

## SPECIAL REPORT

# THE PATIENT JOURNEY IN AN ERA OF NEW TREATMENTS



**Better Alzheimer’s disease care requires conversations about memory at the earliest point of concern and a knowledgeable, accessible care team that includes physician specialists to diagnose, monitor disease progression and treat when appropriate. This is especially true now, in an era when treatments that change the underlying biology of Alzheimer’s are available.**

The Food and Drug Administration (FDA) approval of two new treatment options in the last two years has generated excitement and hope — and possibly some apprehension — for individuals with mild cognitive impairment (MCI) or mild dementia due to Alzheimer’s disease, their families and their health care providers. In this new era of treatment, it is essential to (1) establish what motivates or dissuades people from discussing memory concerns with their health care providers and (2) investigate the current patient volume of the specialist physician workforce who will be involved in the diagnosis, care and eventual treatment of a possible influx of patients.

### **Cognitive Issues Have Several Causes**

Nearly 10% of Americans age 45 and older experience subjective cognitive decline (SCD): self-perceived worsening of or more frequent difficulties with thinking or memory.<sup>256</sup> For some people, this is normal aging, but for others, these symptoms can be a warning sign of future Alzheimer’s disease.<sup>246-250</sup> Individuals with SCD may eventually be diagnosed with MCI, MCI due to Alzheimer’s disease, or another form of dementia.<sup>251-253</sup> SCD may also be caused by other underlying health conditions (see Prevalence of Subjective Cognitive Decline, page 21).<sup>254</sup>

### **Americans and Their Physicians Are Not Talking About Cognitive Issues or a Medical Diagnosis**

Many people do not discuss cognitive symptoms with their health care provider because they believe what they are experiencing is to be expected with getting older rather

#### **Subjective cognitive decline**

An individual’s perception that their memory and other thinking skills are worsening, independent of cognitive testing, a physician’s diagnosis or anyone else noticing (see Prevalence of Subjective Cognitive Decline, page 21).

#### **Mild cognitive impairment (MCI)**

“Early stage of memory loss or other cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living.”<sup>807</sup>

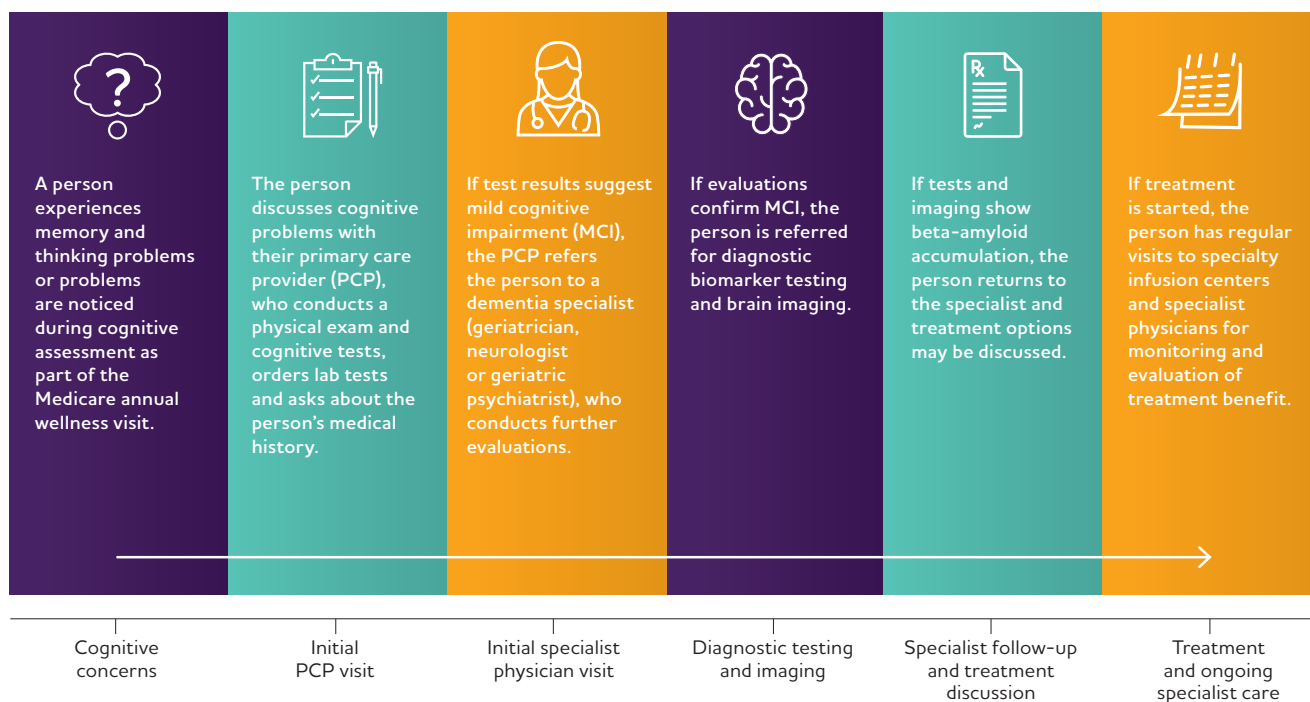
#### **MCI due to Alzheimer’s disease**

Symptoms of MCI along with brain changes characteristic of Alzheimer’s disease; MCI due to Alzheimer’s disease is the symptomatic precursor to Alzheimer’s dementia.

than a diagnosable medical condition. Separate surveys of Americans of all ages and those 65 years and older demonstrate that cognitive issues are commonly misconstrued as normal aging.<sup>245, 808</sup> The Special Report from *2022 Alzheimer’s Disease Facts and Figures* found that most Americans without current memory and thinking problems did not understand the distinction between normal aging and a medical diagnosis of mild cognitive impairment (MCI).<sup>808</sup> In the Special Report from *2019 Alzheimer’s Disease Facts and Figures*, nearly all older

Figure 17

Patient Journey from Awareness of Cognitive Issues to Care from a Physician Specialist and Treatment<sup>655, 809</sup>



adults surveyed (93%) reported that cognitive changes they experienced seemed like a part of normal aging and indicated that these changes were not severe.<sup>245</sup>

Most Americans are reluctant to see a doctor early if they have cognitive issues and tend to wait until the symptoms have a noticeable impact on their lives. The *2022 Alzheimer's Disease Facts and Figures Special Report* found that only four in 10 Americans would talk to their doctor right away when experiencing symptoms of MCI.<sup>808</sup> The rest indicated that they would live with their symptoms for a while, potentially until they become worse or others expressed concern.<sup>808</sup>

Concerns about health care also make people reluctant to broach the topic of cognitive impairment. The most commonly cited reasons for not discussing cognitive issues are receiving an incorrect diagnosis, learning of a serious health problem, receiving unnecessary treatment and believing symptoms might go away.<sup>808</sup> However, 70% of Americans would want to know early if they have Alzheimer's disease if it could allow for earlier treatment.<sup>808</sup>

Even people already experiencing memory and thinking problems are hesitant to speak with a physician. A large survey in the United States found that of the 10% of individuals age 45 and older who reported SCD, 54% had not consulted a health care professional about their

symptoms.<sup>256</sup> When symptoms interfered with function, 41% had not talked to a health care provider.<sup>256</sup> The reasons that people with SCD do not approach their health care providers with their symptoms are explored further in this year's Special Report.

Physicians are not taking the initiative to talk with patients either. Nearly all primary care physicians (PCPs) report waiting for patients (97%) or family members (98%) to make them aware of symptoms or request an assessment.<sup>245</sup>

A collective breakdown in communication about cognitive issues at any point in the patient journey is detrimental to care, especially in an era when treatments that alter the underlying biology of Alzheimer's disease could change the course of the disease if started early enough (Figure 17).

