



BEYOND MEMORY LOSS: *Disparities in the United States Alzheimer's Care System*

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Introduction

Alzheimer's Disease (AD) is a disease with major symptoms including difficulties with memory, language, problem-solving, and other thinking skills [1]. Biologically, AD is characterized by the accumulation of abnormal proteins beta-amyloid *outside* neurons (A), and phosphorylated tau *inside* neurons (T), as well as the degeneration of neurons (N) [2,3]. Together, these changes are known as the AT(N) framework for Alzheimer's. Neuronal damage from Alzheimer's Disease is the most common contributor to memory loss. The patient will start exhibiting mild cognitive impairments in the Early stage of AD. Then parts of the brain that enable basic bodily functions, such as walking and swallowing, will be affected and ultimately the disease becomes fatal.

For diagnosis of AD, standard medical exams are a) Positron emission tomography (PET) imaging and b) cerebrospinal fluid examination, which detect the amyloid positivity in patients' brains and bloodstream [4]. Assessment of brain structures can be done with Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) where PET facilities are not available. Recent developments have been devoted to Tau and amyloid tracers for PET scans.

For treatments of AD, ongoing research aims to create more affordable and reliable drugs for Alzheimer's. Current treatments include monoclonal antibodies, such as Aducanumab [5], the yet-to-be FDA-approved Donanemab [6], recently approved Lecanemab [7], and the behavioral drug REXULTI [8]. It is worth noting that Aducanumab and Lecanemab are mainly effective for Early-stage AD. In addition, Gantenerumab and Anti-A β mAb, both FDA-approved, show promise in reversing and slowing down Alzheimer's, albeit for \$30,000 for the latter (Dr. Brett Parker, Personal Communication, November 3, 2023).

Given the current efforts in advocacy, policy, diagnosis, treatments, and care for patients with AD, the disease disproportionately affects individuals across demographics and socio-economic statuses [9-11]. In this work, our team examined the persisting *Disparities in the United States Alzheimer's Care System*. Such disparities include Health Insurance, Clinical Research, and Public Awareness factors. We compile insights from 1) literary sources including government policy articles, statistical reports NGOs/NPOs, and published medical research, and 2) interviews with healthcare professionals, policymakers, and caregivers.

This document highlights the **Systems Thinking Approach** that renders marginalized groups with the disease in Section 1. Then, Section 2 consolidates our **Problem factors**. The existing **Solutions Landscape, Gaps, Levers, and Changes** are outlined in Section 3. Finally, the **Insights and Lessons Learned** are shared in Section 4. The final **Conclusion** is given in Section 5.

The Iceberg Model

EVENTS

- **Inadequate** insurance coverage for specific age groups.
- Patients **without** family support **cannot provide** the expenses for aftercare treatments. [12]
- **Non-White populations** in Alzheimer's are often **underdiagnosed**.
- Patients' families are often **overwhelmed** with how to handle new symptoms. [13]

PATTERNS

- Patients' medical **insurance is not sufficient** for their treatments (Medicare will often not cover expensive tests/treatments.)
- **Lack of guidance** and information to assist patients and their families.
- **Many AD diagnostic tests** have been developed in almost exclusively White AD populations at an early stage in the disease, these tests may **not be representative of other populations**. [14]

