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### Title

Mapping racial and ethnic healthcare disparities for persons living with dementia: A scoping review.

### Permalink

<https://escholarship.org/uc/item/80s506n6>

### Journal

Alzheimers & Dementia: The Journal of the Alzheimers Association, 20(4)

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### Publication Date

2024-04-01

### DOI

10.1002/alz.13612

Peer reviewed

## REVIEW ARTICLE

## Mapping racial and ethnic healthcare disparities for persons living with dementia: A scoping review

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## Funding information

National Institutes of Health, Grant/Award Number: U54AG063546

## Abstract

**INTRODUCTION:** We set out to map evidence of disparities in Alzheimer's disease and Alzheimer's disease related dementias healthcare, including issues of access, quality, and outcomes for racial/ethnic minoritized persons living with dementia (PLWD) and family caregivers.**METHODS:** We conducted a scoping review of the literature published from 2000 to 2022 in PubMed, PsycINFO, and CINAHL. The inclusion criteria were: (1) focused on PLWD and/or family caregivers, (2) examined disparities or differences in health-care, (3) were conducted in the United States, (4) compared two or more racial/ethnic groups, and (5) reported quantitative or qualitative findings.**RESULTS:** Key findings include accumulating evidence that minoritized populations are less likely to receive an accurate and timely diagnosis, be prescribed anti-dementia medications, and use hospice care, and more likely to have a higher risk of hospitalization and receive more aggressive life-sustaining treatment at the end-of-life.**DISCUSSION:** Future studies need to examine underlying processes and develop interventions to reduce disparities while also being more broadly inclusive of diverse populations.

## KEYWORDS

dementia, dementia disparities, health equity, healthcare disparities, racial/ethnic disparities

## 1 | INTRODUCTION

As the older adult population in the United States, including those living with dementia, becomes more ethnically and racially diverse, there is increased recognition of the importance of conducting research to identify and eliminate disparities in the care and outcomes for persons living with dementia (PLWD).<sup>1,2</sup> Reducing disparities in both Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) disease burden and receipt of timely, high-quality healthcare services is essential to advance health equity.<sup>2</sup> Despite substantial under-representation of minoritized populations in AD/ADRD

research,<sup>3</sup> there is now growing evidence of higher levels of AD/ADRD-related risk factors in certain minoritized communities<sup>4-6</sup> as well as higher incidence<sup>7,8</sup> and prevalence rates<sup>9,10</sup> of AD/ADRD. The COVID-19 pandemic further underscored the need for research on health and healthcare disparities for minoritized persons, especially those with dementia and their family caregivers.<sup>11,12</sup>

An increasing number of studies have examined healthcare disparities for PLWD and family caregivers, from diagnosis to end-of-life care.<sup>2,13</sup> More than a decade ago, a meta-analysis found evidence that Black and Hispanic American older adults with dementia access diagnostic services later in the course of their illness than

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non-Hispanic White (NHW) older adults and were less likely to receive anti-dementia medications.<sup>14</sup> Another review concluded that Hispanic and Black American older adults often receive delayed or inadequate healthcare services or were diagnosed in an emergency department (ED) or other non-traditional setting.<sup>15</sup> Finally, a more recent review of access to health services among PLWD found that Black Americans were more likely to be hospitalized.<sup>16</sup> Barriers to healthcare may stem from many sources, including inadequate health insurance, limited English language proficiency, transportation barriers, lack of specialty clinics in disadvantaged communities,<sup>17,18</sup> lack of diversity in the healthcare profession, and discrimination when seeking care.

As momentum builds to advance care and services for PLWD in healthcare systems, there is an urgent need to identify issues of access, quality, and outcomes for AD/ADRD in existing healthcare systems.<sup>19</sup> This study's goal was to map the evidence of disparities in AD/ADRD healthcare including issues of access, quality, and outcomes for racial/ethnic minoritized PLWD and their family caregivers, and to identify gaps in the field. This scoping review was undertaken because of the exponential growth of research in this area over the past decade and the need to both map and synthesize existing evidence to guide future systematic and/or meta-analytic reviews and research.<sup>20</sup>

## 2 | METHODS

Our methodological approach for this scoping review was guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>21</sup> for scoping reviews as well as the framework of Arksey and O'Malley.<sup>22</sup> To define the scope of our review, we focused on areas of healthcare that are included in the following definition of a healthcare disparity from the Kaiser Family Foundation to narrow the scope of our study: "A healthcare disparity typically refers to differences between groups in health insurance coverage, access to and use of care, and quality of care."<sup>23</sup>

### 2.1 | Inclusion and exclusion criteria

Studies were included if they (1) focused on PLWD and/or their family caregivers, (2) examined disparities or differences in healthcare, (3) were conducted in the United States, (4) included the comparison of two or more racial/ethnic groups, (5) reported quantitative or qualitative findings, and (6) were published in a peer-reviewed journal with full-text available in English from January of 2000 to July of 2022. We excluded studies that used case-study study designs as well as editorials, commentaries, and reviews.

We included a variety of settings, including hospitals, clinics, home-based primary care, and long-term care facilities, including healthcare delivered to the person with dementia and services or support delivered to a family member related to AD/ADRD.

### RESEARCH IN CONTEXT

1. **Systematic review:** The scoping review was conducted to map evidence of disparities in healthcare including issues of access, quality, and outcomes for racial/ethnic minoritized persons living with dementia (PLWD) and their family caregivers and to identify gaps in the field.
2. **Interpretation:** Minoritized populations are less likely to receive an accurate and timely diagnosis, be prescribed with anti-dementia medications, and use hospice care, and more likely to have a higher risk of hospitalization and receive more aggressive life-sustaining treatment at the end of life.
3. **Future directions:** Future studies need to examine underlying processes and develop interventions to reduce disparities while also being more broadly inclusive of diverse populations.

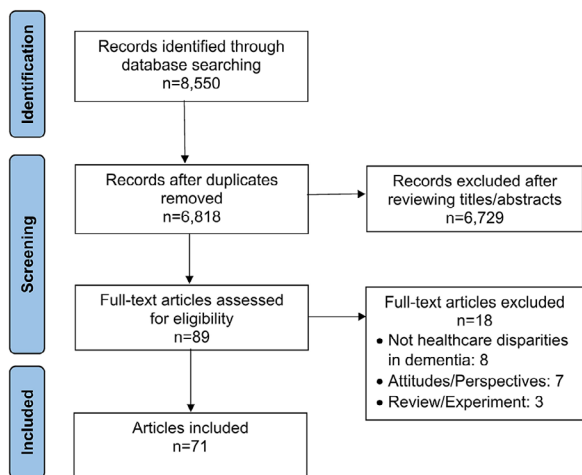
## 2.2 | Search strategy

This scoping review was conducted of the literature published from 2000 to 2022 in PubMed, PsycINFO, and CINAHL. To generate the search terms, we began with the MEDLINE/PubMed National Institute on Minority Health and Health Disparities Strategy<sup>24</sup> suggested search terms for health disparity populations, eliminated terms that were not relevant to this search, and added additional terms. Next, we added search terms for dementia due to AD and other related degenerative dementias (see the [Appendix](#) in supporting information for search terms).

A multi-step process was used to identify records meeting inclusion criteria. First, duplicates were removed. Second, the remaining record abstracts were pulled and screened for eligibility by two independent reviewers. A random subset of 100 record abstracts was pulled and independently reviewed by the two study members, who achieved agreement at a level of kappa > 0.8, prior to screening the remaining abstracts. Full-length articles were pulled for all abstracts that met eligibility criteria and were reviewed by the two independent study members to determine eligibility for inclusion. Discrepancies at the abstract or full-length article review stage were resolved through team review and discussion until arriving at a consensus.

## 2.3 | Data extraction and synthesis

Characteristics of full-length articles meeting inclusion criteria were extracted and charted into tables. Extraction was done independently by two research staff who then compared their results and resolved any discrepancies in consultation with other authors. Data extraction elements included: study author and year of publication, stage of care and treatment (i.e., initial assessment, diagnosis,



**FIGURE 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of the study selection process.

and referral; ongoing treatment and support; later stages of illness including end-of-life care), study design (i.e., cross-sectional, longitudinal), racial/ethnic groups included, setting, primary study objective, whether racial/ethnic disparities or differences were a stated purpose of the study, how the sample was identified, and any reported differences in healthcare between racial/ethnic groups.

To synthesize the data, the lead author reviewed the findings from the studies in the chart and generated a list of healthcare categories that captured the range of findings from the studies. Multiple team members reviewed the categories, reviewed the chart data, and then the team developed a consensus about the categories related to healthcare that best described the findings/results. Findings from the studies were then categorized according to these healthcare categories. The abstracted results are the basis for the summaries in the next section. In abstracting and reporting the results in tables, we retained the racial/ethnic categories used by the study authors. To develop the final tables, we focused on reporting statistically significant (i.e.,  $P < 0.05$ ) results comparing two or more racial/ethnic categories from the studies related to each of the healthcare domains.

