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 study 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 Analysis, 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. Similarly, a study of the current and future U.S. neurology workforce projected a 19% shortage of neurologists by 2025.

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

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

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. 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. 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, 2) recent medical school graduates currently completing a residency in primary care and 3) recent primary care residency graduates. 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.

- 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.
### 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

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**FIGURE 17**

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

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every day</td>
<td>19%</td>
</tr>
<tr>
<td>Every few days</td>
<td>34%</td>
</tr>
<tr>
<td>Once a week</td>
<td>18%</td>
</tr>
<tr>
<td>Every two weeks</td>
<td>12%</td>
</tr>
<tr>
<td>Once a month</td>
<td>10%</td>
</tr>
<tr>
<td>Less than once a month</td>
<td>8%</td>
</tr>
</tbody>
</table>

Created from data from the Alzheimer’s Association Primary Care Physician Dementia Training Survey.\(^{a,20}\)
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.
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%).

However, only two of five PCPs (42%) have completed...
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%). 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%).

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.
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 areas and directly influence the decision of osteopathic medical graduates to become primary care physicians. 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. 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.”

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. 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%.

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 C and complex diabetes. 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 and nursing home placement. 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 and the gross savings to Medicare on an annual basis totaled $2,404 per patient per year. A similar collaborative care model in Indiana — the Healthy Aging Brain Center (HABC) — resulted in gross savings of $3,474 per patient per year. 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.

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.
The estimates for the number of Americans age 65 and older with Alzheimer’s dementia for 2020 (prevalence of Alzheimer’s in 2020) is from unpublished prevalence estimates based on incidence data from the Chicago Health and Aging Project (CHAP) and population estimates from the 2010 U.S. Census.12

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 65,21 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 2002,147 while the CHAP estimate for 2000 was 4.5 million.146 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.146 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,77 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.160 Specific prevalence numbers for 2020 were derived from this analysis and provided to the Alzheimer’s Association by a team led by Lies 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.115 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.12

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.88 Other projections are somewhat lower (see, for example, Brookmeyer et al.151) 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.12

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.54 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.

End Notes
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.

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)\(^{12}\) 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.\(^{13}\) 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).\(^{14}\) 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 Leavitt, Piercy & Associates, Nov. 11, 2009). 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 colleagues\(^{15}\) and included in this report ($5.8 million in 2019);\(^{16}\) 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.\(^{16}\) 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 who 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.\(^{16}\) Hurd and colleagues 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 of respondents 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 Northeast, 25% in the West, 22% in the Midwest and 19% in the South.

A21. Alzheimer’s Association Recent Medical School Graduate Dementia Training Survey. Of the 200 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 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 (51%), 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 (18%), 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%).
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The Alzheimer’s Association leads the way to end Alzheimer’s and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

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