Differences in survival and mortality in minority ethnic groups with dementia: A systematic review and meta-analysis

Melissa Co1 | Elyse Couch1 | Qian Gao1 | Andrea Martinez2 | Jayati Das-Munshi3,4 | Matthew Prina1

1Department of Health Service and Population Research, Institute of Psychiatry, Psychology & Neuroscience, King’s College London, London, UK
2Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King’s College London, London, UK
3Department of Psychological Medicine, Institute of Psychiatry, Psychology & Neuroscience, King’s College London, London, UK
4South London and Maudsley NHS Trust, London, UK

Correspondence
Melissa Co, Department of Health Service and Population Research, Institute of Psychiatry, Psychology & Neuroscience, King’s College London, David Goldberg Centre, De Crespigny Park, London SE5 8AF, UK.
Email: melissa.co@kcl.ac.uk

Funding Information
Economic and Social Research Council

Abstract
Objectives: Although there are disparities in both risk of developing dementia and accessibility of dementia services for certain minority ethnic groups in the United States and United Kingdom, disparities in survival after a dementia diagnosis are less well-studied. Our objective was to systematically review the literature to investigate racial/ethnic differences in survival and mortality in dementia.

Methods: We searched Embase, Ovid MEDLINE, Global Health and PsycINFO from inception to November 2018 for studies comparing survival or mortality over time in at least two race/ethnicity groups. Studies from any country were included but analysed separately. We used narrative synthesis and random-effects meta-analysis to synthesise findings. The Newcastle–Ottawa Scale was used to assess quality and risk of bias in individual studies.

Results: We identified 22 articles, most from the United States (n = 17), as well as the United Kingdom (n = 3) and the Netherlands (n = 1). In a meta-analysis of US studies, hazard of mortality was lower in Black/African American groups (Pooled Hazard Ratio = 0.86, 95% CI = 0.82–0.91, I² = 17%, from four studies) and Hispanic/Latino groups (Pooled HR = 0.65, 95% CI = 0.50–0.84, I² = 86%, from four studies) versus comparison groups. However, study quality was mixed, and in particular, quality of reporting of race/ethnicity was inconsistent.

Conclusion: Literature indicates that Black/African American and Hispanic/Latino groups may experience lower mortality in dementia versus comparison groups in the United States, but further research, using clearer and more consistent reporting of race/ethnicity, is necessary to understand what drives these patterns and their implications for policy and practice.

Keywords
dementia, ethnicity, meta-analysis, mortality, race, survival, systematic review
1 | INTRODUCTION

Dementia is an increasingly important challenge in public health across the globe: in 2017, dementia was the leading cause of death in the United Kingdom, causing 12.7% of deaths, and the sixth-leading cause of death in the United States.\(^1\,^2\) However, dementia does not affect all populations the same way. Risk of dementia incidence is thought to be higher in some minority ethnic (ME) groups in both the United States and United Kingdom. In the United States, studies have found higher risk of dementia in some African American and Hispanic/Latino groups.\(^3\,^5\) Black and South Asian populations in the United Kingdom are also thought to have higher risk for dementia than the White British population due to higher rates of vascular risk factors.\(^6\,^7\) ME groups in both countries are also thought to access care for dementia later in the disease course and at lower rates due to barriers imposed by structural and institutional racism, negative experiences with healthcare systems, discrimination, language barriers and stigma.\(^8\,^9\,^10\)

Despite evidence of disparities in risk of dementia and access to care, it is unclear how this affects the course of dementia, including survival patterns. A 2013 systematic review on predictors of mortality in dementia only identified five studies examining race/ethnicity, and only one found differences: lower mortality in African American and Latino individuals with Alzheimer’s disease (AD) versus comparison groups.\(^11,^12\) Since then, additional US studies have reported reduced mortality risk in ME groups as compared to non-Hispanic White groups using health record data.\(^13\) Total deaths attributed to dementia were also higher among the non-Hispanic White population in 2017: 70.8 per 100,000 as compared to 65.0 in the non-Hispanic Black population and 46.0 in the Hispanic population.\(^2\) Although there are fewer studies outside the United States, some studies from the United Kingdom indicate that Asian, Mixed, and White Other ME groups may survive longer after dementia diagnosis than White British groups.\(^14,^15\)

One difficulty in carrying out this research is that there is not a consensus on the language used to describe race and ethnicity; the two are often used interchangeably despite having different meanings.\(^16,^17\) While both terms are socially constructed, ‘race’ has historically implied that there are visible physical or biological differences among people, whereas ‘ethnicity’ tends to refer to social groups and include more fluid, self-defined and cultural in-group characteristics.\(^16\,^18\) Here, we use the hybrid ‘race/ethnicity’ or substitute ‘ethnicity’ alone. Ethnicity is self-ascribed, which may not match what researchers or outside observers report based on visible characteristics.\(^16\) However, studies do not always ask participants themselves what ethnicity they identify with. Ethnicity is also context dependent,\(^16\) and while health disparities due to structural racism are an issue globally,\(^19,^20\) race/ethnicity groups are not comparable across countries. Thus, countries are analysed separately in this review (Further details on the interpretation and use of race and ethnicity terminology may be found in Text S1).

Nevertheless, it is important to explore inequalities between ethnic groups in order to set priorities for policy and plan equitable health services. To date, there has been no systematic review comparing mortality rates across different racial/ethnic groups with dementia. The objective of this study is to determine whether there are racial/ethnic differences in mortality in dementia in the literature.

2 | METHODS

2.1 | Protocol and registration

The study protocol was registered in PROSPERO (CRD42018118129) (Appendix B). While this review focuses on mortality, it is part of a larger project investigating racial/ethnic disparities in both mortality and access to services in dementia. Thus, it shares a search strategy with another review exploring use of healthcare services in ME groups (PROSPERO CRD42018118132).\(^21\) Screening for both was done concurrently.

2.2 | Inclusion and exclusion criteria

The following inclusion criteria were applied: (1) must be quantitative observational studies; (2) must compare survival or mortality across multiple race/ethnicity groups, even if not the primary study aim; (3) population followed longitudinally; (4) participants have any type of dementia or mild cognitive impairment; (5) studies including participants without dementia must provide an estimate for survival by...
ethnicity in the dementia-only group. Studies were excluded if: (1) the study population was defined by another unrelated disease or treatment; or (2) the outcome was specific-cause mortality rather than all-cause mortality. Cohort studies following individuals from diagnosis or first presentation to health services until death and reporting hazard ratios were further eligible for meta-analysis.

2.3 | Search

The search was conducted in Ovid on 7 November 2018 and included peer-reviewed articles from Embase, Ovid MEDLINE, Global Health and PsycINFO from inception until the search date. The shared search strategy followed this structure, including subject headings and synonyms of each term: (dementia OR Alzheimer’s disease) AND (ethnicity OR race) AND (mortality OR survival OR service use). A full list of search terms is in Appendix C and PROSPERO.

2.4 | Study selection

Titles and abstracts of articles were double-screened by four authors (MC, EC, QG, AM) using Rayyan, an online application for managing systematic reviews.22 One author (MC) screened all records and three screened 50% of the records. Any disagreements at this stage led to the paper being included in full-text screening. Full texts of articles were then independently reviewed for eligibility by two authors (MC and EC). Disagreements were discussed between the two authors, and further discussed with a third reviewer (MP), if a decision could not be reached. If more information was required, the corresponding author of the article was contacted.

2.5 | Data extraction

MC extracted data on all studies using a template in Excel. Fields extracted included study characteristics such as: country, study population, setting, type of dementia, years study completed, sample size, ethnicity groups included (maintaining terminology used by study authors), mean age at baseline, percent of female participants and main study objective. Data on study results were also extracted: outcome definition, type of analysis, follow-up time, crude and adjusted statistics, 95% confidence intervals (CIs), and other covariates studied.

2.6 | Risk of bias

The Newcastle–Ottawa Scale (NOS) was used to assess risk of bias in individual studies.23 Two additional questions were included: (1) whether ethnicity was the main study focus (yes/no/exploratory) and (2) whether ethnicity was discussed explicitly in the study results (yes/no). For studies using health record data, it was assumed that there was little loss-to-follow-up. Because ethnicity is best defined through self-identification,15 studies were awarded a star for ‘ascertainment of exposure’ if ethnicity was self-reported.

2.7 | Data synthesis

Results from included studies were tabulated. If no statistics were presented for ethnic differences in survival, we calculated these using data available in the article.