STRUCTURES

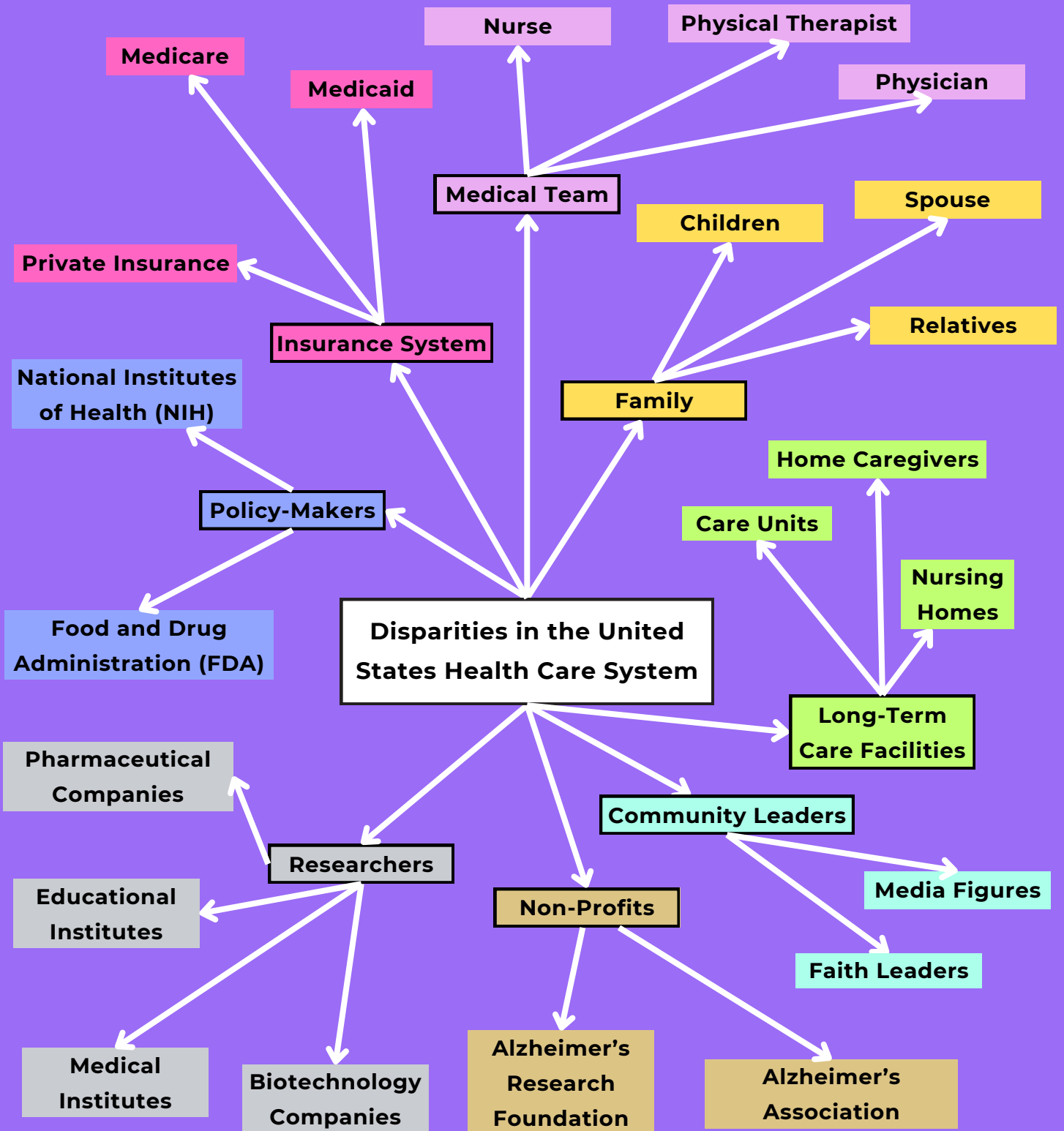
- **Insufficient funding** from the National Institutes of Health (NIH) for high-stakes research programs (Executive Director of Alzheimer's Association Dawne Bunn, Personal Communication, December 1, 2023).
- U.S. Healthcare and **insurance** structures usually **do not include AD aftercare** as part of what is covered for patients.
- Serious physical issues or comorbidities often **overshadow AD** at healthcare screenings.
- **Knowledge gaps** in minority communities regarding the progression of AD.
- **Lack of awareness** for seeking Alzheimer's testing, especially in **younger populations**.
- **Cultural incompetence** between doctors and patients.

MENTAL MODELS

- **Stereotypes and biases** against AD (feelings of shame) inhibit people from reaching out to seek treatment.
- Physical ailments are often thought to be more important and are treated first compared to a **more hidden disease** like AD (Executive Director of Alzheimer's Association Dawne Bunn, Personal Communication, December 1, 2023).
- AD is viewed as a disease for the elderly when in reality **younger populations are also susceptible**.
- Physicians hold off testing for AD in younger people however **treating AD early** is the best way to combat the disease.

Stakeholder Map

The Stakeholder Map highlights the policy-making agencies, healthcare and research institutions, care members, communities, and non-profits that ameliorate the disparities in Alzheimer's care. There are eight categories of stakeholders within our system. Rectangles further away from the center are the examples.

