REVIEW ARTICLE

International Journal of Geriatric Psychiatry WILEY

Use of routine and cohort data globally in exploring dementia care pathways and inequalities: A systematic review

James Watson[1] | Clarissa Giebel[2,3] | Mark Green[4] | Frances Darlington-Pollock[5] | Asan Akpan[6,7,8,9]

[1]School of Environmental Sciences, The University of Liverpool, Liverpool, UK

[2]NIHR ARC NWC, Liverpool, UK

[3]Department of Primary Care and Mental Health, University of Liverpool, Liverpool, UK

[4]Health Geography, School of Environmental Sciences, The University of Liverpool, Liverpool, UK

[5]Population Geography, School of Environmental Sciences, The University of Liverpool, Liverpool, UK

[6]Liverpool University Hospital NHS FT, Liverpool, UK

[7]University of Cumbria, Liverpool, UK

[8]The University of Liverpool, Liverpool, UK

[9]Ageing SRGL, NIHR CRN NWC, Liverpool, UK

Correspondence
Clarissa Giebel, Waterhouse Building B Block 2nd Floor, 1-5 Brownlow Street, Liverpool L69 3GL, UK.
Email: Clarissa.giebel@liverpool.ac.uk

Abstract

Objectives: The aim of this systematic review was to evaluate studies which employed routine and cohort data sets to understand inequalities in dementia care pathways.

Methods: We identified 27 research papers using routine data sets to investigate inequalities in dementia care pathways through electronic and grey literature searches. Papers were independently assessed by two reviewers for inclusion based on defined criteria. Included papers were quality rated using the National Institutes of Health Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies. Data was extracted based on stage(s) in dementia care pathway and socio-economic factors investigated.

Results: Inequalities were noted across dementia care pathways. Socio-economic and protected characteristics were shown to impact the likelihood of people with dementia moving into institutional nursing care, the quality and consistency of their treatment, need for emergency and urgent healthcare, the rate of illness progression and their long-term survival. Research was often disparate ignoring the multiple parts of the dementia care pathway, or the impact of specific factors across multiple stages.

Conclusions: Our study highlights issues in dementia care pathways based on socio-economic or protected characteristics. Equitable service provision, more culturally appropriate services, improved health literacy and increased provision for both early diagnosis and care at home can help narrow the gap in dementia care inequalities. There is greater need for research investigating dementia care pathways as something greater than the sum of its parts; exploring the influence of socio-economic factors from a person's entrance into the system and throughout.

KEYWORDS
care, cohort, dementia, inequalities, pathway, registry, routine data, socio-economic

1 | INTRODUCTION

The number of people diagnosed with dementia in the United Kingdom is set to increase in the next 20 years, which will exacerbate already strained models of health and social care provision. By 2040, Wittenberg et al. project the number of people with dementia (PwD) to double and the reflected cost of care to increase threefold.[1] Crucially, the greatest proportional increase is expected to occur among people who will be diagnosed with severe dementia. Yet staff and services are already struggling to meet current demand. With further increases in the number of people with pressing needs, and their reflected costs, this will likely result in a greater levels of unmet care needs.[2]

Currently, there are marked socio-economic and geographic inequalities in the prevalence of dementia, availability of informal care, access to and use of formal care. Socio-economic status[3–5] and place of residence[6,7] influence access to a diagnosis, and aspects of care, treatment and the support a PwD may receive. Those most socio-economically disadvantaged are more likely to bear the brunt of these inequalities.

Existing socio-economic inequalities will exacerbate many current unmet needs in those affected by dementia, with post-diagnostic care often being underfunded and understaffed.[8] People who are unable to afford their own care will endure worse outcomes relative to more affluent PwD.[4,9] In a time of restricted finances, both individually and in the public provision and staffing for dementia care, it is imperative we better understand inequalities within dementia care pathways. We must provide evidence to inform policy and applied change in health and social care for PwD.

Routine data sets in dementia—such as the National Alzheimer's Coordinating Center in the United States and SveDem in Sweden—are large databases containing standardised clinical and service interaction records for PwD. Such registries are developed with the aim of harnessing data to identify issues in access to, and quality of care, as a means to improve health and social outcomes. Other routine data sets, such as those focussing on hospital admissions, accident and emergency attendances, primary care records and social care interactions can also be used to uncover a wider picture of care pathways for PwD.