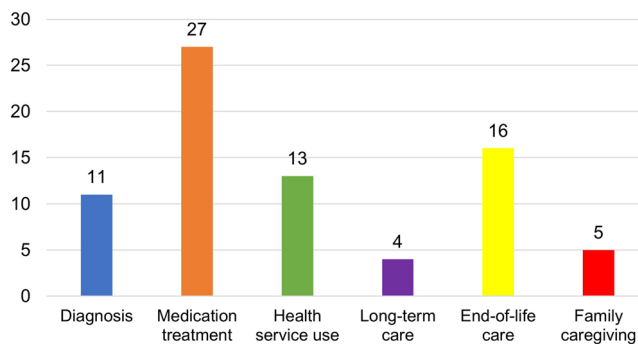
## 3 | RESULTS

### 3.1 | Search results

The search yielded 8550 articles and 6818 unique articles after removing duplicates. An additional 6729 articles were removed based on the review of record abstracts, leaving 89 articles. After review of full-length articles for these 89 studies, 71 met full inclusion criteria (see Figure 1).

### 3.2 | Characteristics of studies

Of the 71 studies identified, all but one study reported one or more statistically significant differences between racial/ethnic groups. The



**FIGURE 2** Number of articles for each healthcare domain ( $n = 71$ ). Some studies report findings across multiple healthcare domains.

most frequently addressed topic (see Figure 2) was medication treatment (38%), followed by end-of-life care (22.5%), health service use (18.3%), diagnosis (15.5%), family caregiving (7%), and long-term care (5.6%). In terms of findings regarding representation of minoritized populations, 85.9% of studies reported findings for Black Americans, 57.7% for Hispanic Americans, 25.4% for Asian Americans/Pacific Islanders (AA/PI), 2.8% for American Indians/Alaska Natives (AI/AN), and 32.4% reported "other" or aggregate categories (e.g., other, non-White, minority). For most studies, NHW was the reference for comparison. Overall, 18.3% ( $n = 13$ ) of studies did not include racial/ethnic differences or disparities as a stated aim or focus but reported relevant findings in their results section. Studies varied widely in size and were primarily observational covering a range of services and settings, including community, outpatient clinics, EDs, hospitals, and long-term care.

### 3.3 | Synthesis of study results

We synthesized our results by grouping them into six broad topic areas reflecting different aspects of healthcare for PLWD: (1) diagnosis (timeliness, accuracy, initial referral), (2) medications (anti-dementia medications, psychotropics, and medications for other health conditions), (3) healthcare service use and costs (excluding studies of healthcare services specific to the end of life), (4) long-term care, (5) end-of-life care, and (6) family caregiving (see Figure 2). For each of these categories, Tables 1–6 summarize statistically significant results (i.e.,  $P < 0.05$ ) for racial/ethnic comparisons with some of the studies reporting findings that crossed several topic areas.

To further synthesize and integrate the results, we mapped key results onto an adapted and simplified version of the dementia care trajectory,<sup>25,26</sup> beginning with initial assessment, diagnosis, and referral at the early stages of the clinical disease process and awareness of symptoms (i.e., diagnosis), followed by ongoing treatment and support as disease and disability progresses (i.e., medications, health service use and costs), and finally to the later stages of the disease (i.e., long-term care, end-of-life care). The family caregiving topic cuts across the three stages. Figure 3 summarizes our synthesis of results onto

**TABLE 1** Diagnosis (n = 11).

Author, year	Study design	Total sample (N), Racial/ethnic populations	Results
Chen et al., <sup>27</sup> 2019	Longitudinal, Health, and Retirement Study linked to Medicare claims, 2000–2008	N = 10,450 Year 2000: White: n = 86.8% Black: n = 9.0% Hispanic: n = 4.1%	<ul style="list-style-type: none"> <li>• Dementia identified by cognitive test only: Black, Hispanic &gt; White</li> <li>• Dementia identified by diagnosis only: Hispanic &gt; White</li> <li>• Diagnosed over 2 years before the incident dementia based on cognitive tests: White &gt; Black, Hispanic</li> <li>• Diagnosed within 2 years of incident dementia: White &gt; Black</li> <li>• Received diagnosis 2 years after cognitive test–based dementia incidence: Black &gt; White</li> </ul>
Gianattasio et al., <sup>28</sup> 2019	Longitudinal, Health and Retirement Study linked to fee-for-service Medicare claims, 2000–2010	N = 4647–5201 (varies by wave) Non-Hispanic White: n = 91%–93% Non-Hispanic Black: n = 7%–9%	<ul style="list-style-type: none"> <li>• Risk of underdiagnosis: Non-Hispanic Black &gt; Non-Hispanic White</li> <li>• Risk of overdiagnosis in 2002, 2004, 2010: Hispanic &gt; Non-Hispanic White [reported in Supplement]</li> </ul>
Amjad et al., <sup>29</sup> 2018	Cross-sectional, National Health, and Aging Trends Study linked to retrospective Medicare A and B claims data, 2011	N = 585 Undiagnosed: N = 229 Non-Hispanic White: n = 63.7% Non-Hispanic Black: n = 12.5% Hispanic or other: n = 21.4%	<ul style="list-style-type: none"> <li>• Frequency of undiagnosed dementia: Hispanic/Other non-White race &gt; White</li> </ul>
Tsoy et al., <sup>30</sup> 2021	Cross-sectional, California Medicare fee-for-service data, 2013–2015	N = 10,472 Asian: n = 993 Black: n = 407 Hispanic: n = 1255 White: n = 7817	<ul style="list-style-type: none"> <li>• Received timely diagnosis: White &gt; Asian, Hispanic, Black</li> <li>• Received recommended diagnostic workup: White &gt; Asian</li> </ul>
Lin et al., <sup>31</sup> 2021	Longitudinal, Health and Retirement Study linked to Medicare and Medicaid claims, 2000–2014	N = 3966 Non-Hispanic White: n = 2908 Non-Hispanic Black: n = 687 Hispanic: n = 371	<ul style="list-style-type: none"> <li>• Missed or delayed diagnosis: Non-Hispanic Black and Hispanic &gt; Non-Hispanic White</li> </ul>
White et al., <sup>32</sup> 2022	Longitudinal, Health and Retirement Study, 1995–2016	N with incident dementia = 4760 Non-Hispanic White: n = 3039 Non-Hispanic Black: n = 1031 Hispanic: n = 584 Other: n = 106	<ul style="list-style-type: none"> <li>• Received a timely diagnosis: Non-Hispanic White &gt; Non-Hispanic Black</li> </ul>
Kalkonde et al., <sup>33</sup> 2009	Cross-sectional, Veterans Affairs medical clinic chart data, 2004–2005	N = 410 Caucasian: n = 265 African American: n = 109 Hispanic: n = 34 Other ethnic groups: n = 2	<ul style="list-style-type: none"> <li>• Neuropsychological testing: Caucasian &gt; Non-Caucasian</li> </ul>
Drabo et al., <sup>34</sup> 2019	Longitudinal, Medicare claims data, 2008/2009	N = 226,604 White: n = 196,180 Black: n = 17,261 Hispanic: n = 9540 Asian: n = 3623	<ul style="list-style-type: none"> <li>• Likelihood of postdiagnosis dementia healthcare visit with dementia specialist: White, Black &gt; Hispanic, Asian</li> <li>• No follow-up after diagnosis: Hispanic, Asian &gt; White, Black</li> </ul>
Chow et al., <sup>35</sup> 2000	Longitudinal, Minimum Uniform Dataset from California Alzheimer's Disease Diagnostic and Treatment Centers, 1988, 1993, 1995	N = 9451 Asian (primarily Chinese): n = 4.2%, Filipino: n = 0.8%, Pacific Islander: n = 0.3% Caucasian: n = 75.9%	<ul style="list-style-type: none"> <li>• Sought second opinion on dementia diagnosis: Caucasian &gt; Asian</li> <li>• Referrals from physician or community support group for dementia diagnosis: Caucasian &gt; Asian</li> <li>• Refused reassessment: Filipino &gt; Caucasian</li> <li>• Referrals patients to case management, Alzheimer's disease day care: Asian &gt; Caucasian</li> <li>• Referrals patients to home healthcare services: Caucasian &gt; Asian</li> </ul>

(Continues)

**TABLE 1** (Continued)

Author, year	Study design	Total sample (N), Racial/ethnic populations	Results
Boustani et al., <sup>36</sup> 2006	Cross-sectional	N = 434 White: n = 139 African American: n = 294	• Refused diagnostic assessment for dementia (age < 80): White > African American
Hinton et al., <sup>37</sup> 2004	Cross-sectional, qualitative interview	N = 39 Black: n = 10 Chinese: n = 14 Anglo Euro-American: n = 15	• Differences in care pathways to diagnosis across ethnic/racial groups