### Specialists in the Spotlight: Essential for Timely Diagnosis and Ongoing Alzheimer's Disease Care

If those with cognitive concerns overcome their hesitations, the first medical professional many people approach is their primary care provider (PCP). But PCPs have reported they don't have enough time during a visit to perform a thorough cognitive evaluation and are not entirely comfortable using existing cognitive assessment tools.<sup>245</sup> Instead, they point to specialists who are more

qualified to assess, diagnose and manage care for people who may have Alzheimer's disease or other dementia.<sup>245, 810</sup> More than one in three PCPs (38%) say that specialists are better equipped to assess and diagnose patients with cognitive impairment, and 43% say that specialists are better equipped to discuss the results of cognitive assessments.<sup>245</sup> Nearly all PCPs (99%) refer patients to a specialist when they detect cognitive impairment.<sup>245</sup> While in the future emerging digital technologies might reduce barriers to diagnosis and help PCPs feel more confident in their diagnoses, the next steps for patients would again lead them to physician specialists because they are best versed in the advantages and disadvantages of treatment options.

Physician specialists involved in Alzheimer's care include geriatricians (geriatric internal medicine, geriatric family medicine and geriatric psychiatry), neurologists, psychologists and neuropsychologists (see Screening and Diagnosing Workforce, page 57). Emergency medicine physicians also play a role in addressing symptoms and behaviors of Alzheimer's disease in the emergency department; in some instances, they may be the first to evaluate an individual for dementia.<sup>628</sup> Specialists are essential care team members for people with Alzheimer's disease, providing ongoing care and considering potential treatment options (see Medical Treatment and Care Team, page 59).

### **If Millions of Americans Decide to Seek an Early Diagnosis for Cognitive Issues, Will There Be Enough Specialists?**

Millions of Americans could potentially be eligible for available treatments for MCI due to Alzheimer's disease or mild dementia due to Alzheimer's disease (sometimes described as early-stage Alzheimer's disease), assuming they receive a timely diagnosis and want medical intervention. A shortage of crucial dementia care specialists has broad implications for people with memory and thinking problems who seek medical care, including:

- Decreased or delayed access to health care professionals.
- Delayed diagnosis of potential medical conditions.
- Perpetuated uncertainty about the availability of and access to treatment.
- Incomplete understanding of the risks and benefits of treatment.
- Delayed treatment (if appropriate) and delayed access to treatment centers.
- Delayed access to services and support.

PCPs raised concerns in the *2020 Alzheimer's Disease Facts and Figures* Special Report about insufficient numbers of specialists to receive their patient referrals.<sup>810</sup> More than

## **5 to 7 MILLION**

Estimated number of older Americans (age 65+) with MCI due to Alzheimer's disease in 2023 (see Prevalence Estimates, page 22).

half of PCPs said there were not enough specialists in their area to meet patient demand; this shortage was particularly evident in rural areas.<sup>810</sup>

Health care workforce shortages that were problematic before have only worsened due to the COVID-19 pandemic. One major concern is that with workforce shortages in many health care sectors, there won't be enough physicians, including specialists, to diagnose and care for the millions of patients seeking an Alzheimer's diagnosis or treatment. Another concern is the waiting period to see the limited number of specialists currently in practice.

Burnout attributed to COVID-19 is one reason health care providers are leaving the workforce in droves, and the burnout rate is at an all-time high. A 2021 survey found that nearly 63% of physicians in all specialties were experiencing at least one manifestation of burnout.<sup>811</sup> Of note, PCPs and specialists who diagnose Alzheimer's disease or provide ongoing care for those with Alzheimer's disease exhibit some of the highest rates of burnout.<sup>811</sup>

Numerous reports predict nationwide shortages of specialists, including geriatricians and neurologists, over the next few decades; this shortage will be felt most acutely in rural settings.<sup>630, 631, 633-635</sup> In fact, 20 states are already described as "dementia neurology deserts," with fewer than 10 neurologists per 10,000 people projected to be available in 2025.<sup>632</sup> The Screening and Diagnosing Workforce section on page 57 covers contributing factors to workforce shortages and additional insights on the gravity of this situation.

### **The State of Patient-Provider Dialogue About Cognitive Issues and Specialist Physicians' Patient Panel Makeup: Quantitative and Qualitative Evaluations of Individual and Physician Perspectives**

This year's Special Report builds on previous Special Reports to inform our understanding of why Alzheimer's disease is not detected and diagnosed promptly and, for the first time, gathers perspectives from specialist physicians who are involved in Alzheimer's disease care.

In 2019 and 2020, the Special Report highlighted challenges to detection and diagnosis in the primary care setting.<sup>245, 810</sup> The 2021 Special Report uncovered how perceptions and experiences of different racial and ethnic groups act as barriers to diagnosis and better care.<sup>694</sup> And in 2022, the Special Report looked at the lack of understanding of MCI and its impact on an early diagnosis of Alzheimer's disease.<sup>808</sup> This year, the Special Report examines two additional concerns:

1. Why do Americans not talk to physicians about memory issues at the earliest sign of a problem?
2. How many patients are specialist physicians seeing, and do they care for patients at all phases of the Alzheimer's disease continuum?

The Alzheimer's Association commissioned two studies for this year's Special Report. The first, funded through the Association's Healthy Brain Initiative grant from the Centers for Disease Control and Prevention (CDC), is a qualitative inquiry conducted by L&M Policy Research (L&M) that consisted of focus groups of PCPs and Americans with SCD. The second is a quantitative survey of physician specialists conducted by Versta Research.

## Key Findings

Focus groups revealed persistent challenges for patients and their PCPs in communicating effectively about memory and thinking issues.

### Focus Groups of Individuals with SCD

- Barriers to effective communication about memory and thinking problems were attributable to gaps in knowledge and awareness of cognitive health issues.
- Individuals with SCD exhibit a great tolerance for their symptoms, leading them to delay discussing them with their health care providers.
- People with SCD do not discuss symptoms with their PCP because they are waiting for the problem to have a meaningful impact on their life first, suggesting that the problem is serious and not normal aging.
- Ideal circumstances to initiate a conversation varied, but across the board, individuals desired health care providers who engaged them as partners in planning and management. Most participants said they would be more comfortable talking to a friend about memory and thinking problems than a medical professional.
- Personal preferences, social expectations and cultural beliefs dissuaded some conversations; in particular, participants identified wanting a holistic approach instead of prescription medication as a factor.
- Individuals with SCD also indicate that they do not bring up issues with their physician because they do not want medication to be their PCP's first treatment recommendation.

### Focus Groups of PCPs

- Informal conversation at the beginning of a visit was the first step toward cognitive assessment.
- PCPs saw family members as crucial facilitators to initiate conversations about memory and thinking problems; increasing the availability of telemedicine visits enabled more communication with family members.
- PCPs felt that limitations related to diagnosis, lack of treatment options, and the ability to refer to specialists and social support services impeded their conversations with patients and their ability to assuage patient concerns.

### Specialist Physician Survey

- Emergency medicine specialists report seeing the most patients age 60 and older each year and encounter the most patients with Alzheimer's disease at all stages of the disease continuum, followed by geriatric subspecialists and neurologists.
- Neuropsychologists consistently report seeing the fewest number of patients overall and the fewest number of patients age 60 and older.
- Specialists resoundingly point to their geriatrician colleagues, followed by neurologists, as best equipped to diagnose, treat and manage Alzheimer's disease.
- Specialist physicians report that they see patients with Alzheimer's disease at all phases of the disease continuum, however, most are patients living with MCI or mild dementia.
- Three of the four specialty physician groups indicate that they are seeing the highest number of Alzheimer's patients at the MCI phase of the disease.
- Two in three geriatricians and neurologists report being familiar with clinical trials related to Alzheimer's disease.
- All specialists likely overestimate the percentage of patients they see who are non-White based on overall U.S. population demographics.