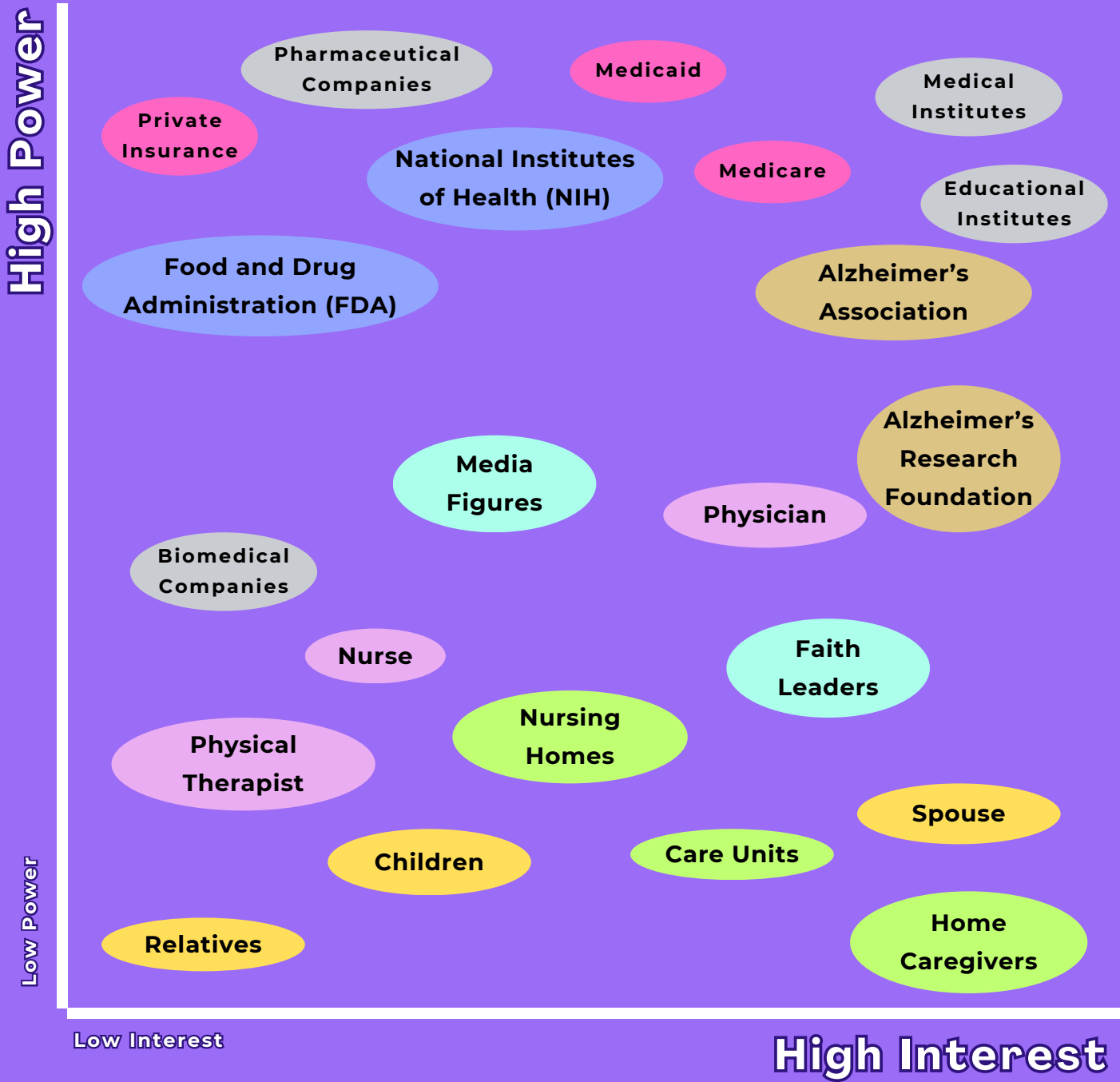


Power-Interest Map

This map showcases the Power and Interest of major stakeholders in addressing the *Disparities in the United States Alzheimer's Care System*.

Power can be defined as the *ability* of a person or group to change the disparities within Alzheimer's care or influence other groups on this topic.

Interest can be defined as how much a person or group wants to see change within the disparities in Alzheimer's care.