**TABLE 2** Anti-dementia, psychotropic, and other medication use (n = 26).

Author, Year	Study design, data source if specified	Total sample (N), Racial/ethnic populations	Results
Kalkonde et al., <sup>33</sup> 2009	Cross-sectional, Veterans Affairs medical clinic chart data, 2004–2005	N = 410 Caucasian: n = 265 African American: n = 109 Hispanic: n = 34 Other ethnic groups: n = 2	• Cholinesterase inhibitors (CHEIs) used: Non-African American > African American; Caucasian > African American
Lind et al., <sup>38</sup> 2018	Longitudinal, Cost and Use Medicare Current Beneficiary Survey, 2003–2013	N = 4304 Non-Hispanic White: n = 5586 Non-Hispanic Black: n = 750 Hispanic: n = 530 Other: n = 359 (Note: racial/ethnic group n's reported in person years)	• Anti-dementia medication use: White > Ethnoracial minorities
Mehta et al., <sup>39</sup> 2005	Cross-sectional, Minimum Uniform Dataset from Alzheimer's Disease Research Centers of California, 1999–2003	N = 2573 African American: n = 6% Asian: n = 7% Latino: n = 14% Other ethnicity: n = 2% White: n = 71%	• CHEIs use: White > Minority (African American, Asian, Latino)
Giebel et al., <sup>40</sup> 2020	Longitudinal, National Alzheimer's Coordinating Center, 2005–2019	N = 15,742 White: n = 82.4% Minority: n = 17.6%	• Anti-dementia medication use: White > Minority ethnic backgrounds
Lerner et al., <sup>41</sup> 2008	Cross-sectional	N = 117 White: n = 94 African American: n = 23	• Memantine use: White > African American
McClendon et al., <sup>42</sup> 2009	Cross-sectional, Uniform Data Set from National Alzheimer's Coordinating Center, 2005–2007	Total N = 2512 N with Alzheimer's disease = 877 Hispanic/Latino: n = 7% Non-Hispanic White: n = 80% Non-Hispanic Black: n = 10% N with other dementia = 219 Hispanic/Latino: n = 4% Non-Hispanic White: n = 86% Non-Hispanic Black: n = 7%	• Acetylcholinesterase inhibitors (AChEIs) use: Non-Hispanic White > Non-Hispanic Black • Memantine use: Non-Hispanic White > Non-Hispanic Black
Barthold et al., <sup>43</sup> 2020	Longitudinal, random 20% sample of Medicare beneficiaries, 2008–2016	N = 721,878 White: n = 600,358 Black: n = 57,412 Hispanic: n = 44,082 Asian: n = 20,026	• Anti-dementia drug use: White > Black, Asian, Hispanic
Hernandez et al., <sup>44</sup> 2010	Cross-sectional, Uniform Data Set from National Alzheimer Coordinating Center, 2005–2007	N = 3049 White: n = 77.63% Black: n = 14.56% Non-Black Hispanic: n = 7.81%	• AChEIs use: Non-Hispanic White > Black • Memantine use: Non-Hispanic White > Black, Non-Black Hispanic

(Continues)

TABLE 2 (Continued)

Author, Year	Study design, data source if specified	Total sample (N), Racial/ethnic populations	Results
Zuckerman et al., <sup>45</sup> 2008	Longitudinal, Medicare Current Beneficiary Survey, 2001–2003	N = 1120 Non-Hispanic White: n = 855 Non-Hispanic Black: n = 131 Hispanic: n = 91 Other: n = 43	<ul style="list-style-type: none"> <li>• Anti-dementia medication use: Non-Hispanic White &gt; Other racial/ethnic groups</li> </ul>
Poon et al., <sup>46</sup> 2009	Longitudinal, the Veterans Health Administration: the Patient Treatment Files and the Pharmacy Benefit Management, 2000–2005	N = 56,561 White: n = 70.5% African American: n = 15.6% Hispanic: n = 6.6% Other races: n = 0.5% Unknown: n = 6.8%	<ul style="list-style-type: none"> <li>• AChEIs and anti-dementia medication use: White &gt; African American</li> <li>• Angiotensin-converting enzyme (ACE) inhibitors: White &gt; African American; Hispanic &gt; White</li> <li>• Angiotensin receptor blockers (ARBs): White &gt; African American and Hispanic</li> <li>• <math>\beta</math>-blockers: White &gt; African American and Hispanic</li> <li>• Non-dihydropyridine calcium-channel blocker (CCB), loop diuretic, <math>\alpha</math>-agonist, or potassium-sparing diuretic (PSD): White &gt; Hispanic</li> <li>• Medication adherence rates in all classes except for ARBs, loop diuretics, and PSDs: White &gt; African American</li> <li>• Medication adherence rates dihydropyridine CCBs and acetylcholinesterase inhibitors: White &gt; Hispanic</li> </ul>
Sano et al., <sup>47</sup> 2005	Cross-sectional, baseline data of phase 4 study of patients with mild to moderate AD, 2001	N = 2114, Patient: N = 2105 White: n = 1807 Black: n = 143 Hispanic: n = 131 Asian n = 18 Other: n = 6	<ul style="list-style-type: none"> <li>• AChEIs use: White &gt; Other ethnic groups</li> </ul>
Zhu et al., <sup>48</sup> 2022	Longitudinal, Uniform Data Set from National Alzheimer's Coordinating Center, 2005–2020	N = 3276 Non-Hispanic White: n = 2454 Non-Hispanic Black: n = 532 Hispanic: n = 290	<ul style="list-style-type: none"> <li>• Anti-dementia medication use: White &gt; Black, Hispanic</li> <li>• Persistently treated with AChEIs and memantine: White &gt; Black, Hispanic</li> </ul>
Thorpe et al., <sup>49</sup> 2016	Longitudinal, Medicare enrollment, Part A and B, medical claims, and Part D prescription data for a 10% national sample of Medicare fee-for-service beneficiaries, 2009–2010	N = 84,043 Non-Hispanic White: n = 66,806 Non-Hispanic Black: n = 9781 Hispanic: n = 7456	<ul style="list-style-type: none"> <li>• Anti-dementia medication use: Hispanic &gt; White</li> <li>• Anti-dementia medication discontinuation: Hispanic, Black &gt; White</li> </ul>
Gilligan et al., <sup>50</sup> 2012	Cross-sectional, Medicaid Analytic extract file from the Centers for Medicare and Medicaid Services, 2004	N = 158,974 White: n = 88,529 Black: n = 16,180 Hispanic: n = 21,483 Other: n = 10,649 Unknown: n = 22,133	<ul style="list-style-type: none"> <li>• Anti-dementia use: Hispanic &gt; Non-Hispanic White; Hispanic &gt; Non-Hispanic Black; Non-Hispanic Other &gt; Non-Hispanic Black; Hispanic &gt; Non-Hispanic Other</li> <li>• Anti-dementia use: Hispanic &gt; Non-Hispanic White in Florida; Hispanic &gt; Non-Hispanic Black in California and Florida; Non-Hispanic Other &gt; Non-Hispanic Black in California and New York; Non-Hispanic Other &gt; Hispanic in California and New York</li> </ul>
Perryman et al., <sup>51</sup> 2009	Longitudinal, Medicare Current Beneficiary Survey Cost and Use Files, 2000–2002	Y2000: N = 347, Y2001: N = 367, Y2002: N = 412 N by Year, 2000, 2001, 2002 Caucasian: n = 278, 291, 328 African American: n = 50, 52, 57 Hispanic: n = 9, 10, 12	<ul style="list-style-type: none"> <li>• Aricept use: Black, Hispanic &gt; White; Hispanic &gt; Black</li> </ul>

(Continues)