## Focus Group Design and Research Methods

The Alzheimer's Association worked with L&M to conduct focus groups with individuals experiencing SCD who had not talked to their PCP or another health care provider about their cognitive changes.<sup>A17</sup> The main objective was to collect and assess perspectives on factors that underlie the lack of patient-physician communication about memory and thinking issues.

Six focus groups included individuals with SCD who had not talked to a health care provider. Participants represented diverse backgrounds (Black Americans, Hispanic Americans [English and Spanish-speaking], Asian Americans and Pacific Islanders [AA/PI], American Indians and Alaska Natives [AI/AN] and non-Hispanic White

Americans). Three focus groups were conducted with PCPs. All focus groups took place from June 2 to August 4, 2022.<sup>A18</sup>

This report uses approximate terms to indicate the number of participants who expressed a given view rather than numbers or percentages (see box).<sup>A19</sup>

**Most:** two-thirds of participants or more

**Many:** more than half of participants

**Some or several:** more than one-third of participants

**Few:** less than one-third of participants

## Focus Groups: Individuals with SCD

### Emotional Reactions and Limited Vocabulary to Express Cognitive Issues Impede Conversations With Medical Professionals

All focus groups revealed that many participants contextualized memory and thinking problems within the personal experiences of family members or friends diagnosed with Alzheimer's disease or dementia. Watching a family member's struggles with these diseases made them more fearful, yet at the same time more tolerant, of their cognitive problems. Furthermore, their experiences with cognitive problems sparked "hot thoughts" — instant, automatic, negative reactions — that reflected worst-case scenarios, including perceptions of inevitable, precipitous cognitive decline. Speaking with a doctor meant risking a diagnosis, and a diagnosis was associated with loss: loss of self-confidence, independence and control.

**"My parents are from India, and I feel like memory problems — if an adult or grandparent has them — they try not to discuss it and try to sweep it under the rug. They don't want it to be an issue." — AA/PI focus group member**

When participants faced the challenge of speaking about their problems in a medical context, the conversation reflected a dearth of language, vocabulary and health literacy regarding mild cognitive issues. Most were unfamiliar with the recommended assessments required for diagnoses. The participants proposed that having educational materials and assessment tools would help people learn the language and terms necessary to talk about cognitive health. AA/PI participants specifically

wanted to see educational materials before seeing their doctors and to be able to access such materials at their doctor's office. Some participants were uncertain about the specialists they might need to see about memory and thinking issues. Furthermore, they worried about the time services would take and the cost or implications of a diagnosis on their insurance coverage.

Racial and ethnic groups shared their unique perspectives.<sup>A20</sup>

- Black Americans indicate that knowledge and awareness of memory and thinking issues and the potential causes of these problems have increased in their communities over time. However, they are still uncertain and fearful about the root causes of memory and thinking problems and how progression will impact their ability to perform in current caregiver roles.
- AI/AN Americans have culturally-specific beliefs about the causes of memory and thinking issues and the ramifications of these issues. They noted the impacts that trauma and loss of ancestral oral traditions have had on memory and thinking skills and expressed substantial concerns about being able to fulfill their responsibilities as Elders if they have memory or thinking issues.
- AA/PI, Hispanic English-speaking and Hispanic Spanish-speaking Americans indicated that they avoid discussing memory or thinking issues because they do not want to be a burden or are embarrassed by their symptoms.
- Hispanic Americans indicate that if they broach the subject of cognitive issues, they tend to do so with humor.
- White Americans indicate that they seek out information about their memory and thinking issues to help them manage these changes on their own.

**"I don't want to use the word shame, but there's a discomfort, especially when we are in a ceremony, and I can't remember the order I'm supposed to do something [in], and I do feel embarrassed." — AI/AN focus group member**

### Perceived Risks Seem to Outweigh Benefits of Speaking with a Physician About Cognitive Issues

Across all groups, participants thought there were risks associated with a diagnosis that outweighed any benefits, especially at the early stages. Many participants were willing to believe that their memory or thinking issues were part of the "normal" aging process. Feeling scared and anxious about the possibility of a diagnosis often resulted in avoidance and denial for many participants.

**“I don’t [speak to my doctor] because it doesn’t seem like that big of a deal...not yet. It would have to be something dramatic. Losing my train of thought is not enough.”**

– Black American focus group member

To warrant a discussion with their physician, most participants said that their memory and thinking problems would need to have a significant negative impact on their quality of life or the lives of their family members. However, the “tipping point” is subjective and may be clouded by norms and expectations of aging. Concern about access to resources and support services, such as quality health care or assistance from family or friends, may be contributors to a higher tolerance for cognitive symptoms. Common examples of alarming memory or thinking problems shared by individuals with SCD that would prompt a conversation included forgetting where they were, getting lost in a familiar place or forgetting family members’ names. A few participants felt that their problems would need to severely impact their work performance and productivity or threaten their financial ability to provide for themselves or their families before they would speak to a doctor. A few participants said that openly discussing these issues in a group moved them to talk with their doctors.

**“Creo que si me empezara a fallar la memoria con mas frecuencia o con mas importantes, si definitivamente iria con el doctor.”**  
**(I think that if it were to begin to happen more frequently or [become] more important... then, yes, definitely, I would go see a doctor.)**

– Hispanic Spanish-speaking focus group member

### **Assumptions About What Doctors Will Say and Do Prevent People From Speaking About Memory Issues**

Many participants were reluctant to raise memory issues with their providers because they assumed their doctors’ first response would be to take a medication-based approach. Several participants felt their physicians would first opt for prescriptions before creating a care plan. Many preferred a more holistic approach by planning around diet and exercise instead of medication. Several individuals from racial and ethnic minority groups said they relied on treatment strategies grounded in cultural beliefs and practices and shared a more holistic view of health and wellness. They opted to use herbal remedies, religion (e.g., prayer for healing) and music (e.g., drumming, piano) before, or in place of, seeking medical advice.<sup>A21</sup>

**“I haven’t talked to my doctor yet because I don’t want prescription drugs to take to alleviate it. I don’t want to be dependent on prescription drugs. I think I’m hesitant about taking any type of medication for this.”** – AA/PI focus group member

Participants from the Black American and AI/AN groups alluded to historical racism in the medical field, making individuals feel that they do not receive adequate, culturally competent health care. Some participants also felt that their community’s mistrust of doctors and/or Western medicine prevents them from talking to a doctor.

Different racial and ethnic groups expressed perceptions about ideal care and barriers to care that influenced their interactions with health care providers:<sup>A21</sup>

- Black Americans emphasized how institutional and societal barriers affect their ability to access high-quality, equitable care. Prejudice, racism and implicit bias limit trust in health care providers.
- Black Americans, AI/AN Americans and Hispanic Spanish-speaking Americans strongly preferred holistic approaches to treatment that minimize the use of biomedical interventions or prescription medication.
- Hispanic Spanish-speaking Americans tend to speak to a medical professional about memory or thinking problems before family or friends.
- White Americans were more likely to bring up concerns about insurance coverage if they discussed memory problems with their doctor.
- White Americans were the only group to mention that talking about memory or thinking issues to a specialist may be more appropriate than discussing them with their primary care physician.

**“It’s a matter of, is there enough to do about these things like eating healthy, working out, sleeping more? Should I practice this first, and if it doesn’t get better, then let me talk to somebody?”**

– Hispanic English-speaking focus group member

### Ideal Conversations About Memory and Thinking Issues Would Emphasize Options for Diagnosis and Health Care

Participants provided a range of actions their doctors may take to evaluate their thinking and memory issues. Some participants expected their doctors to give referrals to specialists and recommend medication and lifestyle changes to help improve their cognitive health.