A meta-analysis combining studies which reported hazard ratios of mortality from diagnosis, onset, or first presentation to services was performed in R version 3.6.0 using ‘meta’, ‘metafor’ and ‘robumeta’ packages.24–26 Due to expected heterogeneity (from factors such as study locations with different racial/ethnic makeup), we used a random-effects meta-analysis with inverse variance weighting. When studies provided estimates from multiple models, the most-adjusted estimate was used. Because definitions and experiences of ME groups vary by country, we did not combine studies from different countries. Ethnicity was analysed as a subgroup, and we preserved the original ME groupings from the primary papers. See Text S1 for further information on treatment of race/ethnicity variables.

Studies often used the same comparison group to calculate hazard ratios for multiple ME groups, but a naïve meta-analysis assumes independence between each estimate. To account for this dependence, we used robust variance estimation (RVE).27 Correlated effects weights were used, as well as Tipton’s small sample correction because there were few studies.28 Rho was set at 0.80. Both naïve and RVE estimates are reported. Further statistical subgroup analyses were not completed due to the small number of studies. As there were fewer than 10 studies in the meta-analysis, risk of publication bias was not quantified or shown as a funnel plot.29

3 | RESULTS

The combined search strategy retrieved 8977 records after auto-deduplication in Ovid and Endnote. After title-and-abstract screening, 8897 records were removed. Full texts of 80 articles were assessed for inclusion. Three additional articles were identified and included in full-text screening; two from known papers in background literature15,30 and a full journal article for a conference abstract found in the search.31,32

Twenty-two articles from 19 studies fulfilled the eligibility criteria. There was 90% agreement between the two reviewers (Cohen’s kappa = 0.78). Most articles excluded were conference abstracts. Many articles were excluded because they did not compare different ethnic groups or included participants without dementia. Four studies were considered potentially eligible because ethnicity was mentioned in their analyses but were ultimately excluded because no statistics were reported or could be calculated, and authors did not respond to requests for data.33–36 We were also unable to obtain exact statistics for two included studies, although both reported non-significant results for difference in mortality by ethnicity group.37,38 The PRISMA flow diagram in Figure 1 includes more details on the selection process.
3.1 | Study characteristics

All but four studies were from the United States (n = 14, from 17 articles), with one from the Netherlands and three from the United Kingdom. Four articles used data from the Washington Heights Inwood Columbia Ageing Project, but their outcomes were too different to combine. 39–42

Ethnicity groups studied in the United States included: White (all studies), African American/Black (n = 13 articles/10 studies), Hispanic/Latino (n = 10/7), Non-white (n = 4/4), Asian (n = 2/2) and Indigenous (n = 4/4). Studies did not always report whether ethnicity groups labelled as ‘White’ or ‘Black’ also included people identifying as Hispanic/Latino. In the study from the Netherlands, the authors defined ethnicity by country of birth and included Dutch, Indonesian, Turkish, Surinamese and Antillean groups. One study from the United Kingdom followed Office of National Statistics ethnicity categories, while two others used different terminology or aggregated categories.

On average, articles included 63.9% female participants (range: 44.9%–81.8%) and 32.8% minority racial/ethnic participants (range: 3.3%–92%). The average baseline age in each study (where reported) ranged from 71.5–87 years old. Twelve articles included only participants with probable/possible AD, while the rest defined dementia more broadly or included multiple dementia subtypes (n = 10). Further details on characteristics of studies can be found in Table 1.

3.2 | Risk of bias in individual studies

Study quality was mixed (one to nine total stars), as quality was assessed according to the analysis of racial/ethnic differences and
| Study                                      | Ethnicties compared (authors’ terminology) | Type of dementia studied | Population and setting                                                                 | Years of study follow-up | Total n size | % ethnic/racial minority | % female | Baseline mean age |
|-------------------------------------------|-------------------------------------------|--------------------------|----------------------------------------------------------------------------------------|--------------------------|--------------|------------------------|----------|------------------|
| Netherlands                               |                                            |                          | Patients with first hospitalisation or first day clinic attendance for dementia from data linkage of Dutch national registers. | 2000–2010                | 55,827       | Indonesian: 2.4% Surinamese: 0.56% Turkish: 0.18% Antillean: 0.12% | 61.0%    | 81.45            |
| Agyemang et al. (2017)                    | Dutch, Indonesian, Turkish, Surinamese, Antillean Dementia (generic) |                          |                                                                                        |                          |              |                        |          |                  |
| United Kingdom                            |                                            |                          | University Hospital Birmingham NHS Trust patients with AD between 2000 and 2007        | 2000–2007                | 634          | South Asian: 0.79% Afro-Caribbean: 1.6% Other/unknown: 4.9% | 65.1%    | 85.1             |
| Heun et al. (2013)                        | Caucasian, South Asian, Afro-Caribbean, Other/unknown AD |                          |                                                                                        |                          |              |                        |          |                  |
| Lewis et al. (2018)                       | White British, White other, Asian, Black, Mixed and other Dementia (generic) |                          | Patients with an ICD-10 diagnosis of dementia and accessing secondary mental health services from the Camden and Islington National Health Service (NHS) Foundation Trust in London | 2008–2016                | 3374         | White other: 25% Asian: 5% Black: 10% Mixed and other: 5% | 61.0%    | 78.37            |
| Mueller et al. (2017)                     | White, non-White AD and mild dementia     |                          | Patients with a diagnosis of AD and at least 18/30 MMSE at diagnosis accessing secondary mental health services in the South London and Maudsley NHS Foundation Trust | 2006–2016                | 5473         | Non-White: 21.2%       | 64.0%    | 81.03            |
| United States                             |                                            |                          | Relatives of people with dementia in San Francisco Bay Area and greater Los Angeles who were listed as having contacted their local Alzheimer’s Disease and Related Disorders Associations. (Caregivers were interviewed about their relative with dementia) | 1988–1993                | 555          | Non-White: 16.0%       | 59.0%    | 77% over 70       |
| Aneeshensel et al. (2000)                 | White, Non-White Dementia (multiple subtypes) |                          |                                                                                        |                          |              |                        |          |                  |
| Black et al. (2018)                       | White, Black, Hispanic, other (Asian and Native American) AD |                          | 5% random sample of the national Medicare Administrative Database and Minimum Data Set (MDS) of people with one primary or two secondary AD diagnoses | 2010–2014                | 8995         | Black: 10% Hispanic: 4.5% Asian: 2.8% Native American: 0.5% Other: 1.3% | 74.3%    | 82.98            |
|                                           |                                            |                          |                                                                                        |                          |              |                        |          |                  |
|                                           |                                            |                          |                                                                                        |                          |              |                        |          |                  |
| Study              | Ethnicities compared (authors’ terminology) | Type of dementia studied | Population and setting                                                                 | Years of study follow-up | Total n | % ethnic/racial minority | % female | Baseline mean age |
|-------------------|--------------------------------------------|--------------------------|----------------------------------------------------------------------------------------|--------------------------|---------|-------------------------|----------|------------------|
| Gambassi et al. (1999) | White, African American, other             | AD                       | Newly admitted residents of Medicare/Medicaid certified nursing homes in Kansas, Maine, Mississippi, New York and South Dakota | 1992–1995                | 9264    | African American: 6.5%  | 48.6%    | 37.0% 85+        |
| Heyman et al. (1996)  | White, Non-White                           | Probable/possible AD     | AD patients enrolled in university medical centres which were part of CERAD between Apr 1987 and Jan 1995 | 1987–1995                | 1036    | Non-White: 19.0%       | 58.0%    | 73 (median)      |
| Kaszniak et al. (1978) | Black, White                              | Dementia (presenile and senile) | Hospital patients over 50 years old with suspected presenile or senile dementia | Not reported             | 47      | Black: 29.8%            | 46.8%    | 71.5             |
| Mayeda et al. (2017)   | Asian American, Latino, African American, American Indian/Alaska Native, White | Dementia (generic)       | Kaiser Permanente Northern California insurance plan members over 60 years of age in 1996 with incident dementia | 1996–2013                | 59,494  | Asian American: 6.5%   | 59.5%    | 83.4             |
| Mehta et al. (2008)    | African American, Latino (all races), Asian/Pacific Islander (Asian), American Indian, other, White | AD                       | National Alzheimer’s Coordinating Centre dataset of patients 65 and older with a diagnosis of possible/probable AD from 30 AD centres | 1984–2005                | 30,916  | African American: 12%  | 77.6     | 84.8             |
| Meier et al. (2001)    | Black, White, Hispanic, Asian (although Asian had too small n to analyse) | Advanced dementia        | Patients hospitalised in Mount Sinai Hospital in New York City with acute illness and advanced dementia | 1994–1997                | 99      | Black: 39.3%            | 81.8%    | 84.8             |
| Rountree et al. (2012) | White, Non-White                           | Dementia (probable AD)   | Dementia patients in the community with probable AD, evaluated at Baylor College of Medicine AD and Memory Disorders Centre | 1989–2005                | 641     | Non-White: 13%         | 68.0%    | 73               |
| Sherzai et al. (2016)  | White, African American, Hispanic           | Dementia (generic)       | Patients with dementia diagnosis from the Nationwide Inpatient Sample from 20% of US community hospitals | 1999–2008                | 7,515,975 | (Stratified by age 60–90 years/90+ years) | 63.8%    | 81.42  |
| Study                        | Ethnicities compared (authors' terminology) | Type of dementia studied | Population and setting                                                                 | Years of study follow-up | Total n size | % ethnic/racial minority | % female | Baseline mean age |
|-----------------------------|--------------------------------------------|--------------------------|----------------------------------------------------------------------------------------|--------------------------|--------------|--------------------------|----------|------------------|
| Steenland et al. (2010)     | White, Non-White (predominantly African American) | Dementia (multiple subtypes) | Patients from the research registry of Neurology Department at Emory Wesley Woods Health Centre | 1993–2004 | 2731 total; 1381 Probable/ Possible AD | African American: 9.7%/9.6% Hispanic: 6.3%/5.4% Other: 4.0%/3.9% | Not reported | 44.9% 71.61 |
| Waring et al. (2005)        | Caucasian, African American, Hispanic      | AD and non-AD dementias  | All patients diagnosed with dementia at the Baylor AD Centre (secondary service) and living in Houston area | 1989–2002 | 956 | African American: 11.3% Hispanic: 3.9% | 66.0% 71 (median at onset) 75 (median at diagnosis) 72.3 (mean at diagnosis) |