Low Power

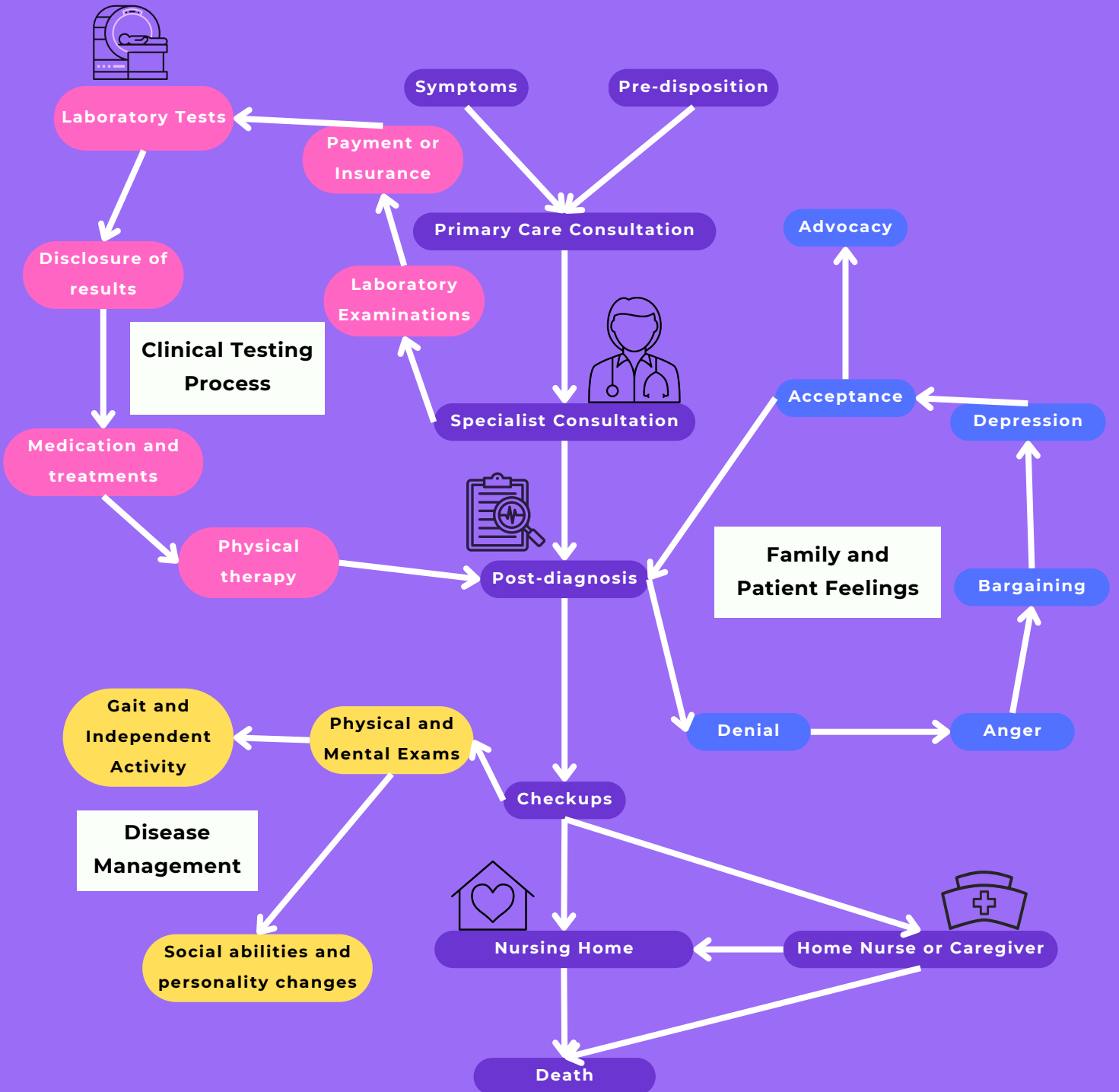
High Power

Low Interest

High Interest

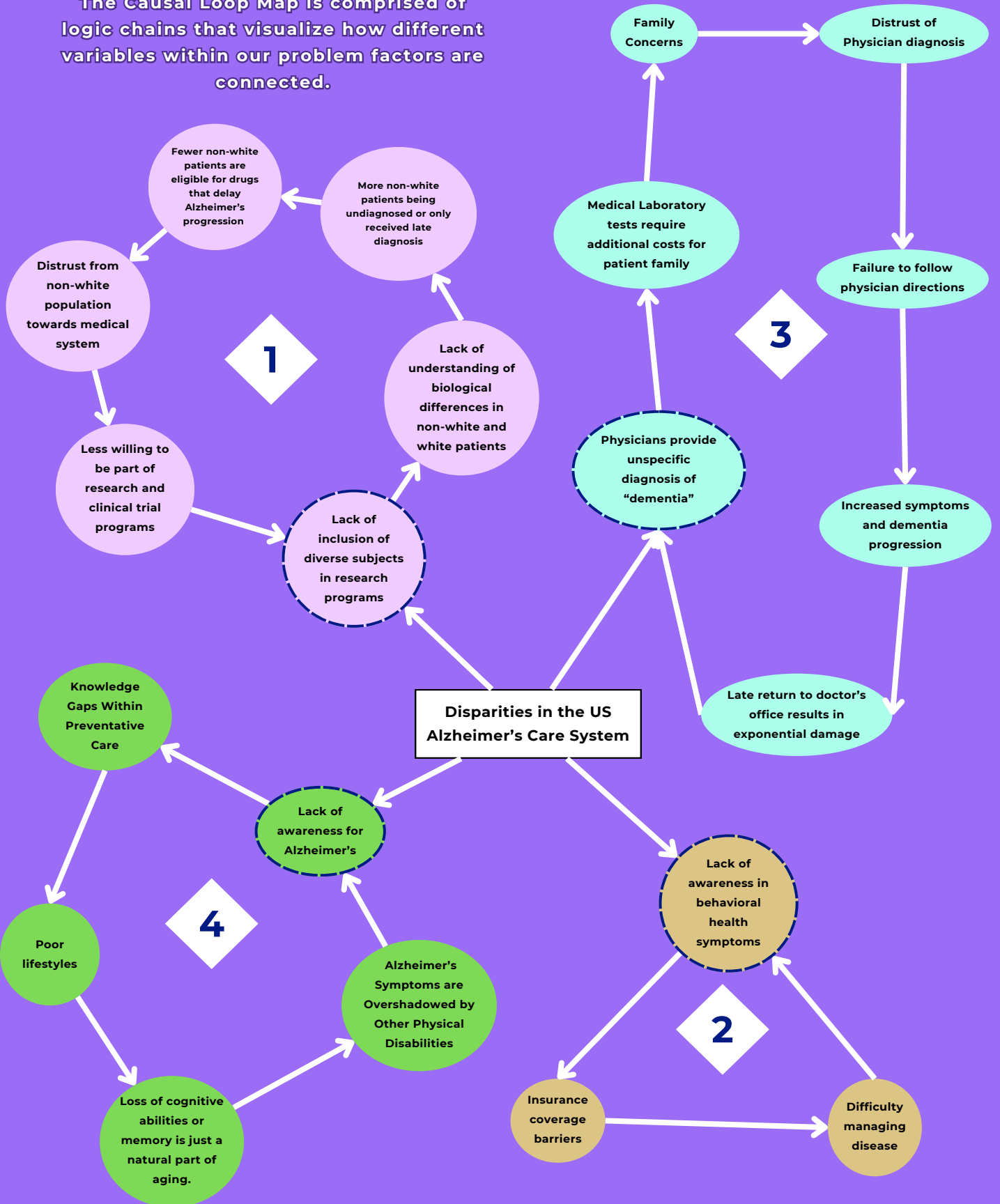
Journey Map

The Journey Map displays the major events that a person may experience as a result of Alzheimer's. Often, what a patient experiences is a combination of both physical and psychological milestones, affecting his or her life in a varying capacity.