**“At my doctor’s office, they have a screening form that looks like it’s for depression. If they had a screening form for forgetfulness, it might be easier to open the door for people if they have those issues. I would not want to take a drug for it, but I want to open up a discussion for it.”**

– AA/PI focus group member

Across individual focus groups, people with SCD expressed a desire for inclusive, culturally appropriate conversations and shared decision-making with their health care team.

- Black Americans preferred empathetic care that focuses on holistic wellness, education and an options-oriented approach to intervention. A key feature of improving opportunities for conversations and care is the doctor’s ability to actively listen to patients’ concerns and holistic health needs. Many participants expressed interest in a holistic approach to medicine that honors mental and physical wellness while putting less stress on biomedical interventions unless necessary. Further, participants shared a need for education about memory and thinking issues and wanted practical upstream intervention options.
- AI/AN participants expressed an interest in doctors doing more than diagnostics or pointing out problems or deficits. They wanted an action-oriented, strength-based plan that honors their connection to their cultural ways and the complex intergenerational trauma they connected to memory and thinking issues.
- The AI/AN group also expressed interest in improving communication and bedside manner between patients and providers through increased awareness and appreciation of local Indigenous Ways of Knowing. Within tribal communities, being an Elder is a revered and earned title that conveys the acquisition of important and transcendent knowledge. As a result, there are particular protocols for engaging and communicating with Elders respectfully.
- AA/PI participants want their doctors to reassure them, educate them and refer them to specialists experienced in dealing with thinking and memory issues. As mentioned, they did not want to be prescribed medications, preferring natural alternatives. They also wanted access to screening tools and tests to better diagnose problems.

- Hispanic English-speaking participants want answers, reassurance and honesty when discussing memory and thinking issues with doctors while expecting to be treated with respect and concern. The group expressed a need for guidance on what they could do to address their memory issues. For some, this included whether they should take medications, while for others, it consisted of whether there are lifestyle changes they should make.
- Some Hispanic English-speaking participants want their doctors to develop a specific action plan. The group wanted their doctors to document the progression of cognitive issues if any, so they could assess a baseline and monitor their situation over time. Some also wanted their doctor to administer tests to have a more concrete diagnosis and to be able to determine that baseline.
- Hispanic Spanish-speaking participants wanted their doctor to help them understand why they are having these issues and reassure them. Participants wished their family members were part of the conversations so doctors could guide them together.
- White focus group participants wanted their doctors to put them at ease and help them plan for and be optimistic about the future. They also wanted concrete guidance on knowing when their issues are serious enough to take significant steps. Some also wanted their doctors to develop an action plan for the future.

**“I’ve been keeping it under wraps. It’s just something I don’t really think about all that often. I’m pretty sure [I] will talk to the doctor, but they would have to be the one to bring it up.”**

– White focus group member

### Individuals Prefer to Discuss Cognitive Issues with Friends Instead of Medical Professionals or Family

Most participants said they would be more comfortable talking to a friend about memory and thinking problems than a medical professional. Talking about memory and thinking issues in a medical context elicited intense emotional responses, so participants preferred talking with their peers for reassurance and normalcy. With friends, participants said that they could “compare notes” on cognitive problems and commiserate with a sense of humor about sharing the journey of getting older together.

**“My friend has the same issues. We laugh about it, but if he said to go to a doctor, I’d go in a minute. I respect what he says.”**

– Black American focus group member



Many individuals with SCD refrained from serious conversations with family members because they were “difficult.” They spoke of experiences with other relatives who had memory problems, acknowledging that fear, respect for elders, aging norms and stigma surrounding aging and memory loss were all barriers to talking directly with their family members.

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**“In my community, it’s scary because it’s been in my family. I don’t want to say it’s frowned upon, but my dad has been forgetting some things, but my mom says, ‘Don’t say anything, because he’s scared about it too,’ but he won’t talk about it. For me, it’s not discussed. It doesn’t exist.”**

– Hispanic English-speaking focus group member

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## Focus Groups: Primary Care Providers

### An Informal Conversation is a Crucial First Step Toward Formal Cognitive Assessment

Many primary care provider participants described how they prefer to start a clinical visit with informal social conversation, which disarms patients and puts them at ease. Informally initiating the visit may provide important cues to help identify potential recall issues during the conversation.

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**“People sometimes try to hide it as a coping mechanism. I pinpoint it by asking cognitive and other questions, and if the answer is not direct, I begin to think there may be a problem. When you press them a little, you find they can’t count backward, for example.”**

– Small practice PCP member

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Once they suspect a patient may have memory problems, many construct subtle, indirect questions that could determine the extent of memory issues rather than asking them explicitly about problems. They ask a patient to describe their neighborhood, their daily routine or how they perform a specific task. Doctors feel this collaborative investigation is more accurate, as it prevents patients from denying any memory or thinking problems. Most expressed the importance of showing compassion and patience, techniques that build trust and decrease barriers to discussing sensitive topics.

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**“One way I involve the patients in my observation and assessment is I say, hey, this is what I’m looking at. ‘What do you think?’ I get them involved if they are concerned or notice it as well. I ask family members about their opinions. It’s more of a collaborative investigation or inquiry.”**

– Large practice PCP member

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Short appointment times make it difficult to notice subtle changes in a patient’s thinking over time. Many PCPs noted that patients prioritize discussing physical health issues such as diabetes or high blood pressure over cognitive health issues. For PCPs to initiate conversations about cognitive concerns, they suggested a consistent, standardized process as an entry point. They felt that standardized processes (for example, conversation starters or other prompts to facilitate dialogue and uncover any cognitive concerns) would help overcome barriers to initiating conversations independently. By following a standard process, the decision to begin the conversation would be taken out of the patient’s hands entirely, enabling the provider to assess the patient’s cognitive health more frequently.

### Family Members Are Crucial Facilitators of Dialogue and Follow-Up Care for Memory and Thinking Issues

If primary care providers want to ask directly about cognitive ability, most choose to speak with the family or family members instead of the patient; they see family members as crucial facilitators to initiate conversations about memory and thinking problems. Almost all participants learned of their patients’ memory problems when a family member communicated concerns rather than hearing directly from the patients themselves. Many felt the issues were more serious when a relative provided an outside perspective.

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**“When you ask, a large percentage of people say they forget things, but it’s not particularly sensitive nor specific. I was always taught that if people come in and tell you they are having memory problems, the majority of the time it is not significant, compared to when relatives and friends come in and complain... If a family member says, ‘Yes, I’m seeing things (with memory problems),’ that to me is much more of a red flag.”** – Small practice PCP member

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The uptake of telemedicine during the COVID-19 pandemic offered a window into home life and another avenue to engage with family members. Remote visits enabled primary care providers to observe home environments to gather insights into a patient’s well-being, which would not be possible in a clinical setting. Many patients needed assistance with virtual visits, so family members often helped them set up and manage the technology — creating more opportunities for doctors to engage with family members about cognitive concerns.

Primary care providers noted that patients were generally more accepting of their issues and the need to address them when a family member or caregiver attended their visit. PCPs stated that family members also played a major role in making sure that the patient followed through on steps after cognitive assessments. At the same time, PCPs recognized that cultural factors might influence family members' and patients' decisions to avoid medical help. For example, they talked about their experiences with AI/AN and Hispanic cultures, with tightly knit extended families who placed value on caring for elders on their own, at home, instead of seeking care from the medical system.

