alzheimer's disease. *Health Aff* 2014;33(4):626-32.
502. French DD, LaMantia MA, Livin LR, Herceg D, Alder CA, Boustani MA. Healthy Aging Brain Center improved care coordination and produced net savings. *Health Aff* 2014;33(4):613-8.
503. Borson S, Chodosh J. Developing dementia-capable health care systems: A 12-step program. *Clin Geriatr Med* 2014;30(3):395-420.
504. Reuben DB, Evertson LC, Wenger NS, Serrano K, Chodosh J, Ercoli L, et al. The University of California at Los Angeles Alzheimer's and Dementia Care Program for comprehensive, coordinated, patient-centered care: Preliminary data. *J Am Geriatr Soc* 2013;61(12):2214-8.
505. Thyrian JR, Hertel J, Wucherer D, Eichler T, Michalowsky B, Dreier-Wolfgramm A. Effectiveness and safety of dementia care management in primary care: A randomized clinical trial. *JAMA Psychiatry* 2017;74(10):996-1004.
506. Callahan CM. Alzheimer's Disease: Individuals, dyads, communities, and costs. *J Am Geriatr Soc* 2017;65(5):892-5.
507. Dreier-Wolfgramm A, Michalowsky B, Austrom MG, van der Marck MA, Illiffe S, Alder C. Dementia care management in primary care: Current collaborative care models and the case for interprofessional education. *Z Gerontol Geriatr* 2017;50(Suppl 2):68-77.
508. Reuben DB, Tan ZS, Romero T, Wenger NS, Keeler E, Jennings LA. Patient and caregiver benefit from a comprehensive dementia care program: 1-year results from the UCLA Alzheimer's and Dementia Care Program. *J Am Geriatr Soc* 2019;67:2267-73.
509. Boustani M, Alder CA, Solid CA, Reuben D. An alternative payment model to support widespread use of collaborative dementia care models. *Health Aff (Millwood)* 2019;38(1):54-9.
510. Clevenger CK, Cellar J, Kovaleva M, Medders L, Hepburn K. Integrated memory care clinic: Design, implementation, and initial results. *J Am Geriatr Soc* 2018;66(12):2401-7.
511. Odenheimer G, Borson S, Sanders AE, Swain-Eng RJ, Kyomen HH, Tierney S, et al. Quality improvement in neurology: Dementia management quality measures (executive summary). *Am J Occup Ther* 2013;67(6):704-10.
512. LaMantia MA, Alder CA, Callahan CM, Gao S, French DD, Austrom MG, et al. The Aging Brain Care Medical Home: Preliminary data. *J Am Geriatr Soc* 2015;63(6):1209-13.
513. Gaugler JE, Kane RL, eds. *Family Caregiving in the New Normal*. Philadelphia, Pa.: Elsevier, Inc.; 2015.
514. Alzheimer's Association. Alzheimer's Impact Movement: Use of Medicare Planning Benefit. Available at: <https://alzimpact.org/media/serve/id/5d2c9620e4f5d>. Accessed September 27, 2019.
515. The Lewin Group. Process Evaluation of the Older Americans Act Title III-E-National Family Caregiver Support Program: Final Report, 2016. Available at: https://acl.gov/sites/default/files/programs/2017-02/NFCSF_Final_Report-update.pdf. Accessed December 4, 2019.
516. Alzheimer's Association. Alzheimer's Association Dementia Care Practice Recommendations. Available at: <https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf>. Accessed November 5, 2019.
517. Camp CJ. Denial of human rights: We must change the paradigm of dementia care. *Clin Gerontol* 2019;42(3):221-3.
518. Gaugler JE, Bain LJ, Mitchell L, Finlay J, Fazio S, Jutkowitz E, et al. Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes. *Alzheimers Dement (NY)* 2019;5:388-97.
519. Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. *Curr Opin Psychiatry* 2019;32(6):557-62.
520. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med* 2013;368:1326-34.
521. Yang Z, Zhang K, Lin PJ, Clevenger C, Atherly A. A longitudinal analysis of the lifetime cost of dementia. *Health Serv Res* 2012;47(4):1660-78.
522. Murman DL, Chen Q, Powell MC, Kuo SB, Bradley CJ, Colenda CC. The incremental direct costs associated with behavioral symptoms in AD. *Neurology* 2002;59:1721-9.
523. Fishman P, Coe NB, White L, Crane PK, Park S, Ingraham B, et al. Cost of dementia in Medicare Managed Care: A systematic literature review. *Am J Manag Care* 2019;25:e247-53.