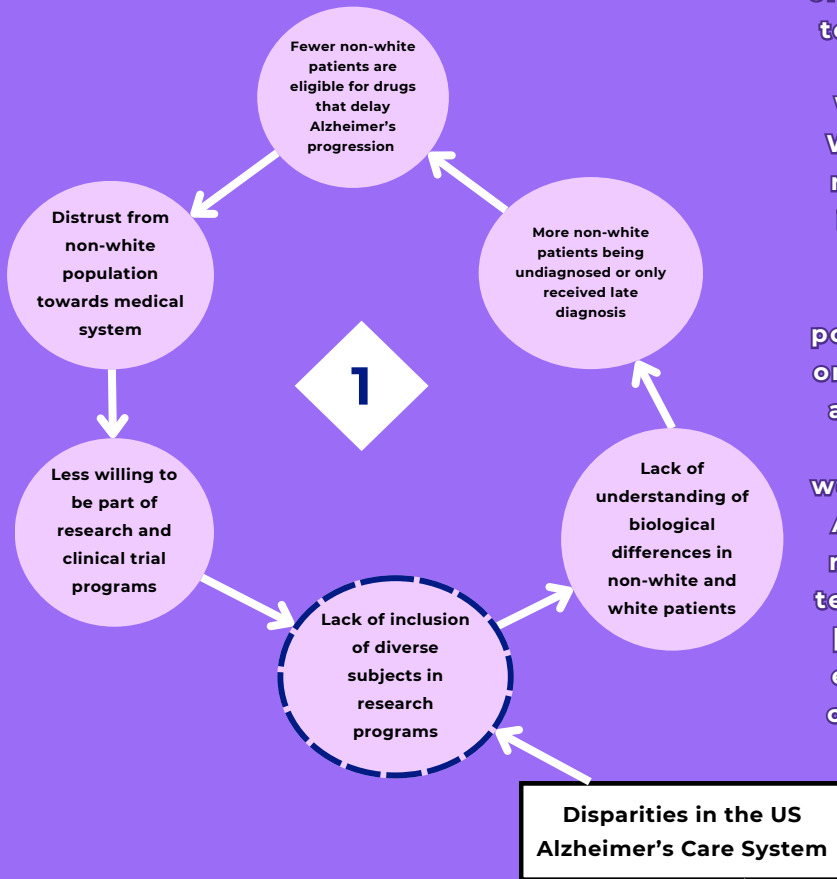
Causal Loop Map

The Causal Loop Map is comprised of logic chains that visualize how different variables within our problem factors are connected.

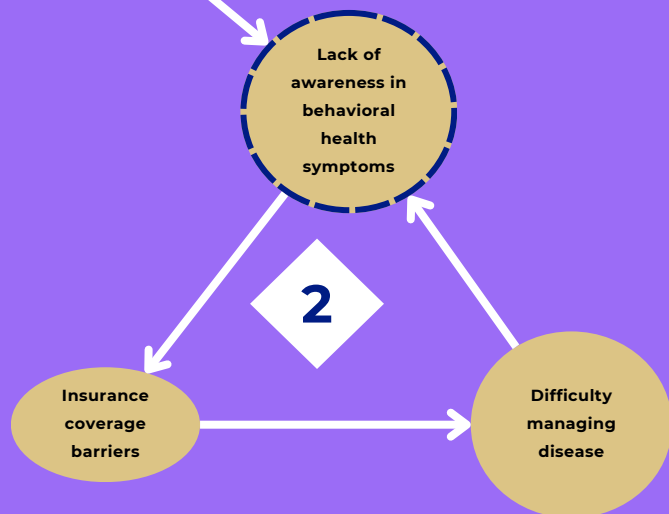


Causal Loop #1 & #2

We identify a **lack of diversity of subjects** in research programs as a root cause for **disparities in diagnosis efficacy** between White and non-White patients [15]. A lack of colored patients in research leads to an insufficient understanding of **biological differences** between White and non-White. Since non-White patients tend to have lower rates of amyloid positivity on PET imaging tests, fewer of them get diagnosed with AD in the early stages [16]. Therefore, those populations often receive diagnoses only when their symptoms are more advanced. However, this suggests that fewer non-White patients would be eligible for **drugs** delaying Alzheimer's progression [15]. As a result, the non-White populations tend to **distrust** the medical system [17]. Thus, they are less willing to engage in research programs and clinical trials. This loops back to a lack of inclusion in research programs.