### Small and Rural Practices Have Unique Barriers to Effective Communication

PCPs shared insights about the barriers to effective conversations they experience in their practice type, including visit duration, patient preferences and emotions related to memory issues, and appointment frequency, among other factors.

PCPs in all three groups described the value of long-term, personal relationships with patients and their families and that this helps increase comfort in discussing sensitive issues. However, setting type (small, large or rural) affected providers' ability to initiate conversations with patients about cognitive issues.<sup>A22</sup>

PCPs in small practices tended to view thinking problems, such as forgetting car keys, as minimal. Even if a patient expresses concern about their brain health, the small-practice group discusses memory issues only when a family member communicates their concern. This system seems to rely on family members to be responsible for the patient's health and minimizes the patient's autonomy, which can delay or shut down conversations if family members are not present or aware. Professionals in small practices would also find it easier to initiate discussions if concerns were disclosed before the visit. This group felt exceptionally constrained by time limits on visits and could not have an extended conversation about the problem.

Another interesting finding from the small-practice focus group is that while physicians felt that medication could be a relatively effective treatment for memory issues, they recognized patients' resistance to prescriptions. This hesitancy prevents conversations with providers about memory issues and often comes from patients' research on the internet about specific medications and their potential side effects.

Rural providers were the only group to report that they do not routinely discuss memory issues with patients unless a family member brings it up first. In rural practices, distance, lack of transportation and availability of appointments are unique barriers that patients and their health care providers face when addressing memory issues.

During times of inclement weather or harvest season for farmers or ranchers, these patients also lack the time or ability to visit their providers regularly. Limited appointment times and less frequent visits add to the challenge. In addition, some rural clinics are only open on certain days or times and thus offer a small number of appointments. Once at an appointment, patients tend to have many issues to address. Memory or thinking issues, when they exist, fall low on the list of priorities.

**“The smaller clinic in one rural setting was only open two mornings a week, so if they wanted to get in, that’s the time they had. There are also competing issues and a time barrier. They have a 15-minute appointment and have to prioritize diabetes, blood pressure, anything other than memory, until something like a bigger incident happens that triggers a visit to a provider.” – Rural practice PCP member**

### Primary Care Providers Say They Lack the Tools to Care for Patients Experiencing Cognitive Issues, Relying on Specialists to Fill This Gap

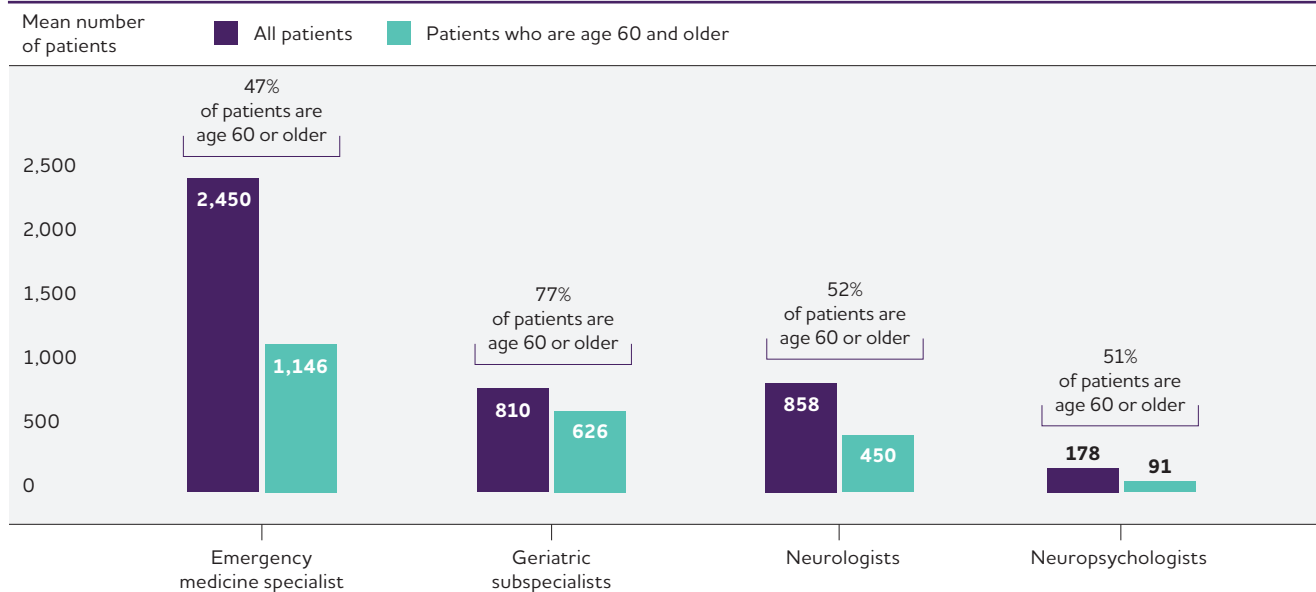
PCPs felt that their conversations with patients, and their ability to assuage patient concerns, are circumscribed by limitations related to diagnosis, lack of treatment options and ability to refer to specialists and social support services. They recognized that patients had strong feelings toward cognitive issues — anxiety, fear, hopelessness with a diagnosis, a sense of loss and shame — making it very difficult to acknowledge problems, let alone discuss them with a doctor. They recognized the push and pull between giving patients hope about the future while delivering an honest opinion about their prognosis.

Health care professionals felt it was challenging to keep up with medical standards, training about cognitive health problems and advances in management. They also recognized the social stigma surrounding cognitive decline. Patients' fears about losing their ability to care for themselves created a cascade of negative emotions, including anticipating feeling disconnected from, and devalued by, their families if they needed to be cared for outside of the home, in a nursing home or a memory care facility. PCPs in large practices indicated that they would like to be able to offer more educational resources to improve conversations, and those in rural practices felt that in-person education during appointments was crucial.

Discussions with PCPs also revealed some inconsistencies and gaps. Providers identified a variety of potential specialist referrals, but a consistent referral protocol was not reflected across groups. Access to specialists and community resource referrals varied, depending mainly on

Figure 18

Mean Number of Unique Patients Each Specialist Reported Seeing in a Year



the practice location and the provider's professional network. For example, PCPs in rural areas indicated that referral options are limited. Most specialists are located hundreds of miles away; as a result, these providers rarely refer their patients. Even if they wanted to consider referring patients with memory issues to specialists via telehealth, many patients do not have the bandwidth available where they live, and/or the patients don't have or know how to utilize the technology.

### Specialist Physician Survey Design and Research Methods

To document the current specialist physician workforce capacity for Alzheimer's care in the United States, the Alzheimer's Association commissioned Versta Research to conduct a nationwide survey of medical specialists (N=1,182) who diagnose and/or provide ongoing care for patients with Alzheimer's disease. Specialists were defined by their inclusion in the American Medical Association's (AMA) Masterfile of practicing U.S. physicians (including residents) or on a list maintained by IQVIA and practice in the following areas:

- Emergency medicine (n=636)
- Geriatric subspecialties, including geriatric internal medicine, geriatric family medicine, and geriatric psychiatry (n=123)
- Neurology (n=232)
- Neuropsychology (n=191)

The survey measured activity (self-reported number of unique patients seen where unique indicates a person, not a visit), including:

- The number of patients age 60 or older.
- How many patients have dementia.
- How many patients have Alzheimer's disease specifically.