**TABLE 2** (Continued)

Author, Year	Study design, data source if specified	Total sample (N), Racial/ethnic populations	Results
Xiong et al., <sup>52</sup> 2015	Cross-sectional, National Alzheimer's Coordinating Center, 2008–2014	N = 8919 African American: n = 983 Hispanic: n = 849 Non-Hispanic White: n = 7,087	• Anti-psychotic use: Hispanic > Non-Hispanic White
Filshtein et al., <sup>53</sup> 2016	Cross-sectional, National Alzheimer's Coordinating Center, 2008–2014	N = 4741 Black: n = 401 Hispanic: n = 337 Non-Hispanic White: n = 3389	• Anti-psychotic use: Hispanic > Non-Hispanic White
Hsieh et al., <sup>54</sup> 2021	Cross-sectional, Medicare Current Beneficiary Survey, 2015–2017	N = 4,953,945 Non-Hispanic White: n = 78.66% Non-Hispanic Black: n = 9.67% Hispanic: n = 7.22% Other: n = 4.45%	• Anti-psychotic use: Hispanic > Non-Hispanic White
Grace et al., <sup>55</sup> 2018	Cross-sectional, baseline data of the Resources for Enhancing Alzheimer's Caregiver Health II	N = 543 Non-Hispanic White: n = 198 African American: n = 176 Hispanic/Latino: n = 169	• Anxiolytic use: African American > Non-Hispanic White • Anti-psychotic use: Non-Hispanic White > Hispanic/Latino
Rivera-Hernandez et al., <sup>56</sup> 2022	Cross-sectional, Residential History File, Medicare Beneficiary Summary File, Minimum Data Set, Certification and Survey Provider Enhanced Reports and the Long-term Care: Facts on Care in the US, 2007	N = 1,005,781 White: n = 78% Black: n = 13% Hispanic: n = 6% Asian/Pacific Islander: n = 2% American Indian/Alaska Native: n = 0.4%	• Anti-depressant use: White > Asian/Pacific Islander, Hispanic, Black • Anti-psychotic medications use: White, Hispanic, American Indian/Alaska Native > Black, Asian/Pacific Islander
Nili et al., <sup>57</sup> 2020	Cross-sectional, Medicare Current Beneficiary Survey and Medicare claims, 2006–2013	N = 2570 White: n = 1932 Latino: n = 209 Other race: n = 429	• Receipt of low-value care anti-psychotic medication: Hispanic or Non-Hispanic White > Other race
Thorpe et al., <sup>58</sup> 2012	Cross-sectional, baseline data of the Resources for Enhancing Alzheimer's Caregiver's Health	N = 566 Non-Hispanic White: n = 380 Non-Hispanic Black: n = 96 Hispanic: n = 90	• Potentially inappropriate medication use: Hispanic > White
Schultz et al., <sup>59</sup> 2017	Cross-sectional, electronic health records, 2006–2010	N = 304 Caucasian: n = 101 Chinese: n = 26 Filipino: n = 21 Hawaiian: n = 28 Japanese: n = 92 Korean: n = 17	• Anti-cholinergics prescribed with anti-dementia medications: Native Hawaiian or Caucasian > Asian
Poon et al., <sup>60</sup> 2010	Cross-sectional, medical chart review, 2003–2004	N = 304 Caucasian: n = 190 African American: n = 114	• Concurrent anti-hypertensive medications, use of thiazide diuretics, dihydropyridine calcium channel blockers, and clonidine: African American > Caucasian
Browning et al., <sup>61</sup> 2022	Cross-sectional, Medicare data linked to the Area Health Resources Files, 2015–2017	N = 623,400 White: n = 75.75% Black: n = 10.40% Hispanic: n = 8.63% Asian: n = 3.63% Other: n = 1.58%	• Likelihood of non-adherence to hyperlipidemia medications (statins): Black and Hispanic > White
Browning et al., <sup>62</sup> 2022	Cross-sectional, Medicare claims linked to the Master Beneficiary Summary File and Area Health Resource Files, 2013–2014 and 2016–2017	N = 381,485 White: n = 306,817 Black: n = 35,981 Hispanic: n = 22,532 Asian/Pacific Islander: n = 11,081 Other: n = 5074	• Enrolled in Medication Therapy Management programs: Hispanic, Asian > White; White > Black



**TABLE 3** Health service use (n = 11).

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Gilligan et al., <sup>63</sup> 2013	Cross-sectional, the Medicaid analytic extract file from Centers for Medicare and Medicaid Services, 2004	N = 158,974 <b>California</b> (N = 53,013): White: n = 25,935 Black: n = 4006 Hispanic: n = 7574 Other: n = 8503 Unknown: n = 6995 <b>Florida</b> (N = 41,292): White: n = 21,830 Black: n = 4542 Hispanic: n = 10,526 Other: n = 182 Unknown: n = 4212 <b>New Jersey</b> (N = 20,910): White: n = 13,458 Black: n = 2930 Hispanic: n = 1457 Other: n = 167 Unknown: n = 2898 <b>New York</b> (N = 43,759): White: n = 27,306 Black: n = 4702 Hispanic: n = 1926 Other: n = 1797 Unknown: n = 8028	<ul style="list-style-type: none"> <li>Costs (inpatient care and long-term care): Black &gt; White, Hispanic, Other; White, Hispanic &gt; Other</li> </ul>
Hermosura et al., <sup>64</sup> 2020	Cross-sectional, Agency for Healthcare Research and Quality, Health Care Cost and Utilization Project, Hawaii State Inpatient Databases, 2010–2014	N = 10,645 Non-Hispanic White: n = 6926 Native Hawaiians and other Pacific Islanders (NHOPi): n = 3719	<ul style="list-style-type: none"> <li>Hospital length of stay: Non-Hispanic White &gt; NHOPi</li> <li>Readmitted within the same month or the month after: NHOPi &gt; Non-Hispanic White</li> </ul>
Ornstein et al., <sup>65</sup> 2018	Longitudinal, Washington Heights-Inwood Columbia Aging Project linked to Medicare claims, 1999–2010	Total N = 4604 Full sample at dementia diagnosis: N = 186 Non-Hispanic White: n = 37 Non-Hispanic Black: n = 47 Hispanic: n = 102 Decedent sample with dementia: N = 86 Non-Hispanic White: n = 26 Non-Hispanic Black: n = 23 Hispanic: n = 37	<ul style="list-style-type: none"> <li>Hospital admissions after diagnosis: Non-Hispanic Black &gt; Non-Hispanic White</li> <li>Medicare expenditures from diagnosis to death: Non-Hispanic Black &gt; Non-Hispanic White</li> </ul>
Gorges et al., <sup>66</sup> 2019	Cross-sectional, National Medicaid Analytic eXtract linked with Medicare claims, Master Beneficiary Summary Files for demographics and Medicare Provider Analysis and Review for hospitalizations, 2012	Total N = 1,659,645 elderly, dual-eligible long-term care users N with dementia = 51.7% Of total sample of elderly, dual-eligible long-term care users: Non-Hispanic White: n = 57.3% Non-Hispanic Black: n = 19% Hispanic: n = 14.8% Asian: n = 9%	<ul style="list-style-type: none"> <li>Hospital admission (including avoidable hospitalization): Non-Hispanic Black &gt; Other Races (Non-Hispanic White, Hispanic, Asian)</li> <li>Home- and community-based long-term care services (HCBS) expenditures: Non-Hispanic White &gt; Other Races</li> <li>Hospital expenditures: Non-Hispanic Black, Hispanic &gt; Non-Hispanic White</li> <li>Total expenditures: Non-Hispanic White &gt; Other races</li> </ul>

(Continues)

**TABLE 3** (Continued)

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Husaini et al., <sup>67</sup> 2003	Longitudinal, Tennessee Medicare claims, 1991–1993	Total N = 33,688 N with dementia = 1366 White: n = 1186 African American: n = 180	<ul style="list-style-type: none"> <li>Hospitalization length: African American &gt; White</li> <li>Health service use (use of inpatient and emergency services), healthcare costs: African American &gt; White</li> </ul>
Husaini et al., <sup>68</sup> 2015	Cross-sectional, Tennessee Hospital Discharged database, 2008	Total N = 154,945 N with dementia = 5,556 White: n = 4847 Black: n = 709	<ul style="list-style-type: none"> <li>Readmissions and hospital stay: Black &gt; White</li> <li>Costs of hospital care: Black &gt; White</li> </ul>
Chen et al., <sup>69</sup> 2021	Cross-sectional, Healthcare Cost & Utilization Project with American Hospital Association Annual Survey, 2015	N = 14,135 White: n = 10,733 African American: n = 1651 Latinx: n = 1751	<ul style="list-style-type: none"> <li>Potentially preventable hospitalization (PPH) for a chronic condition: African American, Latinx &gt; White</li> </ul>
Pereira et al., <sup>70</sup> 2022	Cross-sectional, data collected using the Care Ecosystem Program, 2019–2020	N = 133 dyads White: n = 87 Black: n = 46	<ul style="list-style-type: none"> <li>Emergency department and ambulance use: Black &gt; White</li> <li>Non-emergency hospitalization: White &gt; Black</li> </ul>
Miller et al., <sup>71</sup> 2010	Longitudinal, Clinical Antipsychotic Trial of Intervention Effectiveness—AD at baseline and 3, 6, and 9 months	N = 421 Non-Hispanic White: n = 79% Black: n = 18%* Other: n = 3%*	<ul style="list-style-type: none"> <li>Outpatient costs: Non-Hispanic White &gt; Other races</li> </ul>
Miller et al., <sup>72</sup> 2009	Longitudinal, Clinical Antipsychotic Trial of Intervention Effectiveness—AD at baseline and 3, 6, and 9 months	N = 421 Non-Hispanic White: n = 79% Black: n = 18%* Other: n = 3%* *pull information from another article ("Effectiveness of Atypical Antipsychotic Drugs in Patients with Alzheimer's Disease" by Schneider et al.)	<ul style="list-style-type: none"> <li>Health utilities (health service, outpatient services, AD-related services): Non-Hispanic White &gt; Other races</li> </ul>
Park et al., <sup>73</sup> 2020	Cross-sectional, Medical Expenditure Panel Survey, 1996–2017	N without cognitive deficit = 57,057 N with cognitive deficits without AD/ADRD = 10,088 N with AD/ADRD = 3,420 White: n = 2028 Black: n = 693 Asian: n = 120 Latino: n = 579	<ul style="list-style-type: none"> <li>Out of pocket expenditures: White &gt; Black, Asian, Latino</li> <li>Prescription drug expenditures: White &gt; Black</li> <li>Outpatient expenditures: White &gt; Asian</li> <li>Emergency room expenditures: White &gt; Asian</li> </ul>

Abbreviations: AD, Alzheimer's disease; ADRD, Alzheimer's disease and related dementias.

the adapted model, which we refer to as the dementia healthcare trajectory.