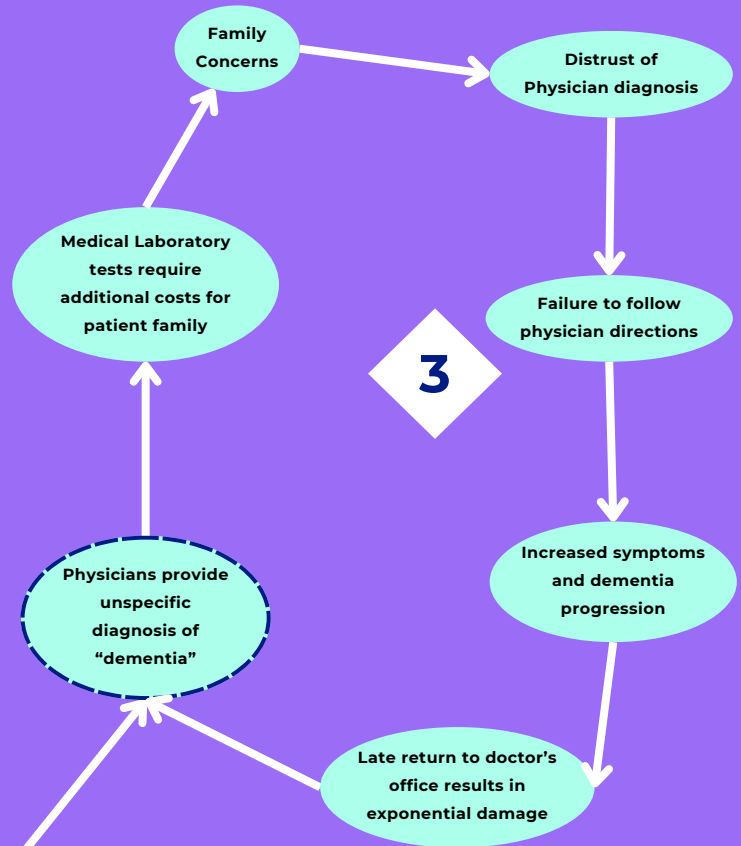


We identify a lack of awareness of **behavioral health symptoms** [18] as a root cause of health insurance disparities. A lack of acknowledgment in this aspect leads to **barriers in insurance coverage** that **fail** to assist individuals in **managing their diseases** at an early stage. Since black individuals display behavioral symptoms at a higher rate [19-23], they tend to be **hindered** by the insurance policy more negatively, which eventually contributes to more disparities in health insurance policies.

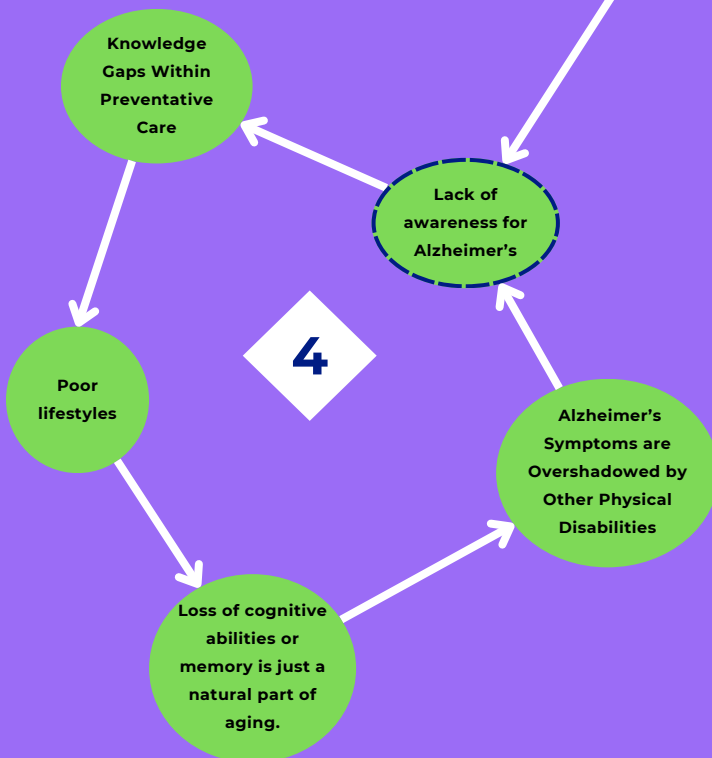


Causal Loop #3 & #4

Furthermore, a **mismatch** between the intentions of the physicians and families is reinforcing the financial problem for Alzheimer's patients. Because of the **extra costs** of medical laboratory tests, physicians prefer skipping medical tests and providing **unspecific** diagnoses of "dementia" to save money for the patients. However, families become concerned about the vagueness of the diagnosis and start doubting the credibility of the diagnosis. Their **distrust** gives rise to failure in following directions from the physicians which brings about advanced progression of AD. Eventually, a **late return** to the doctor's office leads to exponential damage which comes with more **financial burden**. (Dr. Brett Parker, Personal Communication, November 3, 2023)