**Washington Heights Inwood Columbia Project (WHICAP)**

| Study                        | Ethnicities compared                                | Type of dementia studied | Population and setting                                                                 | Years of study follow-up | Total n size | % ethnic/racial minority | % female | Baseline mean age |
|-----------------------------|-----------------------------------------------------|--------------------------|----------------------------------------------------------------------------------------|--------------------------|--------------|--------------------------|----------|------------------|
| Cosentino et al. (2006)     | White, Black, Hispanic                               | AD                       | WHICAP- Incident AD patients either enrolled in a regional medical facility (n = 23) or from the Washington Heights and Inwood (n = 138) probability sample of Medicare beneficiaries in Northern Manhattan | 1989–2004 | 161 | Hispanic: 58% Black: 34% | Not reported | 82.73 |
| Helzner et al. (2008)       | White, African American, Hispanic, other            | AD                       | WHICAP- Medicare enrollees in the community in Northern Manhattan census tracts in with incident AD | 1992–2002 | 323 | Hispanic: 55.4% African American: 32.8% Other: 0.9% | 70.0% 87 |
| Ornstein et al. (2018)      | Non-Hispanic White, non-Hispanic Black, Hispanic    | Dementia (generic)       | WHICAP- Medicare beneficiaries 65+ in northern Manhattan                                 | 1999–2010 | 86 | Non-Hispanic Black: 25.27% Hispanic: 54.84% | 67.4% 85.58 |
| Scarmeas et al. (2011)      | Non-Hispanic Black, Hispanic, Non-Hispanic White, other | AD                       | WHICAP- Medicare beneficiaries in the community with incident AD and having physical activity assessments | 1992–2002 | 357 | Non-Hispanic Black: 31% Hispanic: 58% Other: 1% | 69.0% 78.8 |
| Weiner et al. (2003)        | Native American, White                              | Probable/ possible AD    | Native American patients from the UT Southwestern Medical Centre or its Native American outreach clinics in Oklahoma and Texas, and White patients from the UT Southwestern Medical Centre's Alzheimer's Disease Centre | 1993–2002 | 599 | Native American: 15.0% | 66.1% Age at onset: 69.87 Age at evaluation: 73.62 |
tended to be lower in studies where this was not a main objective ($n = 13$). All but two studies discussed race/ethnicity results explicitly in the article text. Across studies, cohort selection quality was moderate because most articles did not use self-report or did not describe how ethnicity was ascertained ($n = 6$ receiving stars). Twelve articles received three or four stars for cohort selection items. Fourteen articles were given two out of two stars for the comparability item. Seven articles had three (out of three) star ratings for the outcome items; studies with more stars tended to use routine/registry data linked to national death records. NOS results are reported in Table 2 and Table S1.

### 3.3 Results of individual studies

Results of individual studies may be found in Tables 3 and 4, and Table S2. Outcome definition varied considerably—time to death was measured from a variety of start points, including onset, diagnosis, admission, and clinic visit. Two studies measured in-hospital mortality only.\(^{44,51}\)

### 3.4 Synthesis of results

No studies found higher risk of mortality among ME groups in any country, with the exception of one US study which reported slightly shorter mean time from onset to death in African American groups (8.2 years, standard deviation 4.3) and American Indian groups (8.8, SD 4.1) versus White groups (9.0, SD 4.4).\(^{54}\)

In the United States, evidence from 13 articles\(^{12,13,39–42,45–47,51–54}\) suggested differences in mortality in at least one ME group versus comparison groups, while evidence from five\(^{37,38,48–50}\) did not suggest any differences between racial/ethnic groups. Five of the 13 articles which studied Black/African American older adults reported lower mortality versus comparison groups. The majority (8/10) of articles on Hispanic/Latino American groups also reported lower mortality rates versus comparison groups. Two out of four studies reported lower mortality compared to reference groups for Indigenous older adults and one out of two studies for Asian American older adults.

The study from the Netherlands did not find ethnic differences in survival at either one or three years after hospitalisation or clinic visit (after adjustment).\(^{16}\) In the United Kingdom, data from Heun et al.’s study did not indicate differences in in-hospital mortality between Caucasian and non-Caucasian groups.\(^{54}\) However, the other two studies found lower hazards of mortality after diagnosis in ME groups versus comparison groups. Mueller et al. found non-White patients had 0.61 (95% CI 0.53–0.69) hazard compared to White patients, and Lewis et al. found that Asian patients had half the hazard of mortality (0.50, 95% CI 0.34–0.73) as compared to White British patients, with White Other (0.80, 95% CI 0.69–0.94) and Mixed and other (0.63, 95% CI 0.43–0.94)
groups also having lower risk both before and after adjusting for other factors.14,15

Most studies, excluding nine (United States: n = 8, United Kingdom: n = 1), included multivariable models controlling for at least age and gender. Other common covariates included measures of cognition (such as Mini-Mental State Examination) and physical or mental health comorbidities. Only one study from the United States explored differences in survival by type of dementia, finding lower mortality in non-White versus White individuals in a group with probable AD and when analysing all dementias together, but not in individual analyses of other subtypes (including Lewy body dementia, frontotemporal dementia, mild cognitive impairment), although sample size was smaller for these subtype groups.52 Another study found similar survival between AD and all dementias in their population, but this was not broken down by ethnicity.38

### 3.5 Meta-analysis of United States studies

We meta-analysed six studies from the United States (total 101,502 participants) which reported hazard ratios from onset, first presentation to services, or diagnosis. There were too few studies to perform subgroup analyses examining differences between these starting points. All studies included in meta-analyses adjusted for at least age and sex/gender. Figure 2 shows a forest plot of these studies.

The pooled hazard ratio of mortality for all ME groups in the United States versus comparison groups (White, non-Hispanic White, etc.) was 0.79 (95% CI 0.74–0.84, I² = 85%) using a naïve random-effects meta-analysis. With RVE adjustments, including small sample correction, the pooled estimate became 0.77 (95% CI 0.48–1.24). Due to the small degrees of freedom, we adopted a smaller alpha level (α = 0.01) as suggested by Tanner-Smith et al.27 However, a sensitivity analysis comparing results with and without small sample correction found that, without including the correction, confidence intervals did not cross one. Table S2 shows these results.