### 3.3.1 | Diagnosis

The healthcare trajectory begins when awareness of signs and symptoms of AD/ADRD, including cognitive changes and associated func-

tional decline, trigger care seeking on the part of the PLWD and family members and/or are observed by healthcare providers. Diagnosis is a critical aspect of healthcare during this early stage. Eleven studies examined diagnosis, including accuracy, timeliness, quality of care, and initial referral (see Table 1). All 11 studies reported one or more statistically significant differences, primarily in the direction of NHW receiving more optimal care and with several studies reporting differences among minoritized populations. Six studies examined

**TABLE 4** Long-term care (n = 4).

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Rivera-Hernandez et al., <sup>56</sup> 2022	Cross-sectional, Residential History File, Medicare Beneficiary Summary File, Minimum Data Set, Certification and Survey Provider Enhanced Reports and the Long-term Care: Facts on Care in the US, 2007	N = 1,005,781 White: n = 78% Black: n = 13% Hispanic: n = 6% Asian/Pacific Islander: n = 2% American Indian/Alaska Native: n = 0.4%	<ul style="list-style-type: none"> <li>Nursing homes with an Alzheimer's unit: White &gt; Minority groups</li> <li>Nursing homes with high readmission rates: Black, Hispanic &gt; White</li> <li>Nursing homes with high-quality ratings: White &gt; Black, Hispanic</li> </ul>
Rivera-Hernandez et al., <sup>74</sup> 2019	Cross-sectional, Minimum Data Set, Master Benefit Summary File, Certification and Survey Provider Enhanced Reporting system, Long-Term Care: Facts on Care in the US and Nursing Home Compare Five-Star Ratings databases, 2014	Total N = 1,302,099 N with AD/ADRD = 268,181 White: n = 85.1% African American: n = 10.3% Hispanic: n = 4.6%	<ul style="list-style-type: none"> <li>Admitted to LTC facilities with AD special care units: White &gt; African American or Hispanic</li> <li>30-day rehospitalization rate for LTC facility: African American and Hispanic &gt; White</li> <li>Resided in for-profit LTC facilities: African American or Hispanic &gt; White</li> </ul>
Sengupta et al., <sup>75</sup> 2012	Cross-sectional, National Nursing Home Survey, 2004	N = 6332 White: n = 5624 Non-White: n = 708	<ul style="list-style-type: none"> <li>Received specialty care in LTC: White &gt; Non-White</li> <li>Lived in LTC facilities equipped to provide specialty care: White &gt; Non-White</li> </ul>
Resnick et al., <sup>76</sup> 2022	Longitudinal, Evidence Integration Triangle for Behavioral and Psychological Symptoms of Dementia Implementation Study	N = 553 White: n = 76% Black: n = 24%	<ul style="list-style-type: none"> <li>Inclusion of person-centered care approaches in care plans: Black &gt; White</li> <li>Hospitalizations: White &gt; Black</li> <li>Quality-of-care interactions: White &gt; Black</li> </ul>

Abbreviations: AD, Alzheimer's disease; ADRD, Alzheimer's disease and related dementias; LTC, long-term care.

timeliness and accuracy of diagnosis and all found evidence of disparities (i.e., higher rates of misdiagnosis and/or delayed diagnosis) in minoritized populations compared to NHW.<sup>27-32</sup> The study by Lin et al.,<sup>31</sup> for example, estimated that the delay in time to diagnosis was 11% longer for Black Americans and 40% longer for Hispanic Americans compared to NHW. Five studies examined other aspects of diagnostic assessment and post-diagnostic care, with most finding evidence of less optimal care for one or more minoritized populations compared to NHW.<sup>30,33-36</sup> For example, one study found that Hispanic and Asian American older adults were less likely to have a return visit within a year to a dementia specialist and more likely to lack follow-up compared to NHW and Black American patients,<sup>34</sup> while another study found that NHW patients were more likely to be referred for neuropsychological testing compared to Black and Hispanic American patients.<sup>33</sup> Asian American older adults were less likely to receive recommended diagnostic work-up for cognitive impairment compared to NHW older adults.<sup>30</sup> NHW patients who were < 80 years old were more likely to refuse a work-up for dementia compared to Black American patients.<sup>36</sup> A study conducted at state-funded AD diagnostic centers in California found that compared to NHW, Asian Ameri-

can older adults were less likely to seek a second opinion or receive referrals from a physician or community support groups for dementia diagnosis. In that same study, Asian Americans were less likely to receive referrals for home health services yet more likely to be referred for financial help, case management, day centers, and state-funded caregiver resource centers.<sup>35</sup> Finally, one qualitative study found evidence of racial/ethnic differences in patterns of help seeking leading to diagnosis.<sup>37</sup>

### 3.3.2 | Anti-dementia, psychotropic, and other medication use

After diagnosis, ongoing treatment and support of the PLWD and family caregivers becomes a major focus of healthcare. Early in the clinical treatment process, this may include prescription of anti-dementia medications as well as the use of psychotropic medication for more severe behavioral changes. Out of 27 studies, 26 reported racial/ethnic differences in medication use among PLWD, including anti-dementia medications, psychotropics, as well as medications for other medical

**TABLE 5** End-of-life care (n = 16).

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Braun et al., <sup>77</sup> 2005	Longitudinal, three national Veterans Affairs databases: patient treatment file, outpatient clinic, file and the Beneficiary Identification Record Locator Subsystem, 1990–2001	N = 413,627 White: n = 316,893 African American: n = 76,181 Hispanic: n = 14,007 Other: n = 2844 Unknown/missing: n = 3702	<ul style="list-style-type: none"> <li>• Percutaneous endoscopic gastrostomy (PEG) tube placement: African American &gt; White</li> </ul>
Owen et al., <sup>78</sup> 2001	Cross-sectional	N = 63 White caregivers: n = 47 African American caregivers: n = 16	<ul style="list-style-type: none"> <li>• Made life-sustaining treatment decisions prior to relative's death: White &gt; African American</li> </ul>
Meier et al., <sup>79</sup> 2001	Longitudinal	N = 99 Black: n = 39 White: n = 36 Hispanic: n = 22 Asian: n = 2	<ul style="list-style-type: none"> <li>• Received new feeding tube (FT) during hospitalization: African American &gt; White</li> </ul>
Mitchell et al., <sup>80</sup> 2016	Longitudinal, Minimum Data Set, 2000–2015	N = 71,251 White: n = 85.6% Black: n = 9.5%	<ul style="list-style-type: none"> <li>• Likelihood of receiving FT: Black &gt; White</li> </ul>
Sharma et al., <sup>81</sup> 2020	Longitudinal, Medicare Beneficiary Enrollment File, Minimum Data Set, and Medicare Claims, 2001–2014	N = 289,017 2001–2002 White: n = 38,450 Black: n = 10,712 2005–2006 White: n = 36,374 Black: n = 10,466 2009–2010 White: n = 23,696 Black: n = 6722 2013–2014 White: n = 20,277 Black: n = 6394	<ul style="list-style-type: none"> <li>• Likelihood of receiving FT while hospitalized: Black &gt; White</li> <li>• Multiple hospital stays: Black &gt; White</li> <li>• Admitted to the intensive care unit (ICU) during their hospitalization: Black &gt; White</li> </ul>
Shepard et al., <sup>82</sup> 2021	Longitudinal, Texas Medicare beneficiaries from Medicare claims and Long-term Care Minimum Data Set, 2011–2016	N = 20,582 Only reported for 2016: Non-Hispanic White: w/ FT, n = 186 w/o FT, n = 2709 Non-Hispanic Black: w/FT, n = 138 w/o FT, n = 408 Hispanic: w/ FT, n = 210 w/o FT, n = 769 Other: w/ FT, n = 42 w/o FT, n = 113	<ul style="list-style-type: none"> <li>• Likelihood of receiving FT in nursing home: Non-Hispanic Black and Hispanic &gt; Non-Hispanic White</li> </ul>
Henao et al., <sup>83</sup> 2022	Cross-sectional, Epic data from Novant Health, 2015–2018	N = 21,939 Black: n = 4138 White: n = 17,801	<ul style="list-style-type: none"> <li>• Likelihood of PEG tube insertion when hospitalized: Black &gt; White</li> </ul>

(Continues)

TABLE 5 (Continued)