524. Yang Z, Levey A. Gender differences: A lifetime analysis of the economic burden of Alzheimer's disease. *Women Health Iss* 2015;25(5):436-40.
525. Hudomiet P, Hurd MD, Rohwedder S. The relationship between lifetime out-of-pocket medical expenditures, dementia and socioeconomic status in the U.S. *J Econ Ageing* 2019;14:100181.
526. Dwibedi N, Findley AP, Wiener C, Shen C, Sambamoorthi U. Alzheimer disease and related disorders and out-of-pocket health care spending and burden among elderly Medicare beneficiaries. *Medical Care* 2018;56:240-6.
527. White L, Fishman P, Basu A, Crane PK, Larson EB, Coe NB. Medicare expenditures attributable to dementia. *Health Services Res* 2019;54(4):773-81.
528. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med* 2015;163:729-36.
529. Bynum JPW, Meara E, Chang C-H, Rhoads JM. *Our Parents, Ourselves: Health Care for an Aging Population. A Report of the Dartmouth Atlas Project*. The Dartmouth Institute for Health Policy & Clinical Practice; 2016.
530. Rudolph JL, Zanin NM, Jones RN, Marcantonio ER, Fong TG, Yang FM, et al. Hospitalization in community-dwelling persons with Alzheimer's disease: Frequency and causes. *J Am Geriatr Soc* 2010;58(8):1542-8.
531. Beydoun MA, Beydoun HA, Gamaldo AA, Rostant O, Dore GA, Zonderman AB, et al. Nationwide inpatient prevalence, predictors and outcomes of Alzheimer's disease among older adults in the United States, 2002-2012. *J Alzheimers Dis* 2015;48(2):361-75.
532. U.S. Centers for Medicare & Medicaid Services. State Level Chronic Conditions Table: Prevalence, Medicare Utilization and Spending, 2007-2017. Available at: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CC_Main.html. Accessed September 13, 2019.
533. Landon BE, Keating NL, Onnela JP, Zaslavsky AM, Christakis NA, O'Malley AJ. Patient-sharing networks of physicians and health care utilization and spending among Medicare beneficiaries. *JAMA Intern Med* 2018;178:66-73.
534. Medicare. Glossary. Medicare: The Official U.S. Government Site for Medicare. Available at: <https://www.medicare.gov/glossary/a>. Accessed December 4, 2019.
535. Reschovsky JD, Hadley J, O'Malley J, Landon BE. Geographic variations in the cost of treating condition-specific episodes of care among Medicare patients. *Health Services Res* 2014;49(Part 1):32-51.
536. Leibson CL, Hall Lon K, Ransom JE, Roberts RO, Hass SL, Duhig AM, et al. Direct medical costs and source of cost differences across the spectrum of cognitive decline: A population-based study. *Alzheimers Dement* 2015;11(8):917-32.
537. Suehs BT, Davis CD, Alvir J, van Amerongen D, Patel NC, Joshi AV, et al. The clinical and economic burden of newly diagnosed Alzheimer's disease in a Medicare Advantage population. *Am J Alzheimers Dis Other Dement* 2013;28(4):384-92.

538. Lin P-J, Zhong Y, Fillit HM, Chen E, Neumann PJ. Medicare expenditures of individuals with Alzheimer's disease and related dementias or mild cognitive impairment before and after diagnosis. *J Am Geriatr Soc* 2016;64:1549-57.
539. Geldmacher DS, Kirson NY, Birnbaum HG, Eapen S, Kantor E, Cummings AK, et al. Pre-diagnosis excess acute care costs in Alzheimer's patients among a U.S. Medicaid population. *Appl Health Econ Health Policy* 2013;11(4):407-13.
540. Zhu CW, Cosentino S, Ornstein K, Gu Y, Scarmeas N, Andrews H, et al. Medicare utilization and expenditures around incident dementia in a multiethnic cohort. *J Gerontol A Biol Sci Med Sci* 2015;70(11):1448-53.
541. Kirson NY, Desai U, Ristovska L, Cummings AKG, Birnbaum HG, Ye W, et al. Assessing the economic burden of Alzheimer's disease patients first diagnosed by specialists. *BMC Geriatrics* 2016;16:138.
542. Aigbogun MS, Stellhorn R, Hartry A, Baker RA, Fillit H. Treatment patterns and burden of behavioral disturbances in patients with dementia in the United States: A claims database analysis. *BMC Neurology* 2019;19:33.
543. Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, Caffrey C. Long-term care providers and services users in the United States, 2015-2016. *Vital Health Stat* 2019;3(43).