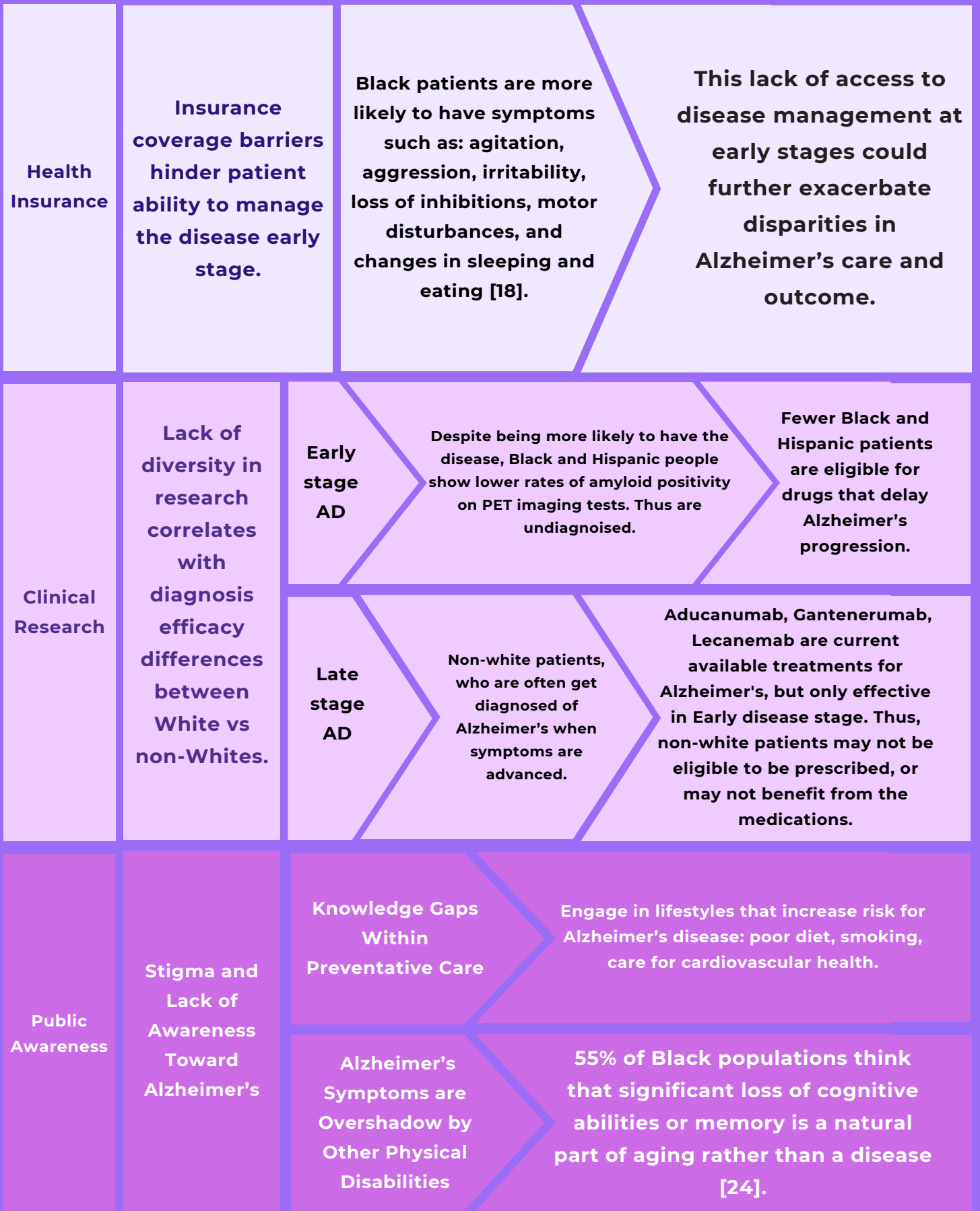


Disparities in the US Alzheimer's Care System



Additionally, a lack of **awareness** of Alzheimer's is another contributing factor to disparities in the US Alzheimer's Care System. As a consequence of the lack of acknowledgment of Alzheimer's, Black populations are more likely to experience **knowledge gaps** within preventative care. As a consequence, they are **less likely** to attend medical checkups which leads back to a lack of awareness of Alzheimer's. Moreover, insufficient knowledge of this disease makes this population more likely to **overlook the symptoms** and then treat a significant loss of cognitive abilities or memories as a natural part of aging [9-11], which ultimately causes insufficient understanding of Alzheimer's.

Problem Factors



Existing Solutions

Health Insurance Disparities

Medicare is a federal health insurance program generally for people aged 65 or older who are receiving Social Security Retirement Benefits or who are under 65 and received Social Security disability benefits for at least 24 months. [25] under 65 and received Social Security disability benefits for at least 24 months. [25]

Medicare will pay for up to 35 hours a week of home health care for people certified as “homebound.” Medicaid will only cover in-home care if there are no other care options that the patient requires.

Clinical Research Disparities

Many AD diagnostic tests have been developed in almost exclusively white AD populations at an early stage in the disease, these tests may not be representative of other populations [14].

Public Awareness Disparities

NGO’s organize conventions, maintain virtual support groups, and helplines [26].

Levers and Changes

Area of focus	Gap	Levers	Change
Health Insurance Disparities	Patients <u>under 65</u> qualify for Medicare but are not covered for <u>behavioral health medications</u> [27]; they exhaust their resources and are left financially disadvantaged.	Recognize the significance of <u>behavioral</u> needs for patients <u>under 65</u>	Adjust the eligibility criteria for Medicare coverage for patients with Alzheimer's <u>under 65</u> .
Clinical Research Disparities	Different racial and ethnic groups <u>receive healthcare</u> differently.	Recognize diversity among health care and research staff	Preparing a culturally, racially and ethnically competent workforce of clinicians and researchers to care diverse older adult population.
		Recognize representation of Black, Hispanic, Asian, and Native Americans in Alzheimer's research in <u>clinical trials</u> .	Establish regulatory requirements to <u>engage, recruit, and retain</u> participants in clinical trials that are racially and ethnically diverse.
Public Awareness Disparities	Distrust in the medical system from historical context	Recognize appropriate advocacy avenues to <u>shift cultural perspectives</u> of marginalized patient populations.	Establish <u>research & outreach programs</u> at high schools so kids can bridge the knowledge gap about the disease at an early age and educate their family.
		Recognize how <u>government</u> can mobilize resources to support marginalized patient populations.	Identify community-specific <u>media figures/faith leaders</u> and encourage collaborations with established <u>NGOs</u> disease awareness programs.
			Establish <u>disease advocacy alliance</u> across geographical (urban/rural) communities.