### Table 2 Newcastle–Ottawa Scale assessment

| Study | Selection (out of four) | Comparability (out of two) | Outcome (out of three) | Ethnicity as the main analysis of interest (yes or no) | Ethnicity reported in results (yes or no) |
|-------|-------------------------|---------------------------|------------------------|------------------------------------------------------|------------------------------------------|
| Agyemang et al. (2017)43 | ** | ** | *** | Yes | Yes |
| Aneshensel et al. (2000)45 | | ** | | No | Yes |
| Black et al. (2018)46 | | | | No | Yes |
| Cosentino et al. (2006)41 | | ** | | No | Yes |
| Gambassi et al. (1999)47 | | ** | ** | No | Yes |
| Helzner et al. (2008)40 | | ** | *** | Yes | Yes |
| Heun et al. (2013)44 | | | *** | No | No |
| Heyman et al. (1996)48 | | ** | ** | Exploratory | Yes |
| Kasznia et al. (1978)49 | | | | No | No |
| Lewis et al. (2018)54 | | ** | *** | Secondary aim | Yes |
| Mayeda et al. (2017)13 | **** | ** | *** | Yes | Yes |
| Mehta et al. (2008)52 | **** | ** | | Yes | Yes |
| Meier et al. (2001)50 | | ** | | No | Yes |
| Mueller et al. (2017)15 | | ** | *** | No | Yes |
| Ornstein et al. (2018)62 | **** | | | Yes | Yes |
| Rountree et al. (2012)37 | ** | ** | ** | Exploratory | Yes |
| Scarmeas et al. (2011)39 | **** | ** | | No | Yes |
| Sherzai et al. (2016)51 | | ** | | Yes | Yes |
| Steenland et al. (2010)52 | ** | ** | | No | Yes |
| Waring et al. (2005)38 | *** | ** | Exploratory | Yes |
| Weiner et al. (2007)54 | *** | ** | | Yes | Yes |
| Weiner et al. (2003)53 | *** | * | | Yes | Yes |
| Study                        | Definition of mortality outcome                                      | Follow-up time  | Median/mean survival time | Model covariates | Statistics reported (95% confidence interval where given) | Summary of findings reported |
|-----------------------------|-----------------------------------------------------------------------|-----------------|---------------------------|------------------|-----------------------------------------------------------|------------------------------|
| **Netherlands**             |                                                                       |                 |                           |                  |                                                           |                              |
| Agyemang et al. (2017)      | Risk of mortality within 1 or 3 years after initial admission or visit| Median; Dutch: 24 months, Indonesian: 27 months, Surinamese: 37 months, Turkish: 40 months, Antillean: 33 months | -              | Age, sex, CCI | HR after 3-year follow-up from admission: Ethnic Dutch: 1.00 (ref) Indonesian: unadjusted 0.98 (0.90, 1.06), adjusted 0.98 (0.90, 1.06) Surinamese: unadj. 0.77 (0.63, 0.94), adj. 0.90 (0.74, 1.09) Turkish: unadj. 0.85 (0.59, 1.23), adj 1.12 (0.77, 1.63) Antillean: unadj. 0.88 (0.58, 1.32), adj. 1.01 (0.67, 1.52) HR after 3-year follow-up from clinic visit: Ethnic Dutch: 1.00 (ref) Indonesian: unadj. 0.91 (0.77, 1.09), adj. 0.91 (0.75, 1.07) Surinamese: unadj. 0.91 (0.65, 1.28), adj. 0.94 (0.67, 1.33) Turkish: unadj. 0.95 (0.45, 2.00), adj. 1.06 (0.50, 2.22) Antillean: unadj. 1.03 (0.49, 2.17), adj. 1.04 (0.50, 2.18) | No ethnic differences in 1- and 3-year mortality risk post-hospitalisation or clinic visit after adjustment |
| **United Kingdom**          |                                                                       |                 |                           |                  |                                                           |                              |
| Heun et al. (2013)          | Risk of (in-hospital) mortality after admission with AD                | Total 7 years   | -                         | -                | OR of dying during 7-year follow-up time: Caucasian: 1.00 (ref) Non-Caucasian: 0.83 (0.43–1.57), p = 0.562 (Calculated from data presented in paper) | Ethnicity was not discussed in findings nor analysed |
| Lewis et al. (2018)         | Time to death from diagnosis                                          | Mean 3.23 years | -                         | Gender, marital status, age at diagnosis, IMD, MMSE, depression, antidepressants | HR from diagnosis: White: 1.00 (ref) White other: unadjusted: 0.84 (0.72–0.98), adjusted: 0.80 (0.69–0.94) | Asian individuals with dementia had reduced mortality risk compared to White (Continues) |
| Study                        | Definition of mortality outcome                      | Follow-up time | Median/mean survival time | Model covariates                          | Statistics reported (95% confidence interval where given)                                      | Summary of findings reported |
|-----------------------------|------------------------------------------------------|----------------|---------------------------|-------------------------------------------|------------------------------------------------------------------------------------------------|---------------------------------|
| Mueller et al. (2017)14      | Time to death from diagnosis                        | Mean 3.5 years (SD 2.4) | Mean 3.3 years (SD 2.3)   | Age, sex, marital status, deprivation score at dementia diagnosis, MMSE | HR from diagnosis: 
  White: 1.00 (ref)  
  Non-White: unadjusted: 0.52 (0.45–0.58), adjusted: 0.61 (0.53–0.69) | British individuals with dementia were at increased risk of mortality compared to White individuals. |
| United States               |                                                      |                |                           |                                           |                                                                                                 |                                 |
| Aneshensel et al. (2000)15   | Time to death from dementia onset (perceived by caregivers), time to death from admission to nursing home | Total 5 years |                           |                                           | HR from onset: 
  Other (non-white): 1.00 (ref)  
  White: Model 1: 1.59 (log SE 0.195), Model 2: 1.65 (log SE 0.194), Model 3: 1.77 (log SE 0.196)  
  HRSs from nursing home admission: 
  Other: 1.00 (ref)  
  White: unadjusted: 1.87 (0.264), adjusted: 1.88 (0.269) | White individuals with dementia had higher risk of mortality than non-white individuals with dementia, and after adjusting for nursing home admissions and cause of admission, this increased |
| Black et al. (2018)16        | Time to death from diagnosis                        | Mean:          |                           |                                           |                                                                                                 |                                 |
|                             |                                                      | Group with pharmaceutical treatment: 681 days, No treatment: 794 days |                           |                                           |                                                                                                 |                                 |
| Study                     | Definition of mortality outcome                      | Follow-up time        | Median/mean survival time | Model covariates                                                                 | Statistics reported (95% confidence interval where given)                                                                 | Summary of findings reported                                                                 |
|--------------------------|------------------------------------------------------|-----------------------|---------------------------|---------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| Cosentino et al. (2006)  | Time to death from diagnosis                        | Mean 3.90 years       | Mean 5.2 years (95% CI 4.41–6.63) | Age, education, gender, global cognition, CCI                                   | HR from diagnosis:                                                                                                           | Hispanic participants had lower risk of mortality                                          |
|                          |                                                      |                       |                           |                                                                                 | Caucasian: 1.00 (ref)                                                    |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Hispanic: 0.24 (0.09–0.62)                                                |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | African American: 0.56 (0.22–1.45)                                        |                                                                                                                             |
| Gambassi et al. (1999)   | Time to death from admission to nursing home         | Median 23 months      | -                         |                                                                                 | Age, sex, marital status, cognitive function, behavioural problems, delirium, use of restraints, physical function, hearing problems, vision problems, urinary incontinence, pressure ulcers, CVD, stroke, aphasia, PD, depression, COPD, diabetes mellitus, malnutrition (BMI), falls | HR from nursing home admission:                                                                                               |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | White: 1.00 (ref)                                                 |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | African American: unadjusted: 0.81 (0.71–0.92) adjusted: 0.82 (0.72–0.94) |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Other: unadjusted: 0.68 (0.56–0.83), adjusted: 0.69 (0.57–0.85)           |                                                                                                                             |
| Helzner et al. (2008)    | Lifespan (age attained), time to death after diagnosis (in supplementary analysis) | Mean 4.1 years        | -                         |                                                                                 | Shorter lifespan: Sex, education, history of heart disease, hypertension, history of stroke, history of diabetes, study cohort, and follow-up time Post-diagnosis survival: None | HR of shorter lifespan:                                                                                                    | No racial or ethnic differences in hazard of shorter lifespan, but longer post-diagnosis survival in Hispanic participants |
|                          |                                                      |                       |                           |                                                                                 | Hispanic: 1.00 (ref)                                                    |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | White: 0.69 (0.25, 1.36)                                                |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Black: 0.95 (0.63, 1.44)                                                |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Years of post-diagnosis survival:                                                                                           |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Non-Hispanic white: 3.7 years; 95% CI 1.5–5.9                             |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | African American: 4.8 years; 95% CI 4.0–5.7                               |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Hispanic: 7.6 years; 95% CI 6.4–8.7 (log rank statistic: 20.8, p <= 0.0001) |                                                                                                                             |
| Heyman et al. (1996)     | Time to death from enrolment into CERAD              | Median 3.2 years       | Median 5.9 years (95% CI 5.6–6.4) | Age, sex, ADL, CDR, education, marital status, duration of dementia at entry, MMSE | HR from enrolment:                                                                                                          | No racial/ethnic difference in survival post-enrolment                                                                        |
|                          |                                                      |                       |                           |                                                                                 | White: 1.00 (ref)                                                     |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Non-White: unadjusted: 1.08, adjusted: 1.03 (0.74–1.45)                    |                                                                                                                             |
| Kaszniak et al. (1978)   | Mortality within 1 year after hospitalisation        | Total 1 year           | -                         |                                                                                 | OR of mortality within 1 year of hospitalisation:                       | Race not discussed in findings                                                                                             |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | White: 1.00 (ref)                                                    |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | Black: 0.98 (0.24–3.87) p = 1.00 (Fisher’s exact)                               |                                                                                                                             |
|                          |                                                      |                       |                           |                                                                                 | (calculated from data presented in paper)                                |                                                                                                                             |
| Study | Definition of mortality outcome | Follow-up time | Median/mean survival time | Model covariates | Statistics reported (95% confidence interval where given) | Summary of findings reported |
|-------|--------------------------------|---------------|--------------------------|------------------|----------------------------------------------------------|-----------------------------|
| Mayeda et al. (2017, 2015 data) | Time to death from diagnosis | - | Median years: White (3.1 years; 0.9–6.3), American Indian/Alaska Native (3.4 years; 1.2–6.7), African American (3.7 years; 1.1–7.6), Latino (4.1 years; 1.3–8.2), Asian American (4.4 years; 1.4–8.6) | Age, sex | HR from diagnosis: Non-Latino white: 1.00 (ref) Asian American: 0.76 (0.72–0.79) Latino: 0.82 (0.78–0.85) African American: 0.88 (0.85–0.91) Native American: 0.91 (0.85–0.98) | People with dementia who are Asian American, Latino, African American, and American Indian/Alaska Native had lower mortality compared with non-Hispanic White people with dementia across age bands and after adjusting for comorbidities |
| Mehta et al. (2008) | Time to death from first evaluation at an AD centre | Mean: White 2.6 ± 2.9 years since ADC diagnosis, African American 1.9 ± 2.5 years, Latino 1.9 ± 2.4 years, Asian 1.2 ± 1.9 years, American Indian 2.0 ± 2.3 years | Median 4.8 years (SE 0.03) | Age, sex, education, ADC site, marital status, living situation, MMSE, age at first symptom | HR from evaluation: White: 1.00 (ref) African American: 0.85 (0.74–0.96) Latino: 0.57 (0.46–0.69) Asian: 1.06 (0.81–1.39) American Indian: 1.13 (0.91–1.40) | African American and Latino patients had lower mortality than white AD patients, and this was not explained by neuropathology or other variables |
| Meier et al. (2001) | Time to death from admission for acute illness | Range 465–1502 days | Median 175 days | Nursing home placement, RCT intervention status, Reisberg dementia stage, presence of a pressure ulcer, feeding tube status, admitting diagnosis | HR from admission: White 1.00 (ref) Black: 1.10 (0.6–2.1) Hispanic: 0.55 (0.3–1.2) | Association between race and mortality not discussed individually in findings (rather related to feeding tube use), but no racial differences in hazard of mortality when adjusted for other variables |
| Ornstein et al. (2018) | Time from dementia incidence to death | Mean years (SD): Non-Hispanic White: 2.82 (2.09) Non-Hispanic Black: 3.85 (2.55) Hispanic: 4.62 (2.90) | Median 2.4 years | Mean 3.02 years (SD 2.29) | Mean (SD) years from incidence to death: Non-Hispanic White: 2.53 (1.97) Non-Hispanic Black: 2.65 (2.11) Hispanic: 3.59 (2.52) | Based on data from the paper, Hispanic participants with dementia may have higher mean time between... |
**TABLE 3 (Continued)**