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Kim et al., <sup>84</sup> 2021	Cross-sectional, National Hospital Discharge Survey, 2006–2010	Parkinson's disease and related disorders (PDRD): N = 2,862,778 White: n = 72% Black: n = 4.4% Asian: n = 0.9% Other minority group: n = 1.4% Not stated: n = 21.3% Non-Parkinsonian dementia (NPD): N = 4,135,180 White: n = 67.2% Black: n = 9.5% Asian: n = 0.6% Other minority group: n = 1.6% Not stated: n = 21.1%	<ul style="list-style-type: none"> <li>In the NPD, likelihood of receiving gastrostomy tube placement: Black &gt; White; White &gt; Asian</li> </ul>
Luth et al., <sup>85</sup> 2022	Cross-sectional, administrative claims data for Medicare fee-for-service, 2016–2018	Total N = 463,590 N with dementia = 234,737: Non-Hispanic White: n = 197,539 Non-Hispanic Black: n = 19,874 Hispanic: n = 10,258 Asian/Pacific Islander: n = 4361 Other: n = 2705	<ul style="list-style-type: none"> <li>Receive intensive end-of-life (EOL) care (resuscitation, mechanical ventilation, intubation, feeding tube insertion, or new dialysis): Racial/ethnic minoritized groups &gt; Non-Hispanic White</li> </ul>
Jia et al., <sup>86</sup> 2022	Longitudinal, Medicare fee-for-service, 2000–2017	Medicare fee-for-service decedents with dementia: N = 2,170,759 No IMV: White: n = 13.3% Asian: n = 11.8% IMV: White: n = 4.0% Asian: n = 4.4% Medicare Advantage decedents with dementia: N = 282,037 No IMV: White: n = 18.5% Asian: n = 18.9% IMV: White: n = 5.2% Asian: n = 5.7%	<ul style="list-style-type: none"> <li>Hospice enrollment: White &gt; Asian</li> <li>Receiving invasive mechanical ventilation (IMV) when hospitalized at the EOL: Asian &gt; White</li> <li>ICU admission: Asian &gt; White</li> </ul>
Austin et al., <sup>87</sup> 2019	Cross-sectional, National Sample of White and Black fee-for-service Medicare patients, 2013–2015	N = 389,922 Black: n = 61,708 White: n = 328,214	<ul style="list-style-type: none"> <li>Likelihood of ICU admission last 6 months of life, ventilator use: Black &gt; White</li> <li>Hospice care use: White &gt; Black</li> </ul>
Temkin-Greener et al., <sup>88</sup> 2021	Cross-sectional, Minimum Data Set, Medicare Beneficiary Summary Files, Medicare Provider Analysis and Review, Nursing Home Compare, 2014–2017	N = 665,033 White: n = 598,502 Black: n = 66,531	<ul style="list-style-type: none"> <li>Risk of EOL hospitalizations: Black &gt; White</li> </ul>

(Continues)

**TABLE 5** (Continued)

Author, Year	Study design	Total sample (N), Racial/ethnic populations	Results
Lin et al., <sup>89</sup> 2022	Cross-sectional, Health and Retirement Study Linked Medicare & Medicaid data, 2000–2016	N = 5058 Non-Hispanic Black: n = 809 Hispanic: n = 357 Non-Hispanic White: n = 3892	<ul style="list-style-type: none"> <li>Hospice use: Non-Hispanic White &gt; Non-Hispanic Black</li> <li>Inpatient expenditures at the EOL: Non-Hispanic Black, Hispanic &gt; White</li> <li>Emergency department and hospital use among hospice patients: Non-Hispanic Black, Hispanic &gt; White</li> <li>Advance care planning: White &gt; Non-Hispanic Black, Hispanic</li> </ul>
Oud, <sup>90</sup> 2017	Cross-sectional, Texas Inpatient Public Use Data File, 2001–2010	N = 889,008 White: n = 590,806 Hispanic: n = 141,202 Black: n = 107,746 Other: n = 47,502 Missing: n = 2035	<ul style="list-style-type: none"> <li>Hospice use: White &gt; Non-White race</li> </ul>
Luth et al., <sup>91</sup> 2020	Cross-sectional, Electronic Health Records from large not-for-profit hospice agency in New York City, 2013–2017	N = 2629 African American: n = 16% Hispanic: n = 20% Other race/ethnicity: n = 9% Non-Hispanic White: n = 55%	<ul style="list-style-type: none"> <li>Likelihood of live discharge from hospice: African American and Hispanic &gt; Non-Hispanic White</li> </ul>
Luth et al., <sup>92</sup> 2018	Cross-sectional, National Health and Aging Trends Survey, 2011–2016	N = 1588 Non-Hispanic White: n = 72% Non-Hispanic Black: n = 23% Hispanic: n = 5%	<ul style="list-style-type: none"> <li>Reported poor EOL care: Non-Hispanic White &gt; Non-Hispanic Black</li> </ul>

conditions (see Table 2). Studies were conducted in a range of settings including several conducted in long-term care. Among the 15 studies examining rates of anti-dementia medication (i.e., cholinesterase inhibitors and/or memantine) use, 12 reported higher rates of prescription or receipt of these medications in NHW compared to minoritized populations<sup>33,38–48</sup> while 3 found higher rates of anti-dementia medication use in Hispanic<sup>49–51</sup> and Black<sup>51</sup> Americans compared to NHW. Higher discontinuation rates of anti-dementia medications were also reported for Hispanic and Black American older adults compared to NHW individuals.<sup>49</sup>

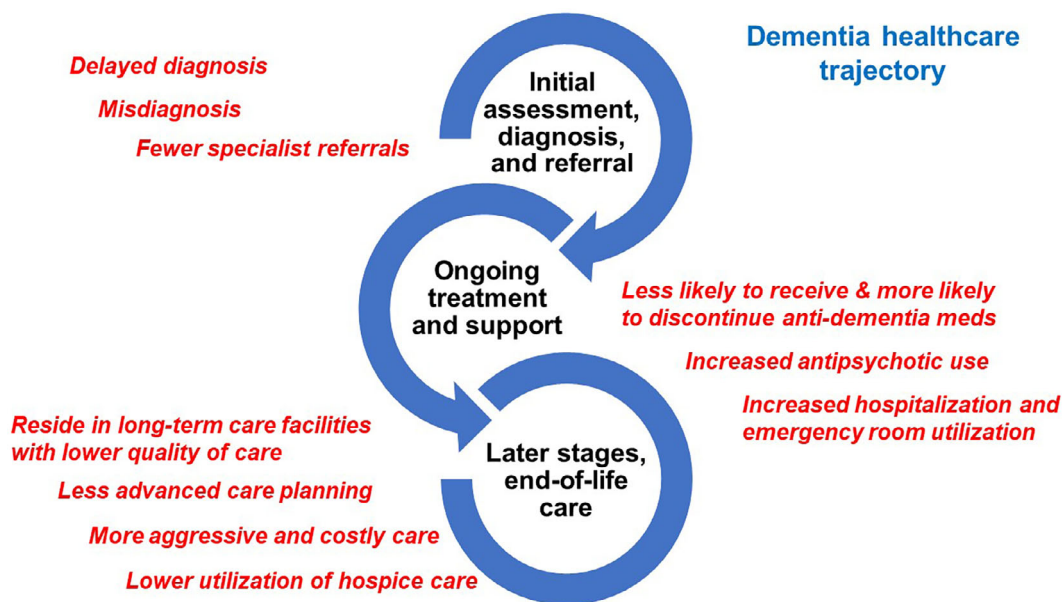
Six studies reported on use of psychotropic medications across racial/ethnic groups.<sup>52–57</sup> Three of these studies found higher use of anti-psychotic medication in Hispanic Americans compared to NHW<sup>52–54</sup> adults while one study reported higher use in NHW compared to Hispanic Americans.<sup>55</sup> One study reported lower use of anti-psychotic medication in Black Americans and AA/PI compared to NHW, Hispanic Americans, and AI/AN groups<sup>56</sup> and another study found higher use of anxiolytics in Black Americans compared to NHW individuals.<sup>55</sup> Anti-depressant use was also higher in NHW compared to other racial/ethnic groups.<sup>56</sup> Finally, one study found higher rates of

anti-psychotic medication (i.e., “low value care”) in Hispanic Americans and NHW compared to the “other race” category.<sup>57</sup>

Two studies reported on potentially inappropriate medication use—“drugs that should generally be avoided because they are ineffective or pose an unnecessarily high risk for older adults, and drugs that are appropriate to use in older persons only at certain doses, frequencies, or duration of therapies.”<sup>58</sup> One study reported higher rates of potentially inappropriate medication use in Hispanic Americans compared to NHW persons<sup>58</sup> and another found higher rates of concurrent use of medications with anti-cholinergic properties and anti-dementia medications in NHW and Native Hawaiians compared to Asian Americans.<sup>59</sup> Finally, several studies reported racial/ethnic differences in patterns of use of drugs for hypertension and other medical conditions in PLWD.<sup>46,60,61</sup> Among the studies of medication for other medical conditions, a Medicare Comprehensive Medication Review was found to reduce disparities in statin non-adherence for Hispanic American PLWD.<sup>61</sup> In a related study, Hispanic and Asian Americans were more likely to be similarly enrolled in Medication Therapy Management (MTM) programs compared to NHW, and Black Americans were less likely to be enrolled in MTM than NHW.<sup>62</sup>