Insights & Lesson Learned

Through our analysis of interviews and research, we have found that there are a few topics with key insights that emerged. The first topic is that of **advocacy**. More than 6 million Americans have Alzheimer's [22]. By 2050, estimates show this number will rise to almost 13 million. In 2022, Alzheimer's and other dementias cost the U.S. \$321 billion, with \$206 billion in Medicare and Medicaid payments combined [22]. Considering that dementia is one of the costliest conditions to society, three patterns with the intersection between advocacy, insurance, and providers emerged with our research, interviews, and discussions

Considering that almost 50% of all caregivers who aid older adults do so for someone with Alzheimer's or another dementia [22]. The number of Americans who are affected by Alzheimer's is massive. There is a **lack of awareness** of Alzheimer's among Americans, including the onset, characteristics, risk factors, symptoms, and more. The **failure to be familiar** with the **progression of AD** prevents patients and their family members from providing help at the optimal time. To address this issue, schools, NGOs, and NPOs should encourage and **educate society early** to equip caregivers with the necessary knowledge.

The **earlier** a caregiver and patient can **recognize symptoms** of AD, the faster and **more effective treatments can be taken** to prevent the rapid degeneration of memory later on. People can be seen with Alzheimer's symptoms as early as age 30 or 40 [9], but **only through awareness** can people recognize them and have patients treated early.

With the **help of NGOs and NPOs**, who can educate and fundraise, the creation of advocacy programs about Alzheimer's can **make resources** more **accessible**. Disease **advocacy alliances** across geographical (urban/rural) areas can **connect minorities** with other **institutional support systems** such as caregivers and voluntary sites. These alliances can **bridge** the local population and different levels of government to share perspectives on current healthcare and policy systems for future improvement. Such disease alliances can be a **trusting platform for patients** and their caregivers to share insights and information, which **helps relieve** the stress of the patients and their family members.

Moreover, it is easier to **identify marginalized groups** in areas receiving meager resources and reallocating from others. Interviews with AD patient caregivers have indicated that **organizations**, such as the Alzheimer's Association, can **link patients with helpful resources**. For example, advice from trained professionals on the Association's 24-7 helpline. **Non-profit organizations** like these can have a **greater impact** on the **development of Alzheimer's' research** and treatment by reaching out to influential stakeholders.

Moreover, the second insight topic we recognize is the **medical diagnosis** and **treatment** landscape for Alzheimer's disease involves a **multifaceted approach**. Current diagnosis methods rely on expensive MRI scans and cognitive assessments triggered by noticeable irregularities reported by family members. This process incurs immense financial and emotional expenses, with insurance coverage limited to Medicare. **Region-specific programs** and policies propose paying healthcare providers based on the quality of care, bridging resource gaps, introducing cross-institutional employees, and promoting support systems for patients.

When it comes to the third topic of **insurance**, there is **extreme variability** from state to state regulations, politics, and demographics. Based on the interviews done so far, Alzheimer's is **not considered** by many states as a disease that affects the "majority" of its population when it comes to **regulating policy** for Medicare and Medicaid programs [source 3]. Furthermore, because providers are not always properly compensated through insurance and because there is no official cure for Alzheimer's, many physicians have similar sentiments that diagnosing and treating Alzheimer's specifically is a waste of resources.

Conclusion

Within the mapping of the *Disparities in the US Alzheimer's Care System*, we outlined the problem factors, the existing solutions, the gaps between them, and possible levers of change. Within all of these, the **three basic pillars** of this system revolve around disparities in **Health Insurance, Clinical Research, and Public Awareness**. Furthermore, a few initiatives are being taken within the realm of each **insurance policy**, namely attempting to create a policy based on region. These would be attempts to be **more inclusive** to different populations across the nation, however, the effort and effect being put into these initiatives are **not always beneficial** for Alzheimer's patients in particular.

The current solutions for disparities in the US Alzheimer's care system within the medical field: **clinical research, clear diagnosing for patients, and the majority of patients are being represented**. Alzheimer's is a prominent sector of research in thousands of different institutions, and more things are being discovered with the disease every day. Next, the cause of AD is clear and known, along the treatment used to diagnose patients is effective. The only issue that comes with this is **recognizing symptoms within patients and patient affordability**. Lastly, because the majority of AD patients are white, most Alzheimer's studies include white subjects and are representative and effective for white AD patients. However, other races have been forgotten, **not enough research** has been done to determine possible differences and risk factors between races for AD.

Caregivers and family members are more actively involved in patient care and learning about the disease, therefore **caregivers can educate others and spread awareness** about Alzheimer's. Other modes of support include NGOs and NPOs such as the Alzheimer's Association, an organization that raises money for research, educates the public, and aims to provide further support for Alzheimer's patients. Lastly, there are highly interested media figures that help spread awareness, raise money, and try to build back trust between patients and healthcare providers. This helps the more general public **gain a greater consciousness of disparities** within Alzheimer's and about Alzheimer's in general.