544. Rome V, Harris-Kojetin L, Park-Lee E. Variation in operating characteristics of adult day services centers by center ownership: United States, 2014. *NCHS Data Brief*, No. 224. December 2015.
545. Caffrey C, Harris-Kojetin L, Rome V, Sengupta M. Variation in operating characteristics of residential care communities by size of community: United States, 2014. *NCHS Data Brief*, No. 222. November 2015.
546. U.S. Centers for Medicare & Medicaid Services. Nursing Home Data Compendium 2015 Edition. Available at: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/nursinghomedatacompendium_508-2015.pdf. Accessed December 4, 2019.
547. Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, et al. Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309(5):470-7.
548. Eiken S, Sredl K, Burwell B, Amos A. Medicaid Expenditures for Long-Term Services and Supports in FY 2016. IAP Medicaid Innovation Accelerator Program. IBM Watson. May 2018. Available at: <https://www.medicaid.gov/sites/default/files/2019-12/Itssexpenditures2016.pdf>. Accessed February 3, 2020.
549. Bynum J. Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey. Unpublished; provided under contract with the Alzheimer's Association. Lebanon, N.H.: Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research, January 2009.
550. Clarkson P, Davies L, Jasper R, Loynes N, Challis D. Home Support in Dementia (HoSt-D) Programme Management Group. A systematic review of the economic evidence for home support interventions in dementia. *Value in Health* 2017;20:1198-209.
551. Nickel F, Barth J, Kolominsky-Rabas PL. Health economic evaluations of non-pharmacological interventions for persons with dementia and their informal caregivers: A systematic review. *BMC Geriatrics* 2018;18:69.
552. Callahan CM, Arling G, Tu W, Rosenman MB, Counsell SR, Stump TE, et al. Transitions in care among older adults with and without dementia. *J Am Geriatr Soc* 2012;60(5):813-20.
553. Gozalo P, Teno JM, Mitchell SL, Skinner J, Bynum J, Tyler D, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365(13):1212-21.
554. Teno JM, Mitchell SL, Skinner J, Kuo S, Fisher E, Intrator O, et al. Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *J Palliat Med* 2009;12(4):359-62.
555. Genworth. Genworth Cost of Care Survey 2019, Summary and Methodology. <https://pro.genworth.com/rriiproweb/productinfo/pdf/131168.pdf>. Accessed November 3, 2019.
556. Jacobson G, Griffin S, Neuman T, Smith K. Income and Assets of Medicare Beneficiaries, 2016-2035. The Henry J. Kaiser Family Foundation Issue Brief. April 2017.
557. U.S. Department of Health and Human Services. What is Long-Term Care Insurance? Available at: <http://longtermcare.gov/costs-how-to-pay/what-is-long-term-care-insurance/>. Accessed December 4, 2019.
558. U.S. Centers for Medicare & Medicaid Services. Your Medicare Coverage. Long-Term Care. Available at: <https://www.medicare.gov/coverage/long-term-care.html>. Accessed December 4, 2019.
559. National Association of Insurance Commissioners and the Center for Insurance Policy and Research. The State of Long-Term Care Insurance: The Market, Challenges and Future Innovations. CIPR Study Series 2016-1. May 2016.
560. Reaves EL, Musumeci M. Medicaid and Long-Term Services and Supports: A Primer. Menlo Park, Calif: Kaiser Commission on Medicaid and the Uninsured, Henry J. Kaiser Family Foundation; December 2015. Publication #8617-02.
561. House Bill 1087, 66th Legislature, 2019 Regular Session. Long-Term Services and Supports Trust Program. Available at: <http://lawfilesexet.leg.wa.gov/biennium/2019-20/Pdf/Bills/Session%20Laws/House/1087-S2.SL.pdf#page=1>. Accessed December 4, 2019.
562. De Vleminck A, Morrison RS, Meier DE, Aldridge MD. Hospice care for patients with dementia in the United States: A longitudinal cohort study. *J Am Med Dir Assoc* 2018;19:633-8.
563. Gozalo P, Plotzke M, Mor V, Miller SC, Teno JM. Changes in Medicare costs with the growth of hospice care in nursing homes. *N Engl J Med* 2015;372:1823-31.
564. U.S. Centers for Medicare & Medicaid Services. Post-Acute Care and Hospice Provider Data 2017. Available at: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/PAC2017>. Accessed December 3, 2019.
565. Harris-Kojetin L, Sengupta M, Park-Lee E, Valverde R, Caffrey C, Rome V, et al. Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013-2014. *National Center for Health Statistics. Vital Health Stat* 3 2016;(38):x-xii;1-105.