| Study | Definition of mortality outcome | Follow-up time | Median/mean survival time | Model covariates | Statistics reported (95% confidence interval where given) | Summary of findings reported |
|-------|--------------------------------|----------------|---------------------------|------------------|----------------------------------------------------------|-------------------------------|
| Rountree et al. (2012) | Time to death from onset of dementia symptoms | Mean 3.0 years (SD 1.94) | Median 11.3 years (CI 10.4–11.8) | - | $p = 0.08$ that Hispanic and non-Hispanic White group means differ; not significant for non-Hispanic White compared to non-Hispanic Black or non-Hispanic Black compared to Hispanic | dementia incidence and death as compared to non-Hispanic White participants |
| Scarmeas et al. (2011) | Time to death from physical activity assessment | Mean 5.2, SD 4.4 | Median 9 years (95% CI 8–10) from physical activity evaluation, 48 years (95% CI 4.0–5.5) since dementia incidence | - | $\chi^2$ test $p = 0.03$. Authors did not present coefficients for Cox regression. Unadjusted ORs: White 1.00 (ref), Black: 1.00, Hispanic: 0.52 (calculated from data presented in paper) | Hispanic individuals with incident AD were less likely to die during follow up than White or Black individuals with incident AD |
| Sherzai et al. (2016) | In-hospital mortality from admission | - | HR from admission: Age 60–90: White: 1.00 (ref), African American: unadjusted 0.75 (0.72, 0.79), adjusted 0.76 (0.72, 0.79); Hispanic: unadjusted 0.85 (0.80, 0.91), adjusted 0.87 (0.81, 0.92); Age 90+: White: 1.00 (ref), African American: unadjusted 0.78 (0.72, 0.85), adjusted 0.80 (0.74, 0.87); Hispanic: unadjusted 1.03 (0.92, 1.14), adjusted 1.04 (0.93, 1.15) | Insurance type, gender, clinical comorbidity, hospital characteristics | African American and Hispanic people with dementia in both age groups had lower hazard of mortality after adjusting for socio-demographic factors, clinical comorbidities and hospital characteristics. Authors hypothesise that this may be due to underdiagnosis or less hospital use | (Continues) |
| Study                      | Definition of mortality outcome | Follow-up time | Median/mean survival time | Model covariates | Statistics reported (95% confidence interval where given) | Summary of findings reported |
|---------------------------|--------------------------------|----------------|---------------------------|------------------|----------------------------------------------------------|------------------------------|
| Steenland et al. (2010)  | Time to death from first visit to clinic | Mean years: Possible AD: 3.6 years, Probable AD: 4.3 years, FTD: 3.8 years, LBD: 3.7 years, MCI: 4.8 years, PD: 3.8 years, Controls: 4.3 years, total: 4.1 years | -              | Initial MMSE score, age, sex | HR of mortality from first visit for possible and probable AD patients: White: 1.00 (ref) Non-White: 0.83 (0.67–1.03). HR of mortality for all dementias combined: White: 1.00 (ref) Non-White: 0.80 (0.64–0.92) p < 0.05 that non-White group has lower mortality rates in probable AD group alone (insignificant in other disease groups) | Non-White individuals with dementia had lower mortality rates than White individuals with dementia, both for probable and possible AD, and for all dementias (this includes PD and ALS) |
| Waring et al. (2005)     | Time to death from diagnosis, time to death from onset | Median 10.5 years from onset, 5.7 from diagnosis | -              | -                          | Exact statistics not reported | No racial/ethnic differences in survival, however sample size was small, particularly for Hispanic people with dementia |
| Weiner et al. (2003)     | Time to death from onset | -              | -                          | -                      | Mean (SE) years from onset to death: Native American: 8.36 (0.61) White: 7.73 (0.24) p = 0.295 | No ethnic difference in survival after AD diagnosis between Native American and White participants |
| Weiner et al. (2007)     | Time to death from onset, time to death from initial evaluation | -              | -                          | -                      | Mean (SD) years from onset to death: American Indian 8.8 (4.1), White 9.0 (4.4), African American 8.2 (4.3), p < 0.0001, REGWF homogeneous subsets groups: 1 African American and Indian, 2. Indian and White Mean (SD) age at death: American Indian 80.5 (8.8), White 80.1 (8.3), African American 81.0 (8.2), p = 0.0015, REGWF groups: 1. White and Indian 2. Indian and African American | Significant differences between American Indian, African American, and White American people with dementia in time to death from onset and initial evaluation, but these differences amounted to a year or less difference |
weight of the overall pooled estimate. Figures S1 and S2 show forest plots for these groups separately. In the Black/African American group, hazard of mortality was 0.86 that of comparison groups (95% CI 0.82–0.91, $I^2 = 17\%$, four studies), and all but one study reported significantly lower hazard of mortality. Heterogeneity was much lower (17%) in this group. In the Hispanic/Latino group, all four studies showed significantly lower mortality as compared to non-Hispanic White groups (HR 0.65, 95% CI 0.50–0.84, $I^2 = 86\%$, four studies). In both Black/African American and Hispanic/Latino groups, hazard ratios of larger, more highly weighted studies trended closer to one (although still significant).