**TABLE 6** Family caregiving (n = 5).

Author, year	Study design	Total sample (N), racial/ethnic populations	Results
Chow et al., <sup>35</sup> 2000	Longitudinal, Minimum Uniform Dataset from California Alzheimer's Disease Diagnostic and Treatment Centers, 1988, 1993, 1995	N = 9451 Asian: n = 4.2% Filipino: n = 0.8% Pacific Islander: n = 0.3% Caucasian: n = 75.9%	• Referrals to caregiver resource centers: Asian > Caucasian
Badana et al., <sup>93</sup> 2019	Cross-sectional, National Alliance for Caregiving and the American Association of Retired Persons' Caregiving in the U.S. survey, 2015	Total N = 887 N with dementia = 218 White: n = 173 African American: n = 45	• Service use: African American > White
Parker et al., <sup>94</sup> 2020	Cross-sectional, National Health and Aging Trends Study and National Study of Caregiving, 2015	N = 4,590,650 White: n = 75.4% Black: n = 24.6%	• Respite care use: White > Black
Sleath et al., <sup>95</sup> 2005	Cross-sectional, National Longitudinal Caregiver, 1997	N = 2032 African American: n = 316 White: n = 1716	• Anti-depressant/anti-anxiety medication use: White > African American
Parker et al., <sup>96</sup> 2019	Cross-sectional, data from two randomized controlled trials: Advancing Caregiver Training (ACT; n = 272) and Care of Persons with Dementia in Their Environments (COPE; n = 237)	N = 509 Black: n = 135 White: n = 362	• Missed physician appointments: Black > White



**FIGURE 3** Evidence of racial/ethnic disparities in Alzheimer's disease and Alzheimer's disease related dementias healthcare.

### 3.3.3 | Healthcare service use (excluding end-of-life care)

Another set of studies examined aspects of healthcare service use (i.e., inpatient, outpatient, ED) after the point of diagnosis and addressed use, costs, and quality of care (see Table 3). These 13 studies, 11 of which reported racial/ethnic differences, varied substantially, with some examining use and costs from the earliest stages of dementia to the end of life, while others had a more discrete focus. Eleven studies reported on hospitalizations, including the likelihood of admission or readmission, length of stay, and costs.<sup>63-70</sup> In all but two of these studies, Black American PLWD were found to have increased admission rates, longer lengths of stay, and higher costs.<sup>63,65-69</sup> This included two studies examining potentially preventable hospitalization,<sup>66,69</sup> with one study showing higher rates of preventable hospitalization in both Black and Hispanic Americans compared to NHW.<sup>69</sup> In the two remaining studies, NHW had higher rates of non-emergency hospitalizations compared to Black Americans;<sup>70</sup> in a study comparing NHW to Native Hawaiians and other Pacific Islanders (NHPI), the former had long inpatient lengths of stay while the latter had higher rates of readmission.<sup>64</sup> Four studies examined use and/or costs of outpatient healthcare or community-based supports, with all finding higher rates or costs for NHW compared to "other" races<sup>66,71,72</sup> or Asian Americans.<sup>73</sup> ED use was examined separately in two studies, with one finding higher ED and ambulance use in Black Americans compared to NHW<sup>70</sup> and another finding higher ED costs for NHW compared to Asian Americans.<sup>73</sup> Finally, two studies examined different aspects of total expenditures or costs without finding a clear pattern.<sup>66,73</sup> Relatively few studies reported findings separately for minoritized populations other than Black Americans, with a number of studies referring to minoritized populations in aggregate.

### 3.3.4 | Long-term care

As functional impairment and caregiving needs intensify during the middle and later stages of dementia, PLWD may transition from the community to long-term care (LTC) settings and memory care units. Four studies reported racial/ethnic differences in the characteristics of their LTC facilities (see Table 4). NHW individuals with AD/ADRD were more likely to be residents in LTC facilities with AD special care units compared to minoritized populations.<sup>56,74,75</sup> Black and Hispanic American older adults were more likely to be admitted to for-profit facilities<sup>74</sup> and facilities that scored lower on quality indicators including rates of hospital readmission.<sup>56,74</sup> However, one study examined a variety of quality-of-care indicators and found mixed results.<sup>76</sup>

### 3.3.5 | End-of-life care

In the later stages of dementia, treatment shifts toward end-of-life (EOL) and palliative care. Sixteen studies reported on EOL care for PLWD including on life-prolonging procedures, advanced directives,

hospitalizations, and hospice care (see Table 5). Ten studies examined the use of more intensive and life-sustaining procedures, such as feeding tubes and mechanical ventilation in PLWD, with all finding higher rates of use of more intensive life-sustaining procedures in Black American<sup>77-84</sup> PLWD and several studies showing similar results for other minoritized populations<sup>82,85,86</sup> compared to NHW. In terms of specific life-prolonging procedures, compared to NHW adults, Black Americans had higher rates of feeding tube placement.<sup>77,79-84</sup> One study found higher rates of feeding tube placement in Hispanic Americans compared to NHW.<sup>82</sup> Asian Americans were less likely to receive gastrostomy tube placement than NHW<sup>84</sup>; however, Asian Americans were more likely to receive invasive mechanical ventilation than NHW.<sup>86</sup> One study found that PLWD from racial/ethnic minoritized groups received more intensive EOL care (e.g., resuscitation, mechanical ventilation, intubation, feeding tube insertion, or new dialysis) than NHW.<sup>85</sup> Finally, NHW caregivers were also more likely to make life-sustaining treatment decisions prior to a relative's death than Black American caregivers.<sup>78</sup>

The remaining studies examined a variety of other aspects of EOL care. Five studies examined rates of hospitalization, including intensive care unit use, at the EOL, with higher rates reported for Black Americans,<sup>81,87-89</sup> Hispanic Americans,<sup>89</sup> and Asian Americans<sup>86</sup> compared to NHW. Consistent with these findings, inpatient hospital expenditures at the EOL were higher for Black and Hispanic Americans compared to NHW.<sup>89</sup> Four studies examined hospice care use, with all reporting higher use in NHW compared to minoritized populations.<sup>86,87,89,90</sup> Potentially burdensome and disruptive discharges ("live discharge") from hospice, on the other hand, were more common in Black and Hispanic American patients compared to NHW patients.<sup>91</sup> Proxies for Black American decedents were less likely to report poor EOL care compared to NHW.<sup>92</sup> Advanced care planning was more frequent in NHW compared to Black and Hispanic Americans.<sup>89</sup>

### 3.3.6 | Family caregiving

Family caregivers often play a very important role in helping PLWD navigate the healthcare system and communicate with formal care providers. Support of family members in their role as caregivers is an important aspect of clinical care and can include psychoeducation, referral to community programs and supports, skills for non-pharmacological management of behavioral changes, and assistance with respite care and legal issues. Five studies reported significant ethnic/racial differences in healthcare and services for the family caregivers of PLWD (see Table 6). Black American caregivers reported greater service use compared to NHW caregivers<sup>93</sup> while in another study Black American caregivers were less likely to use respite services compared to NHW caregivers.<sup>94</sup> In one study, NHW caregivers were more than twice as likely as Black American caregivers to be taking anti-depressants or anti-anxiety medications.<sup>95</sup> Another study found that Asian American caregivers were more likely to be referred for a variety of support services compared to NHW caregivers.<sup>35</sup> Finally,



Black American caregivers were more likely than NHW caregivers to miss physician appointments.<sup>96</sup>

## 4 | DISCUSSION

This scoping review of healthcare disparities for PLWD and their family caregivers provides an important update to previous reviews and demonstrates substantial, accumulated evidence for healthcare disparities in several areas, emerging evidence of disparities in several additional areas, as well as important remaining gaps in knowledge. Our scoping review found substantial evidence for healthcare disparities for PLWD in diagnosis, treatment with anti-dementia medications, hospitalization rates, and quality of care at the EOL. The evidence of disparities is strongest for Black Americans and to a lesser extent Hispanic Americans compared to NHW, with a striking lack of reported findings and gaps in evidence for AA/PI and AI/AN groups.

There was substantial evidence of disparities in the accuracy and timeliness of dementia diagnosis. Timely and accurate diagnosis of dementia is recognized as critical and central to good-quality care.<sup>13,97</sup> Delays in assessment and diagnosis in turn lead to delays in initiation or continuation of goals of care discussions, evaluating healthcare decisions, identifying healthcare surrogates, completing and registering advanced healthcare directives, and engaging in financial and estate planning. In addition to these consequences of diagnostic inaccuracy and delays, PLWD and their families may experience distress due to uncertainties regarding the nature of cognitive and behavioral changes. The evidence of delays and misdiagnosis was strongest for Black and Hispanic Americans compared to NHW and is further supported by a recently published large epidemiological study.<sup>98</sup> However, surprisingly few studies have focused on AA/PI and AI/AN groups. In addition, less is known about the underlying processes (e.g., individual level factors, structural racism) that may contribute to disparities in diagnosis as well as strategies to reduce these disparities.