566. U.S. Centers for Medicare & Medicaid Services. Medicare Program; FY 2020 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. Available at <https://www.federalregister.gov/documents/2019/08/06/2019-16583/medicare-program-fy-2020-hospice-wage-index-and-payment-rate-update-and-hospice-quality-reporting>. Accessed February 4, 2020.
567. Taylor DH, Jr., Bhavsar NA, Bull JH, Kassner CT, Olson A, Boucher NA. Will changes in Medicare payment rates alter hospice's cost-saving ability? *J Palliat Med* 2018;21:645-51.
568. Miller SC, Lima JC, Looze J, Mitchell SL. Dying in U.S. nursing homes with advanced dementia: How does health care use differ for residents with, versus without, end-of-life Medicare skilled nursing facility care? *J Palliat Med* 2012;15:43-50.
569. Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001;11(1):38-44.
570. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2010;58(12):2284-91.
571. Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve management of pain at the end of life? *J Am Geriatr Soc* 2002;50(3):507-15.

572. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: Experience at the end of life and impact of hospice care. *J Pain Symptom Manage* 2008;35(5):499-507.
573. Teno JM, Meltzer DO, Mitchell SL, Fulton AT, Gozalo P, Mor V. Type of attending physician influenced feeding tube insertions for hospitalized elderly people with severe dementia. *Health Aff* 2014;33(4):675-82.
574. Mitchell SL, Mor V, Gozalo PL, Servadio JL, Teno JM. Tube feeding in U.S. nursing home residents with advanced dementia, 2000-2014. *JAMA* 2016;316(7):769-70.
575. Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2017 on CDC WONDER Online Database, released December, 2018. Data are from the Multiple Cause of Death Files, 1999-2017, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Available at: <http://wonder.cdc.gov/ucd-icd10.html>. Accessed October 14, 2019.
576. Gilligan AM, Malone DC, Warholak TL, Armstrong EP. Health disparities in cost of care in patients with Alzheimer's disease: An analysis across 4 state Medicaid populations. *Am J Alzheimers Dis Other Dement* 2013;28(1):84-92.
577. Lin P-J, Zhong Y, Fillit HM, Cohen JT, Neumann PJ. Hospitalizations for ambulatory care sensitive conditions and unplanned readmissions among Medicare beneficiaries with Alzheimer's disease. *Alzheimers Dement* 2017;13(10):1174-8.
578. Healthy People 2020. Dementias, Including Alzheimer's Disease. Available at: www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/national-snapshot. Accessed December 24, 2019.
579. Davydov DS, Zibin K, Katon WJ, Pontone GM, Chwastiak L, Langa KM, et al. Neuropsychiatric disorders and potentially preventable hospitalizations in a prospective cohort study of older Americans. *J Gen Intern Med* 2014;29(10):1362-71.
580. Guterman EL, Allen IE, Josephson SA, Merrilees JJ, Dulaney S, Chiong W, et al. Association between caregiver depression and emergency department use among patients with dementia. *JAMA Neurol* 2019;76:1166-73.
581. Patel A, Parikh R, Howell EH, Hsieh E, Landers SH, Gorodeski EZ. Mini-Cog performance: Novel marker of post discharge risk among patients hospitalized for heart failure. *Circ Heart Fail* 2015;8(1):8-16.
582. Lin PJ, Fillit HM, Cohen JT, Neumann PJ. Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders. *Alzheimers Dement* 2013;9(1):30-8.
583. MacNeil-Vroomen JL, Nagurney JM, Allore HG. Comorbid conditions and emergency department treat and release utilization in multimorbid persons with cognitive impairment. *Am J Emerg Med* 2020;38:127-31.
584. Feng Z, Coots LA, Kaganova Y, Wiener JM. Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Aff* 2014;33(4):683-90.
585. Jennings LA, Laffan AM, Schlissel AC, Colligan E, Tan Z, Wenger NS, et al. Health care utilization and cost outcomes of a comprehensive dementia care program for Medicare beneficiaries. *JAMA Int Med* 2019;179:161-6.
586. Godard-Sebillotte C, Le Berre M, Schuster T, Trottier M, Vedel I. Impact of health service interventions on acute hospital use in community-dwelling persons with dementia: A systematic literature review and meta-analysis. *PLoS ONE* 2019;14(6):e0218426.
587. Amjad H, Carmichael D, Austin AM, Chang C-H, Bynum JPW. Continuity of care and health care utilization in older adults. *JAMA Intern Med* 2016;176(9):1371-8.