4 | DISCUSSION

As far as we are aware, this is the first systematic review examining ethnicity/race differences in mortality in people with dementia. We found evidence from the meta-analysis that mortality risk may be lower in Black/African American (by 14%) and Hispanic/Latino (by 35%) groups in the United States as compared to reference groups. However, Asian American and Indigenous groups in the United States and other ME groups in other countries were less well-studied.

These findings are similar to demographic trends which have been described in populations without dementia in the United States—the ‘Black-White mortality crossover’ and ‘Hispanic mortality paradox’. The Black-White mortality crossover posits that Black American groups have disproportionately higher risk of mortality compared to White American groups until they reach older age, after which mortality rates ‘cross over’ and they begin to have lower mortality risk.\textsuperscript{56,57} It is unclear why this trend exists; theories have been proposed arguing both underlying demographic mechanisms as well as spurious results due to data biases (namely, inaccurate or incomplete recording of ME individuals’ data). One demographic theory proposes that individual differences in frailty result in healthier individuals surviving past the initial higher mortality risk to older age and surpassing comparison groups’ average life expectancies.\textsuperscript{57–59} However, other studies have reported that systematically inaccurate reporting of age and mismatched linkages to death data, which become even more pronounced as a cohort ages and there are fewer members, may underlie these findings rather than a true crossover pattern.\textsuperscript{60–62} The ‘Hispanic paradox’ describes the comparable-or-better health outcomes, including longer survival, reported in Hispanic American groups despite lower-on-average socioeconomic status and education levels.\textsuperscript{63–66} Lower mortality in Hispanic/Latino groups has been reported in general populations\textsuperscript{64,66} and specifically in older adults.\textsuperscript{67} Possible demographic mechanisms for these findings relate to migration trends, such as the ‘healthy migrant effect’ (migrating to another country requires one to be of better health) and the ‘salmon effect’ (older migrants move back to their country of birth in later life, particularly if they become sick, leading to a numerator–denominator
| Study                        | Definition of mortality outcome                                                                 | Covariates included                                                                 | African American/Black | Hispanic/Latino | Asian       | Indigenous | Other | Non-white                |
|-----------------------------|------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|------------------------|----------------|------------|------------|-------|--------------------------|
| Aneshensel et al. (2000)    | Time to death from dementia onset (perceived by caregivers)<sup>a</sup>, time to death from admission to nursing home | Onset: Recent hospitalisation, physical health, age, gender, family income, nursing home admission From admission: Recent hospitalisation, physical health, cognitive impairment, AD duration, age, gender, income | Lower; HR: 1.77 (log SE 0.196) | Lower; HR: 1.88 (log SE 0.269) | Lower; HR: 0.69 (0.68, 0.90) | Lower; HR: 0.69 (0.68, 0.90) | Lower; HR: 0.66 (0.53, 0.83) (includes Asian and Native American groups) |
| Black et al. (2018)         | Time to death from diagnosis<sup>b</sup>                                                                 | Treatment, age, gender, US geographic region, comorbidities                          | Lower; HR: 0.78 (0.68, 0.90) | Lower; HR: 0.69 (0.68, 0.90) | -          | -          | -     | Lower; HR: 0.66 (0.53, 0.83) (includes Asian and Native American groups) |
| Cosentino et al. (2006)     | Time to death from diagnosis<sup>b</sup>                                                                 | Age, education, gender, global cognition, comorbidities                               | None; HR: 0.56 (0.22–1.45) | Lower; HR: 0.24 (0.09–0.62) | -          | -          | -     | Lower; HR: 0.69 (0.57–0.85) (includes Non-white/Non-African American groups) |
| Gambassi et al. (1999)      | Time to death from admission to nursing home                                                             | Age, sex, marital status, cognitive function, behavioural problems, delirium, use of restraints, other health issues | Lower; HR 0.81 (0.71–0.92) | Lower; HR 0.69 (0.57–0.85) (includes Non-white/Non-African American groups) |
| Helzner et al. (2008)<sup>40</sup> | Time to death after diagnosis (in supplementary analysis)                                             | None; Years post-diagnosis (4.8 years; 95% CI 4.0–5.7) compared to (3.7 years; 95% CI 1.5–5.9) | Lower; Years post-diagnosis (7.6 years; 95% CI 6.4–8.7) compared to (3.7 years; 95% CI 1.5–5.9) | Lower; Years post-diagnosis (7.6 years; 95% CI 6.4–8.7) compared to (3.7 years; 95% CI 1.5–5.9) | Lower; Years post-diagnosis (7.6 years; 95% CI 6.4–8.7) compared to (3.7 years; 95% CI 1.5–5.9) | Lower; Years post-diagnosis (7.6 years; 95% CI 6.4–8.7) compared to (3.7 years; 95% CI 1.5–5.9) |
| Heyman et al. (1996)<sup>48</sup> | Time to death from enrolment into CERAD                                                                  | Age, sex, ADL, CDR, education, marital status, duration of dementia at entry, MMSE  | -                      | -              | -          | -          | -     | None; HR 1.03 (0.74–1.45, p = 0.85)     |
| Study                | Definition of mortality outcome                                                                 | Covariates included                                                                 | African American/Black | Hispanic/Latino | Asian | Indigenous | Other | Non-white |
|---------------------|------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|------------------------|----------------|-------|-----------|-------|-----------|
| Kaszniak et al. (1978) | Mortality within 1 year after hospitalisation                                                   | -                                                                                    | Not discussed/none     | -              | -     | -         | -     | -         |
| Mayeda et al. (2017) | Time to death from diagnosis\(^a\)                                                           | Age, sex                                                                            | Lower; HR: 0.85 (0.75–0.96) | Lower; HR: 0.82 (0.79–0.85) | Lower; HR: 0.76 (0.73–0.79) | Lower; HR: 0.91 (0.85–0.98) | -     | -         |
| Mehta et al. (2008) | Time to death from first evaluation at an AD centre\(^a\)                                      | Age, sex, education, site, marital status, living situation, MMSE, age at first symptom | Lower; HR: 0.85 (0.74–0.96) | Lower; HR: 0.57 (0.47–0.69) | None; HR: 1.06 (0.81–1.39) | None; HR: 1.13 (0.91–1.40) | -     | -         |
| Meier et al. (2001) | Time to death from admission for acute illness                                                  | Nursing home placement, RCT intervention status, Reisberg dementia stage, pressure ulcers, feeding tube use, admitting diagnosis | None; HR: 1.10 (0.6–2.1) | None; HR: 0.55 (0.3–1.2) | -     | -         | -     | -         |
| Ornstein et al. (2018) | Years between incidence of dementia and death                                                   | -                                                                                    | None; \(t = −0.20, p = 0.84\) (calculated from data in paper) | Lower; \(t = −1.79, p = 0.08\) (calculated from data in paper) | -     | -         | -     | -         |
| Rountree et al. (2012) | Time to death from onset of dementia symptoms                                                  | -                                                                                    | -                      | -              | -     | -         | -     | None; Exact statistics not reported |
| Scarmeas et al. (2011) | Time to death from physical activity assessment                                               | -                                                                                    | None; Calculated OR from data in paper: 1.00 | Lower; Calculated OR from data in paper: 0.52 | -     | -         | -     | Sample size too small |
| Sherzai et al. (2016) | In-hospital mortality from admission                                                            | Insurance type, gender, comorbidities, hospital characteristics                      | Lower; HR: Ages 60–90: 0.76 (0.72–0.79), Ages 90+: 0.80 (0.74–0.87) | Lower; HR: 60–90: 0.87 (0.81, 0.92), 90+: 1.04 (0.93, 1.15) | -     | -         | -     | -         |