The aim of this systematic review was to evaluate studies which employed routine and cohort data sets to understand inequalities in dementia care pathways. Existing systematic reviews have explored specific socio-economic inequalities in dementia care pathways, including age, ethnicity, gender, deprivation and country of residence.[10–14] However, this is the first to explore how routine data sets have been used internationally to understand dementia care pathways, variance in care and inequalities in dementia care pathways. With continued restricted government funding for dementia care and an increase in the number of PwD reliant on state-funded care, the use and application of routine data is crucial to understand where and how inequalities emerge. This knowledge can enable improved person-centred care that generates a better quality of life

---

Key points

- The first systematic review identifying research using routine and cohort data sets to explore inequalities in dementia care pathways
- We highlight inequalities in care pathways for people with dementia, by socio-economic factors and protected characteristics
- There is a greater need for appropriate and equitable dementia service provision
- Future research needs to encompass a more holistic view of dementia illness trajectory and the related change in care needs

---

for PwD and their carers, and attempt to reduce related inequalities in care.

2 | METHODS

This systematic review was registered on the PROSPERO International prospective register of systematic reviews (ID: CRD42020162934).

2.1 | Search strategy

We searched the Cochrane Central Register of Controlled Trials, CINAHL, Google Scholar, MEDLINE, PsycINFO, PubMed and Web of Science databases up to and including 2020. The search terms 'dementia' AND 'care' AND 'routine data' AND 'cohort' were used in combination. Initially, titles and abstracts of papers were read by JW and CG, retaining those which were relevant. Discrepancies over inclusion of papers were discussed between reviewers and an agreement reached. JW and CG read through the remaining papers in their entirety, to define against inclusion and exclusion criteria. Any ambiguity over inclusion of papers was discussed between reviewers until an agreement was reached.

A search of grey literature and snowballing of references from the papers already included were used to find further papers meeting the inclusion criteria.

2.2 | Inclusion criteria

The population used in the studies had to be dementia-specific and PwD need to have received a formal diagnosis of dementia. Only English language papers, published since 01 January 1990, looking at the use of routine or cohort data to quantitatively explore issues of

care pathways and care utilisation in people living with dementia and their family carers were included.

2.3 | Exclusion criteria

Papers published in any language other than English, published before 01 January 1990, using qualitative research methods, or quantitative papers not using routine or cohort data were excluded; reviews of any kind were also discounted. Papers with populations with no formal dementia diagnosis, non-dementia study populations or those with mixed diagnoses, for example, dementia and mild cognitive impairment were also excluded.

2.4 | Assessment of quality

The National Institutes of Health (NIH) Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies was employed in this review; a 14-point checklist (see Table 3 footnotes). This tool has been used as it is a practical and pragmatic method of identifying potential flaws in the methodology of cohort studies which may increase bias. Such biases can undermine research strength and quality, casting potential doubt over subsequent results.

2.5 | Data extraction

To process the literature to conduct the data synthesis, the relevant findings were taken from the final research based on the aims and objectives of the systematic review. The following information was taken from each paper: Author name(s), research title, year of publication, country/countries of study, dementia population/subtype, socio-economic analysis in study (if yes, which socio-economic categories are included), outcomes and stages(s) in pathway.

2.6 | Data synthesis

A narrative summary of the evidence taken from the final included papers was conducted. This process involves drawing out specific findings from quantitative papers when a meta-analysis is not feasible.[15] From the included papers we looked at: what their findings tell us and what part(s) of the dementia care pathway they related to—as defined in the four sub-headings of the results section: transitions in nursing care (in the United Kingdom, this includes both residential care homes—which provide support for people with personal care and provide accommodation—and nursing homes—which provide personal care, but also have a greater number of qualified nurses providing specific condition-related care; e.g., dementia or neurological conditions), anti-dementia medications, health and social care interactions, disease progression, mortality and survival.

3 | RESULTS

3.1 | Search outcomes

We identified 1506 studies via database ($n = 1486$) and grey literature searches ($n = 20$), 796 of which remained once duplicate records were removed (see Figure 1 for PRISMA flowchart). Screening of these records based on titles and abstracts led to the exclusion of 583 records; the remaining 113 records were reviewed as full-text papers. Sixty-seven papers were removed leaving a total of 46 studies which met the defined inclusion criteria.

At stage 1, JW and CG reviewed papers on their abstract and title, agreeing on the continued inclusion/exclusion of 677 of the 796 (85.1%) papers. At stage 2, JW and CG reviewed the remaining 113 papers based on the full-text, agreeing on the continued inclusion/exclusion of 74 (64.5%) of the papers.

3.2 | Characteristics of included studies

Table 1 shows the descriptive characteristics of the 46 included studies. The majority of these studies focused their analysis on one country, using one set of routine data. However, some analysed data from multiple routine or cohort data sets, and in some cases, different registries across a variety of countries. The vast majority of studies were conducted in the US (13), England/UK (12), or mainland Europe (29), with one study conducted in Australia, Hong Kong and Puerto Rico, respectively.