The survey also measured perceptions of clinicians best suited to provide Alzheimer's care and physician estimates of the percentage of patients age 60 or older from different racial and ethnic groups.<sup>A19</sup>

### Specialist Physicians See a Substantial Number of Patients Age 60 and Older Every Year

Specialist physicians describe seeing thousands of patients annually; a large portion are 60 or older.<sup>A23</sup> Emergency medicine specialists report seeing the most patients age 60 or older. Nearly four in five emergency medicine specialists noted they see 500 or more patients in this age group each year, and one in two (49%) report seeing 1,000 or more. Many geriatric specialists report seeing 500 or more older adult patients each year (42%). A little more than one in three neurologists (37%) indicate that they see more than 500 patients age 60 and older each year. Neuropsychologists report seeing the fewest number of patients in this age group per year (3% see 500 or more patients, and none see more than 1,000 patients). However, this specialty also reported the lowest annual patient volume of all specialties surveyed.

Specialists estimated how many unique patients they see in a year (see Figure 18, page 95). The number of patients age 60 or older specialists estimate they see in a year varies dramatically and may be related to higher patient traffic to some settings than others (for example, visits to the emergency department for immediate medical needs versus visits to specialists who require referrals and, in some instances, have lengthy wait times that may affect patient volume). Within the specialties, individual clinicians may see anywhere from fewer than 100 to more than 1,000 patients 60 or older each year (Figure 18):

- Emergency medicine: 1,146
- Geriatric subspecialists: 626
- Neurologists: 450
- Neuropsychologists: 91

### Specialists Report Seeing More Patients in Early Stages of Alzheimer’s Disease

The survey findings offer a glimpse into a typical specialist practice using self-reported estimates of (1) the number of patients with Alzheimer’s disease seen each year and (2) patients with a diagnosis of MCI or dementia due to Alzheimer’s disease (Figure 19). All specialists indicated that they see patients with MCI or dementia due to Alzheimer’s disease. Emergency medicine specialists, geriatric subspecialists and neurologists report seeing patients who represent the entire continuum of Alzheimer’s disease, from MCI to severe dementia (Figure 20a). Most of the patients are in the earlier phases of the Alzheimer’s disease continuum. Neuropsychologists also estimate they currently see more patients at the early stages of the continuum than at later stages, likely because of their role in cognitive evaluation and assessment, and possibly, their essential role in evaluating treatment benefit (Figure 20b).

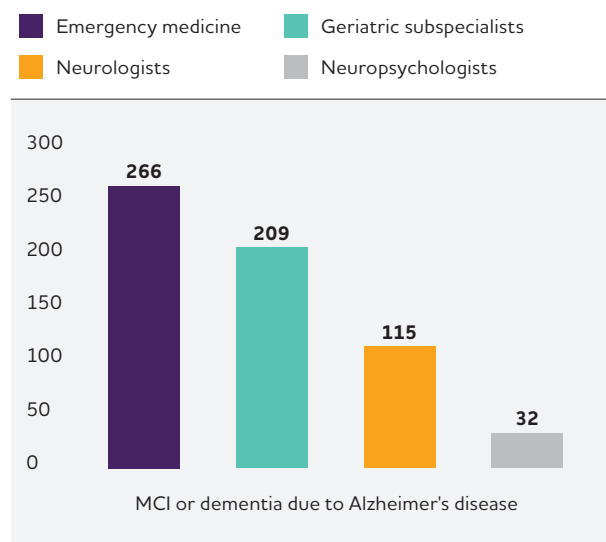
### Specialists See Geriatricians as Best Equipped to Diagnose, Treat and Provide Ongoing Alzheimer’s Disease Care

Specialists said their neurology and geriatrician colleagues could most effectively diagnose Alzheimer’s disease (79% and 68%, respectively) (see Figure 21, page 98). Half of the specialists surveyed believed geriatric psychiatrists and neuropsychologists would be able to effectively diagnose Alzheimer’s disease. Approximately one in three specialists said family medicine (31%), and one in four said psychiatrists (26%), internists (25%) and general practitioners (23%) would be able to effectively diagnose Alzheimer’s disease.

Neurologists and geriatricians are also viewed by other specialists as most effectively able to recommend treatments for Alzheimer’s disease (73% and 71%, respectively), followed by geriatric psychiatrists (57%) and neuropsychologists (32%).

Figure 19

### Mean Number of Unique Patients with Alzheimer’s Disease Per Year by Specialist



Specialists report that by far, they view geriatricians as the specialists most effectively able to provide ongoing care for patients with Alzheimer’s disease (79%), followed by neurologists (54%), geriatric psychiatrists (50%) and family medicine practitioners (46%).

Importantly for recommending treatment options to their patients with Alzheimer’s disease, geriatric subspecialists were the most familiar with clinical trials related to the disease (68% familiar vs. 32% not familiar). Almost as many neurologists (65%) were familiar with clinical trials related to Alzheimer’s disease. Approximately one in two neuropsychologists reported familiarity with ongoing clinical trials.

### Specialists Overestimate the Proportion of Non-White Patients They See

Specialist estimates of the proportion of their patients age 60 or older who are non-White do not reflect U.S. Census Bureau estimates of the U.S. population (see Table 23, page 99). These likely over- and underestimates were similar across specialties. Specialists likely overestimate the proportion of their base that is Black, reporting they see two times more patients than observed in the overall U.S. population. They also overestimate the proportion of the multiracial or biracial patients they see. On the other

Figure 20a

Mean Number of Unique Patients at Each Phase of the Alzheimer's Disease Continuum

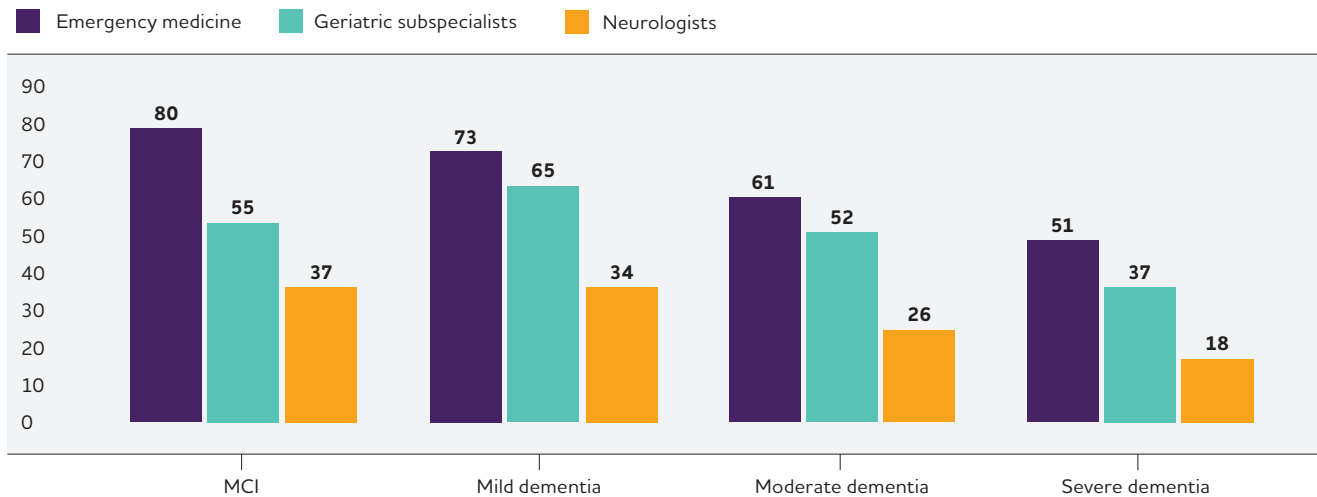
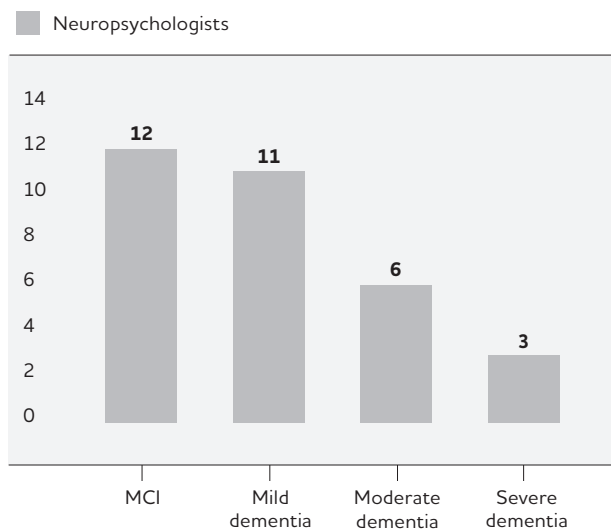


Figure 20b

Mean Number of Unique Patients at Each Phase of the Alzheimer's Disease Continuum



hand, specialist estimates of the number of White patients they see in practice is dramatically low relative to the proportion in the overall U.S. population (see Table 23, page 99).