588. Alzheimer's Association. Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars. Available at: https://www.alz.org/help-support/resources/publications/trajectory_report. Accessed December 4, 2019.
589. Zissimopoulos J, Crimmins E, St. Clair P. The value of delaying Alzheimer's disease onset. *Forum Health Econ Policy*. 2014;18(1):25-39.
590. Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2018;14(3):408-11.
591. Liu JL, Hlávka JP, Hillestad R, Mattke S. Assessing the preparedness of the U.S. health care system infrastructure for an Alzheimer's treatment. The RAND Corporation: Santa Monica, CA. (2017) Available at: https://www.rand.org/pubs/research_reports/RR2272.html. Accessed December 4, 2019.
592. Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census. *Arch Neurol* 2003;60:1119-22.
593. Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health* 1998;88:1337-42.
594. National Alliance for Caregiving and AARP, Caregiving in the U.S., November 2009. Available at: <https://www.caregiving.org/pdf/research/FINALRegularExSum50plus.pdf>. Accessed December 22, 2019.
595. Amo PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff* 1999;18:182-8.
596. U.S. Department of Labor, Bureau of Labor Statistics. Employment, Hours, and Earnings from the Current Employment Statistics Survey. Series 10-CEU 6562160008, Home Health Care Services (NAICS code 6216). Average Hourly Earnings, July 2018. Available at: www.bls.gov/ces/data.htm. Accessed December 24, 2019.
597. Drabo EF, Barthold D, Joyce G, Ferido P, Chui HC, Zissimopoulos J. Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. *Alzheimers Dement* 2019;15:1402-11.
598. U.S. Department of Health and Human Services, Health Resources and Services Administration, National Center for Health Workforce Analysis. National and Regional Projections of Supply and Demand for Geriatricians: 2013-2025. Available at: <https://bhw.hrsa.gov/sites/default/files/bhw/health-workforce-analysis/research/projections/GeriatricsReport51817.pdf>. Accessed February 4, 2020.
599. Petriceks AH, Olivas JC, Srivastava S. Trends in geriatrics graduate medical education programs and positions, 2001 to 2018. *Gerontol Geriatr Med* 2018;4:1-4.
600. Dall TM, Storm MV, Chakrabarti R, Drogan O, Keran CM, Donofri PD, et al. Supply and demand analysis of the current and future U.S. neurology workforce. *Neurology* 2013; 81:470-78.
601. Duffrin C, Diaz S, Cashion M, Watson R, Cummings D, Jackson N. Factors associated with placement of rural primary care physicians in North Carolina. *South Med J* 2014;107(11):728-33.
602. Scheckel CJ, Richards J, Newman JR, Kunz M, Fangman B, Mi L, et al. Role of debt and loan forgiveness/repayment programs in osteopathic medical graduates' plans to enter primary care. *J Am Osteopath Assoc* 2019;119(4):227-35.
603. Auerback DI, Buerhaus PI, Staiger DO. Registered nurse supply grows faster than projected amid surge in new entrants ages 23-26. *Health Aff* 2011;30(12):2286-92.
604. Meyers D, Fryer GE, Krol D, Phillips RL, Green LA, Dovey SM. Title VII funding is associated with more family physicians and more physicians serving the underserved. *Am Fam Physician* 2002;66(4):554.
605. Center for Medicare & Medicaid Services. Center for Medicare & Medicaid Innovation. The Graduate Nurse Education Demonstration Project: Final Evaluation Report. August 2019. Prepared by IMPAQ International, Columbia, Md. Available at <https://innovation.cms.gov/Files/reports/gne-final-eval-rpt.pdf>. Accessed February 7, 2020.
606. Arora S, Thornton K, Murata G, Deming P, Kalishman S, Dion D, et al. Outcomes of treatment for hepatitis C virus infection by primary care providers. *NEJM*. 2011; 364(23):2199-207.

607. Paul M, Saad AD, Billings J, Blecker S, Bouchonville MF, Berry C. Endo ECHO improves patient-reported measures of access to care, health care quality, self-care behaviors, and overall quality of life for patients with complex diabetes in medically underserved areas of New Mexico. *J Endocr Soc* April 15 2019;3(suppl 1):MON-190.
608. Possin KL, Merrilees JJ, Dulaney S, Bonasera SJ, Chiong W, Lee K, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use. *JAMA Intern Med* 2019;179(12):1658-67.

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Our vision is a world without Alzheimer's and all other dementia.®

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