(Continues)
| Study | Definition of mortality outcome | Covariates included | African American/Black | Hispanic/Latino | Asian | Indigenous | Other | Non-white |
|-------|--------------------------------|---------------------|------------------------|----------------|-------|------------|-------|-----------|
| Steenland et al. (2010) | Time to death from first visit to clinic<sup>a</sup> | Initial MMSE score, age, sex | - | - | - | - | - | Lower; HR: Possible/probable AD: 0.83 (0.67–1.03) HR: All dementias combined: 0.80 (0.64–0.92) |
| Waring et al. (2005) | Time to death from diagnosis, time to death from onset | - | None | None | - | - | - | - |
| Weiner et al. (2003) | Time to death from onset | - | - | - | - | - | Lower; Mean (SE) years from onset to death: Native American 8.36 (0.61), White 7.73 (0.24), p = 0.295 |
| Weiner et al. (2007) | Time to death from onset, time to death from initial evaluation | - | Higher; Mean (SD) White 9.0 (4.4), African American 8.2 (4.3) | - | - | Higher; Mean (SD) years From onset: American Indian 8.8 (4.1), White 9.0 (4.4) From initial evaluation: American Indian 3.7 (2.5), White 4.3 (3.0) |

Abbreviations: AD, Alzheimer’s disease; ADL, Activities of Daily Living; CDR, Clinical Dementia Rating; MMSE, Mini-Mental State Exam.

<sup>a</sup>Used in meta-analysis.
<sup>b</sup>Data from Mayeda (2015) conference abstract.
<sup>c</sup>Exact statistics not reported.
<sup>d</sup>Statistics calculated from data presented in paper.
These theories are also disputed, as mortality trends are not consistent across all causes of death, and similar issues of poor reporting/matching of death data have been shown to explain all or part of these trends. For studies in this review using data linkages to ascertain death, it is possible that matching issues may similarly affect their findings.

Economic mortality trends in other countries such as the United Kingdom and the Netherlands seem less well-studied, although a ‘healthy migrant effect’ may still apply. In the United Kingdom, findings of lower risk of mortality in ME groups with dementia is consistent with findings from other conditions, including severe mental illness, depression, and delirium. In the Netherlands, no differences in mortality by ethnicity were found, however, ethnicity was defined only by country of birth. In the United States and United Kingdom, information on generational differences between migrants and non-migrants may support or refute healthy migrant hypotheses.

Differences in mortality might also be related to differences in care or dementia aetiology. Previous studies have found disparities across ME groups in the care they receive; for example, some ME groups in the United States may be less likely to use long-term care facilities or receive certain medications, which may both impact survival in dementia. Certain ME groups are also thought to have delays in getting a diagnosis and accessing care, although studies in this review did not directly measure timing of diagnosis, and there were too few studies to examine differences between studies measuring survival from symptom onset versus survival from first diagnosis. Dementia aetiologies...
may also play a role, as survival can differ by type of dementia. However, only one study reported separate results by type of dementia.

High heterogeneity was found in almost all ME groups. Studies differed greatly in definition of dementia, definition of the mortality outcome, and categorisation of ethnicity/race.

The overall pooled estimate should be interpreted with abundant caution, as ME groups are disparate and combining all ME groups together obscures these differences; the pooled estimates from individual ME groups may be more meaningful. Diverse socio-political histories, migration patterns, and experiences of racism affect health outcomes of different ME groups in different ways, and these details are lost when collapsing them into larger categories. This likely contributes to the high statistical heterogeneity of the overall model. Effect sizes may also differ depending on where or when the study was conducted. Within a country, regions may have different demographics, migration histories, and local politics which influence the survival rates observed even within a single ethnic group.

Lack of reporting around how race/ethnicity is defined makes it difficult to understand the mechanisms by which differences in survival occur. Only six studies defined ethnicity by self-report, and it was unclear for other studies who assigned race/ethnicity to participants. Ethnicity gathered from routine data, for example, may reflect someone else’s judgment and be inaccurate. Also, ‘Hispanic’ ethnicity was often listed alongside ‘White’, ‘Black’ and so on race/ethnicities in US studies, although people may identify as both Hispanic and Black or Hispanic and White. This ambiguity may contribute to the high heterogeneity in the Hispanic/Latino subgroup, though only two articles specified non-Hispanic Black and non-Hispanic White ethnic groups.

High heterogeneity within race/ethnicity groups is also a result of the use of broad ethnicity categorisations. While this may be done to avoid small sample sizes, groups included in these broader categories are not necessarily similar. For example, studies have found significant differences in cardiovascular health burden between Asian American subgroups. Prevalence and incidence of dementia has also been found to differ across groups which are often combined under Hispanic/Latino American categories. Socioeconomic and cultural differences between these groups are also masked. More detailed reporting of race/ethnicity definitions can provide additional clarity around what is being measured, although these concepts are intrinsically fluid and context dependent.

Future research should seek to clarify mechanisms for observed race/ethnic differences in mortality. This includes issues with reporting of variables such as ethnicity, age and death, as well as the clinical, social and economic implications of longer survival in dementia for ME older adults and their families. For example, longer survival may contribute to prolonged medical or residential care expenses, potentially exacerbating the already existing race/ethnic inequalities in out-of-pocket healthcare costs for people living with dementia and their families. ME groups in the United States are also more likely to live in multigenerational homes, potentially allowing for greater familial support and reducing risk of nursing home placement which has been associated with shorter survival in dementia. However, prolonged survival may increase caregiver burden and stress and be detrimental to carers’ mental and physical health and social and family relationships. Larger caregiver burden in turn affects outcomes for the person living with dementia, including risk of nursing home placement. Given the additional literature on disparities in risk of developing dementia and barriers to care faced by ME groups, it is important that future research and policy work to reduce inequalities and improve quality of life for ME people living with dementia and their families.

4.1 Strengths and limitations

Agreement was high between reviewers assessing study eligibility, which may indicate that the inclusion/exclusion criteria will be replicable for future reviews/uploads.

Additionally, the studies included were large, often drawing participants from registries or health record databases. This reduces concerns around low power and unrepresentative samples, although ME groups often comprise a smaller percentage of the sample, and power may still be a concern where ME group sample size is low. Certain populations may also be underrepresented if they do not access formal health services (particularly underserved minorities, who are thought to access dementia services at lower rates). In research-focused AD centres, recruitment processes may differ between ME groups, potentially leading to selection biases in these cohorts as compared to in standard health services.

Because demographics and definitions of race/ethnicity vary by country, we cannot and do not generalise between countries. Furthermore, no studies were found outside the United States and Europe. Although we did not specify language exclusions, we may have been limited by the search terms used to capture race/ethnicity—other countries may use other culturally-specific language to describe race/ethnicity groups of which we are unaware.

Although we were unable to quantify it, publication bias might be less of an issue for studies where race/ethnicity is not the main effect—they may be equally likely to be published even if results comparing race/ethnicity are non-significant. However, this lack of focus on race/ethnicity leads to other issues such as misclassification of ethnicity, lack of power, little information on how ethnicity groups differed demographically and a wider range of covariates between studies. It is also possible that other eligible studies exist which were not found in the search because ethnicity was not mentioned in the title, abstract, or subject headings.

Finally, in our meta-analysis, we chose to use the most-adjusted estimate reported in the study. This approach assumes that these estimates are more comparable, although they may not be. It may have been preferable to calculate a pooled HR based on unadjusted estimates, but only one eligible study included an unadjusted estimate.
5 | CONCLUSIONS

Despite diverse and ageing populations worldwide, few studies exist on mortality in dementia amongst ME groups, especially outside the United States. In the United States, evidence from longitudinal studies indicate that Hispanic/Latino American and Black/African American groups have lower risk of mortality in dementia. Explanations for these findings may lie in existing research on similar mortality patterns in the overall population, although further research is needed to understand what drives these patterns and to inform equitable public health policies for dementia.

Studies differ greatly in their definitions and reporting of ethnicity. More consistent methodology and reporting of ethnicity in future research will be necessary to understand disparities in mortality in dementia across different race/ethnicity groups.

ACKNOWLEDGEMENTS

Jayati Das-Munshi is funded by the Health Foundation working together with the Academy of Medical Sciences, for a Clinician Scientist Fellowship and by the ESRC in relation to the SEP-MD study (ES/S002715/1) and part supported by the ESRC Centre for Society and Mental Health at King’s College London (ESRC Reference: ES/S012567/1) and by the National Institute for Health Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King’s College London. The other authors have no funding to declare. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health, the ESRC or King’s College London.