Recent research indicates that people frequently overestimate the sizes of minority groups and underestimate the size of majority groups in various circumstances—not just when it comes to racial and ethnic group sizes or in health care settings.<sup>812, 813</sup>

### Reinforcing Foundational Specialist Physician Care

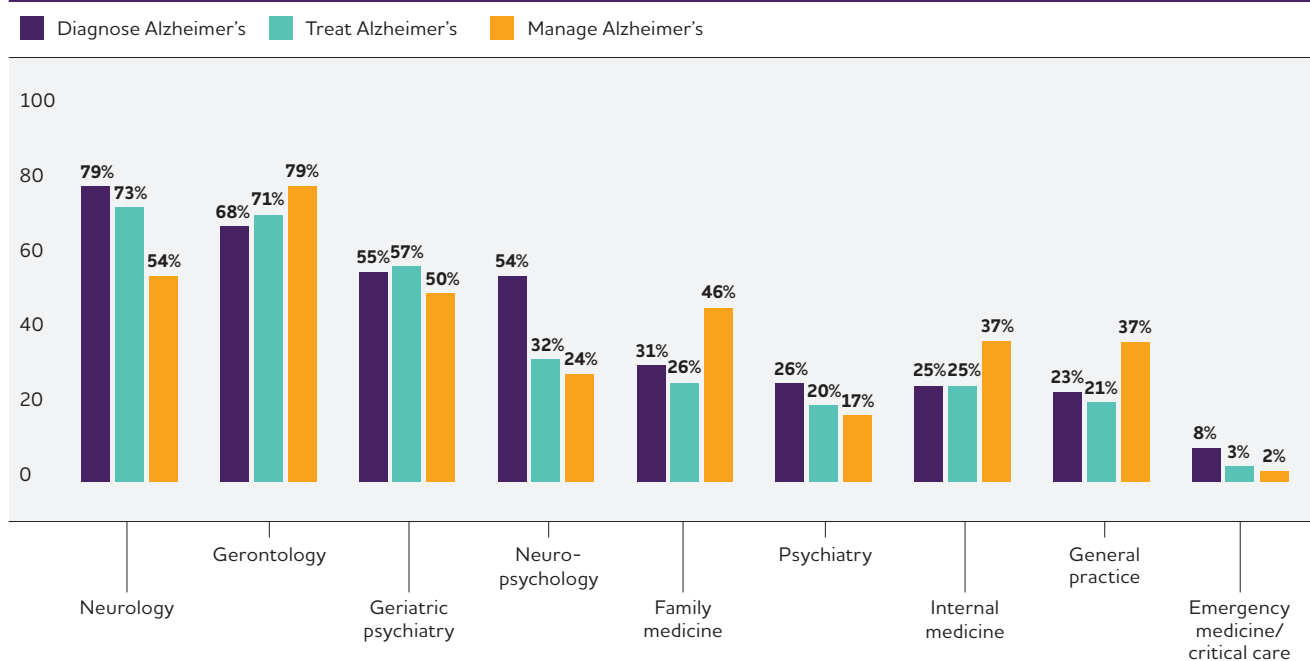
The FDA approval of treatments targeting the underlying biology of Alzheimer's disease is reframing the health care landscape for people with MCI due to Alzheimer's disease. Whether the approval of treatment options will stimulate more conversations between people experiencing cognitive decline and their health care providers remains to be seen. What we do know based on this year's Special Report is that a shortage of dementia care specialists could soon become a crisis for Alzheimer's disease care at all phases of the disease continuum.

In previous surveys, PCPs indicate that they will refer to a specialist if they detect cognitive impairment.<sup>245, 810</sup> In this year's survey, specialist physicians indicate that they believe their geriatrician and neurologist colleagues are best equipped to evaluate cognitive issues in older patients, suggesting that they would likely refer patients too. What happens when specialists receive an influx of referrals to evaluate new patients for cognitive impairment?

A shortage of specialists or specialists who are at capacity and no longer accepting new patients is likely to have the most immediate and obvious impact on people at the MCI phase of Alzheimer's disease who may be eligible for newly-approved treatments. Specialists indicate that most patients with Alzheimer's who already come to their clinics are in the earlier phases of Alzheimer's disease. They were not asked directly about their current capacity or ability to take on new patients; this is an area of interest to the Alzheimer's Association and may be the topic of future surveys.

Figure 21

Percentage of Specialists Citing Specific Specialties as Being Able to Effectively Diagnose, Treat and Manage Alzheimer's Disease\*



\* Specialists could choose more than one specialty.

A RAND® report issued in 2017, before treatments targeting the underlying biology of the disease were FDA-approved, projected that specialists (neurologists, geriatricians and geriatric psychiatrists) would be unlikely to have the capacity to care for an influx of patients either seeking a new diagnosis or requesting treatment for early-stage Alzheimer's disease.<sup>655</sup> The RAND report estimated that specialists would be able to have an initial evaluation visit with fewer than 4 million patients with MCI each year; patients would wait an average of 18.6 months to see a specialist if capacity was insufficient.<sup>655</sup> Delaying a diagnosis of Alzheimer's disease by more than a year translates to a delay in receiving potentially life-changing treatment or enrollment in a clinical trial, along with implications for myriad other personal caregiving and planning efforts as the condition progresses.

Individuals in the later phases of Alzheimer's disease (moderate and severe dementia) will also be negatively affected if specialists are overburdened. Long wait times for initial visits will likely result in long wait times for *any* visit, including ongoing management.

As described earlier, shortages of geriatricians and neurologists necessary to care for the aging U.S. population are imminent — or already evident (see Workforce, page 56). This Special Report reinforces the recommendations outlined previously (see Workforce, Looking to the Future, page 63), including efforts to:

- Expand the workforce through multidisciplinary programs that train PCPs and other health care professionals to care for older adults (e.g., GWEPs).
- Strengthen training and specialization in dementia care, such as with the Alzheimer's and Dementia Care ECHO® Program, so that clinicians other than geriatricians can take an active role in assessing cognitive impairment.
- Increase awareness of Medicare reimbursement for health care visits that result in a comprehensive dementia care plan and support efforts to develop alternative payment models such as the "dementia care management model."<sup>707, 814</sup> If more providers are aware that visits are reimbursable and can access guidance and education on how to conduct these visits, they may opt to perform more evaluations themselves, alleviating the burden on geriatricians by more evenly distributing assessment and management among collaborating care teams.
- Encourage clinicians, health systems and patients to participate in voluntary provider-enrolled patient networks, such as the Alzheimer's Network for Treatment and Diagnostics (ALZ-NET). ALZ-NET collects real world evidence about Alzheimer's patient care and long-term clinical and safety data for enrolled patients evaluated for and treated with novel FDA-approved Alzheimer's disease therapies. ALZ-NET will also track long-term health outcomes (effectiveness and safety) associated with the use of these

Table 23

Estimated Proportions of Patients Age 60 or Older by Racial and Ethnic Backgrounds

Racial or Ethnic Background	Percentage of the U.S. population age 60 or older*	Estimated percentage of specialist's patient base			
		Emergency medicine physician	Geriatric subspecialist	Neurologist	Neuropsychologist
Asian American or Pacific Islander	5%	7%	8%	7%	5%
Black American	10%	22%	24%	19%	21%
Hispanic American	9%	20%	12%	16%	12%
Native American or Alaska Native	1%	2%	3%	1%	1%
White	75%	43%	46%	51%	54%
Multiracial or biracial	1%	5%	5%	5%	5%
Another race or ethnicity	<1%	1%	1%	1%	1%

\*Based on 2019 U.S. Census Bureau estimates.