There now appears to be abundant evidence that minoritized populations are less likely to use or be prescribed anti-dementia medications. While much of this evidence has focused on comparisons of Black and Hispanic Americans to NHW, there is also accumulating evidence that this pattern extends to other minoritized populations as well. Current guidelines recommend a trial of an anti-dementia medication for most types of dementia, yet an overwhelming majority of studies included in this review found that anti-dementia medication use was lower in racial/ethnic populations. Few studies shed light on underlying factors responsible for these differences, but one study found higher rates of discontinuation of these medications in minoritized populations.<sup>49</sup> This area is ripe for a deeper investigation to identify individual (i.e., PLWD, family caregivers, providers, and clinical communication) and systemic factors contributing to these prescribing patterns. Understanding the underlying factors responsible for disparities in anti-dementia medication prescribing is particularly urgent as new, disease-modifying treatments become available.<sup>99</sup>

The most striking finding in the category of service use is substantial evidence that Black American PLWD have a higher likelihood of

hospitalization as well as longer duration and costs compared to NHW and in several studies with other minoritized populations. Hospitalizations can be very difficult and distressing for PLWD because their cognitive impairment makes adjusting to the medical setting more difficult and hospitalization places them at higher risk of delirium. Much more research is needed to elucidate underlying processes resulting in more frequent and longer duration hospitalizations for Black American PLWD compared to NHW. One hypothesis is that Black Americans have less access to, or poorer quality of, outpatient services compared to their NHW counterparts, an interpretation supported by the higher rates of NHW use of outpatient services and higher costs compared to Black Americans as reported by several studies in this review. We also identified emerging evidence for additional gaps and disparities in care, including increased use of emergency services for minoritized populations, a finding that was also highlighted in our review of EOL studies.

The findings from our review highlight less optimal EOL care for minoritized populations, including more aggressive life-sustaining interventions, higher hospitalization rates, and lower use of hospice and advance directives. Our findings are broadly consistent with recent reviews of end-of-life disparities in nursing homes<sup>100</sup> and among patients with cancer<sup>101</sup> not specific to PLWD, as well as a recent large study of Medicare beneficiaries with dementia.<sup>85</sup> These reviews highlight the possible role of multiple factors, including the cultural competence of staff, socioeconomic inequality, and systemic racism, as well as individual-level preferences and values.

Our scoping review has identified important gaps in the field, the most striking of which is the lack of studies on AA/PI and AI/AN populations. Fewer than one third of studies reported findings separately for AA/PI and < 3% for AI/AN populations. An additional issue is that when studies did include minoritized populations other than Black Americans, the numbers were often relatively small and underpowered to detect meaningful differences. Perhaps in part because of low numbers, almost one third of studies used an aggregate category for minoritized populations. Finally, and related to the points above, few studies provided explicit criteria for use of racial/ethnic categories and/or were reliant on administrative datasets that are limited with respect to categorization of minoritized populations.

Our review also identified additional emerging areas and gaps. For example, there is almost no evidence on access to non-pharmacological interventions for behavioral symptoms, and family caregiver supports. In addition, relatively few studies were designed with an explicit focus on racial/ethnic disparities in healthcare and may have important methodological limitations (e.g., underpowered for certain racial/ethnic populations). Finally, very few studies have looked further to examine the underlying processes (e.g., patient/family caregiver preferences, physician implicit bias or racism) that may account for the racial/ethnic differences identified in this scoping review.

The abundant evidence of disparities, summarized in Figure 3, has important implications for clinical care. Knowledge of existing disparities is the first step in addressing these disparities at the individual, clinical, and health systems levels, through monitoring at the local level, educating and training clinicians to reduce bias and improve

communication, enhancing the cultural and linguistic competence of clinical care, and developing targeted initiatives to empower PLWD and family caregivers as they navigate the healthcare system. This knowledge can also form the basis for policy change at the health system level to address systemic racism and promote health equity.<sup>102-104</sup>

## 5 | LIMITATIONS

One important limitation of this review is the possibility that studies, particularly those without a specific focus on racial/ethnic disparities, with null findings may have been missed because our inclusion criteria required that racial/ethnic comparisons were mentioned in the title/abstract. It should also be stressed that while this scoping review identified a range of healthcare disparities and differences, the underlying factors responsible for these differences is unclear and may be driven by a variety of factors at the individual, interpersonal, and systemic levels, including systemic racism and social determinants of health. Additional limitations are artifacts with the goals of a scoping review, including lack of assessment of the quality of studies to weigh the relative importance of study findings. Finally, it is important to emphasize that the focus of this paper was on racial/ethnic populations and did not include consideration of other disparity populations, such as PLWD who identify as LGBTQ, or geography including residing in rural versus urban or suburban areas.

Three identified gaps and recommendations for future research are:

1. *Study processes and interventions where substantial evidence exists.* We recommend that in the areas where substantial evidence of disparities exists, research accelerates by moving beyond description to an examination of underlying processes and more importantly to interventions that reduce disparities. This scoping review has identified some priority areas to accelerate research toward impactful reduction of disparities, including diagnosis, prescription of anti-dementia medications, prevention of hospitalization, and improvement in the EOL quality of care. Our scoping review may be useful in determining the strength of the evidence for specific minoritized populations. For example, our evidence in the areas above is ample for Black Americans and to some extent for Hispanic Americans but less strong for other groups. Research on understanding the mechanism of disparities is critical to advance science using appropriate frameworks, such as the National Institute on Aging Health Disparities Research Framework<sup>105</sup> as well as other frameworks and approaches that specifically address factors that drive healthcare disparities.<sup>106-109</sup> In particular, there is a need to examine the role of social determinants of health as drivers of racial and ethnic disparities in healthcare.<sup>110</sup> Finally, there is also an urgent need for studies that examine the impact of policies and interventions on disparities reduction.
2. *Include a wider range of minoritized populations in sufficient numbers.* Many studies included in this review limited their

analyses to a comparison of NHW to “other” populations or to Black Americans or Hispanic Americans. Future studies should strive to include a broader range of minoritized populations, particularly AA/PI and AI/AN groups. In our review, many of the studies that included results identified differences between minoritized populations, highlighting the importance of including diverse populations in sufficient numbers for meaningful analysis and avoiding, where possible, the practice of aggregating minoritized populations. Aggregating groups masks importance differences among minoritized populations.

3. *Advance research in promising and understudied areas.* Our understanding of healthcare disparities for minoritized populations is, in many respects, at a very early stage, with many areas of clinical and public health importance receiving little or no attention. As an example, there is wide recognition that non-pharmacological management of dementia-related behavioral problems is often the preferred method of treatment. However, none of the studies we identified examined access to these approaches, either through delivery in healthcare settings or referral to community resources. Surprisingly, there were also relatively few studies that examined the use of psychotropics or inappropriate medications in PLWD, an area of significant public health importance given the increased risk of mortality associated with anti-psychotics. We found early evidence suggesting disparities in the use of potentially inappropriate medications in the PLWD, another area of high public health importance. There should be efforts to engage minoritized PLWD and their caregivers who have lived experiences of dealing with healthcare systems and important insights to inform the research agenda. Examination of the role of place is another important area for research to identify community/neighborhood factors that drive inequities in access and quality of care.<sup>111</sup> Additional studies of the impact of changes in healthcare policies and models of payment impact healthcare quality and access for PLWD are needed, including programs such as Medicare Advantage, Medicaid Home and Community-Based Services, and Care Coordination.

## 6 | CONCLUSIONS

Given the strength of accumulated evidence, there is an urgent need to address disparities in healthcare for minoritized populations. Minoritized populations such as Black Americans face a “double disparity” in AD/ADRD, with both a higher burden of clinical disease compared to NHW and a lower quality of healthcare for those who live with dementia. This brings the equity issues that must be addressed into sharp focus. We need to design studies that simultaneously examine interventions, disparities reduction, and mechanisms to accelerate the pace and progress of research. Researchers need to design studies that incorporate equity consideration from the start, with particular attention to inclusion of diverse populations. Disparities research focused

on a disease or health condition moves through different phases, beginning with the demonstration of differences, then understanding underlying mechanisms to explain differences, and then developing and implementing interventions to eliminate or reduce disparities in care.<sup>112</sup> While the field of healthcare disparities for PLWD and family caregivers is clearly in its early stages, this scoping review has identified areas where there is substantial converging evidence of disparities as well as gaps in research that may help the field move forward to generate a more robust body of evidence and move toward understanding the underlying processes, designing interventions that address these mechanisms, and ultimately reducing healthcare disparities in AD/ABDR assessment and treatment.

## ACKNOWLEDGMENTS

This work was supported by the National Institute on Aging (NIA) of the National Institutes of Health under Award Number U54AG063546, which funds the NIA IMbedded Pragmatic Alzheimer's Disease and AD-Related Dementias Clinical Trials Collaboratory (NIA IMPACT Collaboratory). The sponsor did not have a role in the design, methods, data collection, analysis, and preparation of the paper. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare. Author disclosures are available in the [supporting information](#).

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Hinton L, Tran D, Peak K, Meyer OL, Quiñones AR. Mapping racial and ethnic healthcare disparities for persons living with dementia: A scoping review. *Alzheimer's Dement*. 2024;20:3000–3020.  
<https://doi.org/10.1002/alz.13612>