CONFLICT OF INTEREST

The remaining authors declare no other competing interests.

AUTHOR CONTRIBUTIONS

Melissa Co conceived of and designed the review with the help of Matthew Prina and Jayati Das-Munshi. Melissa Co, Elyse Couch, Qian Gao and Andrea Martinez screened papers for eligibility and gave input on the inclusion and exclusion criteria. Melissa Co performed the analyses and drafted the article, with revision help from the other authors. All authors commented on the final draft.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this systematic review as no new data were generated. Data used in the meta-analysis are available from the original published sources.

ORCID

Melissa Co https://orcid.org/0000-0001-7789-0871
Elyse Couch https://orcid.org/0000-0003-4692-5837

REFERENCES

1. Office for National Statistics. Deaths registered in England and Wales (series DR): 2017. 2018.
2. Kramarow EA, Tejada-Vera B. Dementia mortality in the United States, 2000-2017. Natl Vital Stat Rep. 2019;68(2):1-29.
3. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016;12(3):216-224.
4. Manly JJ, Mayeux R. Ethnic differences in dementia and Alzheimer’s disease. In: Anderson NA, Bulatao RA, Cohen B, eds. Critical perspectives on racial and ethnic differences in health in late life. National Academies Press; 2004.
5. Mehta KM, Yeo GW. Systematic review of dementia prevalence and incidence in United States race/ethnic populations. Alzheimers Dement. 2017;13(1):72-83.
6. All-Party Parliamentary Group on Dementia. Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities. Alzheimer’s Society; 2013.
7. Adelman S, Blanchard M, Livingston G. A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain. Int J Geriatr Psychiatry. 2009;24(7):657-665.
8. Kenning C, Daker-White G, Blakemore A, Panagioti M, Waheed W. Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC Psychiatr. 2017;17(1):316.
9. Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. Aging Ment Health. 2002;6(2):101-108.
10. Cooper C, Tandy AR, Balamuruli TBS, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. Am J Geriatr Psychiatry. 2010;18(3):193-203.
11. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: a review. Int J Geriatr Psychiatry. 2013;28(11):1109-1124.
12. Mehta K, Yaffe K, Pérez-Stable EA, et al. Race/ethnic differences in AD survival in US Alzheimer’s Disease Centers. Neurology. 2008;70(14):1163-1170.
13. Mayeda ER, Glymour MM, Quesenberry CP, Johnson JK, Pérez-Stable EJ, Whitmer RA. Survival after dementia diagnosis in five racial/ethnic groups. Alzheimer’s Dementia. 2017;13(7):761-769.
14. Lewis G, Werbeloff N, Hayes JF, Howard R, Osborn DP. Diagnosed depression and sociodemographic factors as predictors of mortality in patients with dementia. Br J Psychiatry. 2018;213(2):471-476.
15. Mueller C, Huntley J, Stubbs B, et al. Associations of neuropsychiatric symptoms and antidepressant prescription with survival in Alzheimer’s disease. J Am Med Dir Assoc. 2017;18(12):1076-1081.
16. Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. J Epidemiol Community. 2004;58(6):441-445.
17. Senior PA. Bhopal R. Ethnicity as a variable in epidemiological research. BMJ. 1994;309(6950):327-330.
18. Krieger N. Refiguring "race": epidemiology, racialized biology, and biological expressions of race relations. Int J Health Serv. 2000;30(1):211-216.
19. Phelan JC, Link BG. Is racism a fundamental cause of inequalities in health? Annu Rev Sociol. 2015;41(1):311-330.
20. Nazroo JY. The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. Am J of Publ Health. 2003;93(2):277-284.
21. Co M, Couch E, Gao Q, Mac-Ginty S, Das-Munshi J, Prina M. Access to health services in older minority ethnic groups with dementia: a systematic review. J Geriatr Psychiatry. 2020;69(3):822-834.
63. Thomson EF, Nuru-Jeter A, Richardson D, Raza F, Minkler M. The Hispanic Paradox and older adults’ disabilities: is there a healthy migrant effect? Int J Environ Res Public Health. 2013;10(5):1786-1814.

64. Ruiz JM, Steffen P, Smith TB. Hispanic mortality paradox: a systematic review and meta-analysis of the longitudinal literature. Am J of Publ Health. 2013;103(3):e52-e60.

65. Markides KS, Eschbach K. Aging, migration, and mortality: current status of research on the Hispanic paradox. J Gerontol Ser B Psychol Sci Soc Sci. 2005;60(Special_Issue_2):S68-S75.

66. Franzini L, Ribble J, Keddie A. Understanding the Hispanic paradox. Ethn Dis. 2001;11(3):496.

67. Elo IT, Turra CM, Kestenbaum B, Ferguson BR. Mortality among elderly Hispanics in the United States: past evidence and new results. Demography. 2004;41(1):109-128.

68. Turra CM, Elo IT. The impact of salmon bias on the Hispanic mortality advantage: new evidence from social security data. Popul Res Policy Rev. 2008;27(5):515-530.

69. Abraido-Lanza AF, Dohrenwend BP, Ng-Mak DS, Turner JB. The Latino mortality paradox: a test of the "salmon bias" and healthy migrant hypotheses. Am J Publ Health. 1999;89(10):1543-1548.

70. Masters RK. Uncrossing the US black-white mortality crossover: the role of cohort forces in life course mortality risk. Demography. 2012;49(3):773-796.

71. Rechel B, Mladovsky P, Ingleby D, Mackenbach JP, McKee M. Migration and health in an increasingly diverse Europe. Lancet. 2013;381(9873):1235-1245.

72. Das-Munshi J, Chang C-K, Dutta R, et al. Ethnicity and excess mortality in severe mental illness: a cohort study. Lancet Psychiatry. 2017;4(5):389-399.

73. Ward G, Perera G, Stewart R. Predictors of mortality for people aged over 65 years receiving mental health care for delirium in a South London Mental Health Trust, UK: a retrospective survival analysis. Int J Geriatr Psychiatry. 2015;30(6):639-646.

74. Das-Munshi J, Chang C-K, Schofield P, Stewart R, Prince MJ. Depression and cause-specific mortality in an ethnically diverse cohort from the UK: 8-year prospective study. Psychol Med. 2019;49(10):1639-1651.

75. Luppa M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. Dementia Geriatr Cognitive Disord. 2008;26(1):65-78.

76. Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: evidence for cross-ethnic differences. Alzheimer Dis Assoc Disord. 2004;18(3):134-144.

77. Strand BH, Knapskog A-B, Persson K, et al. Survival and years of life lost in various aetiologies of dementia, mild cognitive impairment (MCI) and subjective cognitive decline (SCD) in Norway. PLoS One. 2018;13(9):e0204436.

78. Gordon NP, Lin TY, Rau J, Lo JC. Aggregation of Asian-American subgroups masks meaningful differences in health and health risks among Asian ethnicities: an electronic health record based cohort study. BMC Publ Health. 2019;19(1):1551.

79. Karter AJ, Schillinger D, Adams AS, et al. Elevated rates of diabetes in Pacific islanders and Asian subgroups: the diabetes study of northern California (DISTANCE). Diabetes Care. 2013;36(3):574-579.

80. Zhao B, Jose PO, Pu J, et al. Racial/ethnic differences in hypertension prevalence, treatment, and control for outpatients in northern California 2010-2012. Am J Hypertens. 2015;28(5):631-639.

81. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. Ann Intern Med. 2015;163(10):729-736.

82. Gaugler JE, Kane RL, Kane RA, Newcomer R. Predictors of institutionalization in Latinos with dementia. J Cross Cult Gerontol. 2006;21(3):139-155.

83. Cohn DV, Passel JS. A Record 64 Million Americans Live in Multigenerational Households. Washington, DC: Pew Research Center; 2018.

84. Gaugler JE, Leach CR, Clay T, Newcomer RC. Predictors of nursing home placement in African Americans with dementia. J Am Geriatr Soc. 2004;52(3):445-452.

85. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. J Am Acad Nurse Pract. 2008;20(8):423-428.

86. Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. Int J Geriatr Psychiatry. 2011;26(1):12-20.

**SUPPORTING INFORMATION**

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

**How to cite this article:** Co M, Couch E, Gao Q, Martinez A, Das-Munshi J, Prina M. Differences in survival and mortality in minority ethnic groups with dementia: a systematic review and meta-analysis. Int J Geriatr Psychiatry. 2021;36(11):1640-1663. doi:10.1002/gps.5590