Percentages do not total 100 because of rounding.

FDA-approved therapies in real-world settings. Real-world data collection is particularly valuable for establishing health care resource utilization and gaps in care. Information collected from ALZ-NET may also help physicians answer important patient-care questions about treatments and diagnostics, and improve general dementia care. ALZ-NET also serves as a resource for evidence gathering, information sharing, and education across both national and international clinical and research communities, encouraging innovative, inclusive research and supporting opportunities to improve care.<sup>815-817</sup>

Another approach is to develop novel, sustainable collaborative care models.<sup>818-821</sup> One example is the ALIGN (Aging, Life Innovations, Goals & Needs) Program from Mt. Sinai.<sup>822, 823</sup> The ALIGN team, which includes a geriatrician, nurse practitioner and social worker, works closely with PCPs to support complex, high-risk patients who could benefit from an added layer of care temporarily.<sup>822, 823</sup>

### Building Bridges to Better Patient-Physician Communication

Dementia care specialists are unlikely to be engaged if individuals experiencing memory and thinking problems and their families do not understand the potential implications of these cognitive changes or are not acknowledging and discussing them with a PCP.

The focus groups gave a glimpse into barriers to — and potential solutions for — how individuals and physicians approach conversations about cognitive issues. In their own words, participants reinforced what previous Special Report surveys found:

- Individuals are unconcerned about cognitive decline until it impacts their quality of life or ability to participate in regular activities — whether they are experiencing symptoms or not, most view memory and thinking problems as normal aging.<sup>808</sup>
- Individuals prefer to approach family and friends first with memory and thinking problems, which often happens long before they see a doctor with their concerns.<sup>245</sup>
- There is still stigma surrounding cognitive issues and a lack of awareness of what is more than normal aging in many communities, so people remain silent about potential problems.<sup>694, 808</sup>
- People do not want to receive a diagnosis of Alzheimer's disease or other dementia unless there is a treatment available or their physician has a detailed care plan.<sup>694, 808</sup>
- Individuals have a limited understanding of the patient journey to a diagnosis of Alzheimer's disease or other medical condition and beyond.<sup>808</sup>
- Personal experiences, along with sociocultural beliefs, shape perceptions of health care and are a significant barrier to conversations about cognitive issues.<sup>694</sup>
- People avoid conversations because they do not want medication and fear that their physician will reflexively offer a prescription first before trying other approaches.<sup>694</sup>

- PCPs hesitate to initiate conversations about cognitive decline and will wait until family members bring it to their attention.<sup>245</sup>
- PCPs are concerned about how people will be cared for if an assessment uncovers Alzheimer's disease or other dementia in light of specialist shortages and few referral options.<sup>245</sup>
- PCPs view family members as influential and necessary partners in care, often relying on them to initiate conversations about memory and thinking problems they observe in their loved ones.<sup>245</sup>

Many of the recommendations from previous Special Reports are even more relevant today in this era of new and emerging treatments, including:

- Developing public service announcements (PSAs) to destigmatize memory and thinking problems, educate on risk factors, connect people to resources and advocate for routine cognitive health assessments. This approach could help people feel more comfortable sharing their concerns with their friends, families and physicians.
- Establishing education programs tailored to diverse communities that take place in informal settings, such as libraries or community centers. This could guide conversations and help individuals build the vocabulary to communicate their cognitive issues to their health care providers effectively.
- Ensuring Alzheimer's and dementia care is informed by and responsive to cultural beliefs and health care teams are culturally competent.<sup>694</sup>

### Continue to Educate Communities About Memory and Thinking Problems and Health Care

Increasing awareness of cognitive issues could encourage conversation and help stimulate productive discussions.

**“Education is important. I need to know what I should do to delay the process. I want the doctor to provide strategies and education... what can I do to prevent it from [getting] worse.”**  
– Black American focus group member

People with SCD who participated in the focus groups pointed to limitations in their understanding of what health care entails for people experiencing cognitive issues. There was uncertainty about whether the physician would discuss a care plan and if providers were only interested in managing symptoms with medication. Not knowing what to expect contributes to people's

reluctance to talk with a health care provider. One solution is to develop a patient roadmap of the typical process for assessment, referral coordination and care management to help set expectations and educate people navigating memory and thinking issues.

**“My doctor has a patient advocate, and they call me once in a while. They ask how I'm doing and if they need to talk to my doctor. That makes me more comfortable expressing what is going on in my life...even if it is small like memory loss.”** – Black American focus group member

Outreach and educational messages are likely to have the most impact to empower individuals when they do become concerned about cognitive issues. One takeaway from the focus groups is that incorporating themes of self-efficacy, locus of control and hope in messaging could help individuals and family members overcome the challenging and complex emotions that memory and thinking problems elicit — and that prevent them from speaking with their doctor. Any materials developed for individuals with cognitive issues should recognize the vital role that family members play in recognizing symptoms and potentially bringing them up to physicians.

The Alzheimer's Association launched a partnership with the Ad Council in 2019 to develop a national public awareness campaign to encourage families to discuss cognitive concerns with each other and their doctor sooner to enable early diagnosis of Alzheimer's disease and related dementias. The campaign recognized how difficult it can be to take those first steps to share memory and thinking problems with a physician and provided tips to make the process easier.<sup>824</sup> The campaign resources include disease-related information and a discussion guide for use with doctors and health care professionals.<sup>825</sup> Recently, to improve engagement with the Hispanic community, the Alzheimer's Association partnered with the Ad Council and Lopez Negrete to develop a multimedia PSA campaign in English and Spanish.

Community-based, participatory educational campaigns are another way to reach people who may not believe their problems are serious enough to warrant a medical visit. Community engagement with trusted partner organizations, including informal discussion groups through the Community Recreation Centers, Park Districts or library programming on healthy aging and cognitive issues such as SCD or MCI, may instill confidence in people who are hesitant about



discussing their problems. As described in the 2022 Special Report, *More Than Normal Aging: Understanding Mild Cognitive Impairment*, educational materials and programming about cognitive issues should use messaging that resonates with diverse communities.<sup>808</sup> The 2022 Special Report found differences in how racial and ethnic groups view and respond to concerns about cognitive impairment.<sup>808</sup> These differences were reflected in the focus group findings presented here.

A dialogue between individuals with cognitive concerns, their families, and their physicians is a crucial first step on a journey toward understanding the magnitude of the issue. For some, their journey may continue to an evaluation by a specialist clinician and an eventual diagnosis of MCI due to Alzheimer's disease. Only then can the possibly life-changing treatment be initiated. As the treatment landscape continues to evolve, research on the vital connections forged between patients and their physicians will become increasingly important. Robust research designs that include adequate representation of various population groups will also be crucial for a greater understanding of the dynamics between patients and care teams. This research will lead to insight into the ability of the specialist physician workforce to care for patients with Alzheimer's disease or other dementias wherever they are in the patient journey.