Twenty-seven studies have highlighted differences or inequalities in care and, or outcomes as a result of a protected characteristic—such as age, gender or ethnicity—income or deprivation, or personal circumstance—such as availability of informal care. These 27 studies go beyond merely stating, for example, the number of people of each age group, or who were male and female.

Of these 27 studies, seven specifically investigated socio-economic deprivation or geography as factors in care use and quality, and or health and social outcomes for PwD (see Table 2).

3.3 | Study outcomes/stage in care pathway

Literature investigated various areas of dementia care and support (transitions to nursing care, anti-dementia medication, health and social care interaction, and disease progression, mortality and survival). Several studies looked at different stages of the care pathway (i.e., disease progression, medication initiation and mortality), so that some studies were discussed across different areas.

3.4 | Transitions to nursing care

Nine studies investigated care transitions for PwD, primarily analysing the significance and degree to which socio-economic factors
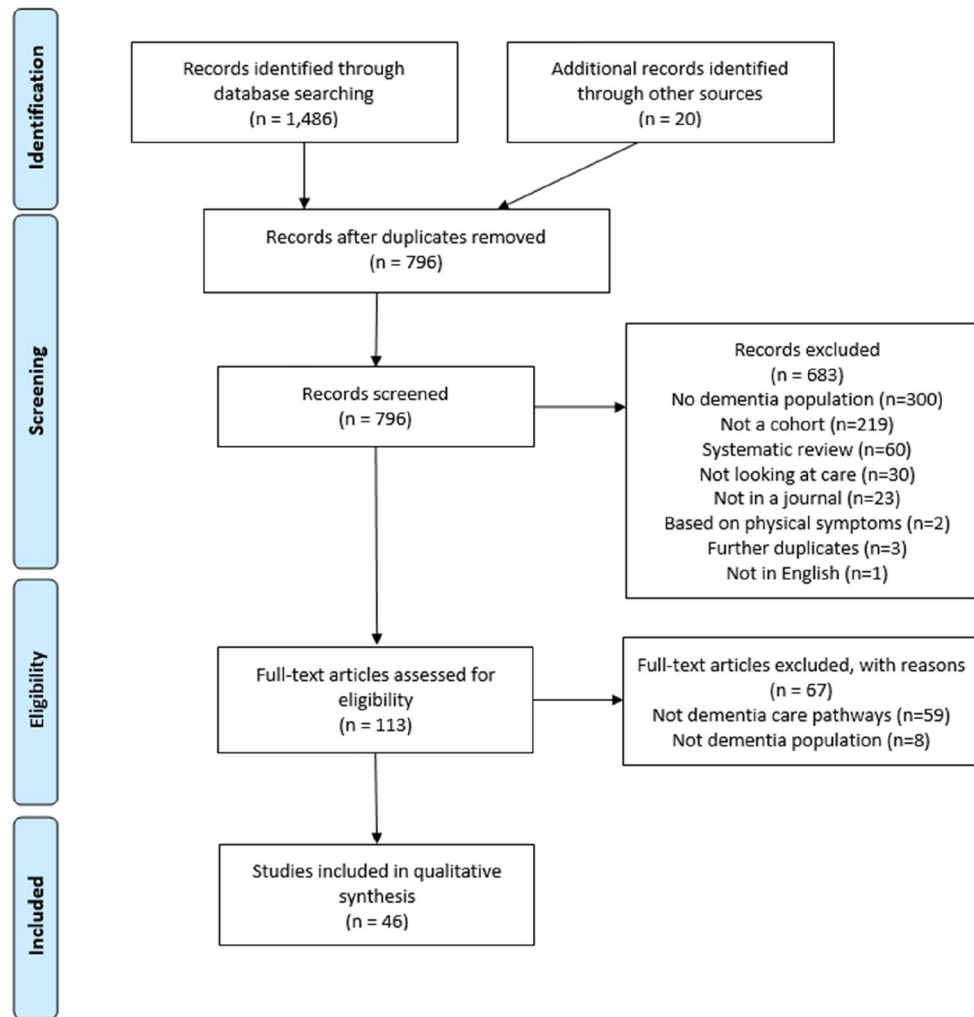
FIGURE 1 Search strategy

can influence the probability of moving into nursing care. Being older was associated with a significantly greater likelihood of admission to nursing care.[7,35,36] Stevnsborg et al.[48] used data from three Danish health registries to demonstrate that the oldest PwD (those aged 70-79 and ≥80 years vs. to 60-69 years) were more likely to live in nursing care when first diagnosed with dementia. Korhonen et al.[36] reported the same association between age and institutionalisation into long-term care, but discovered it was starker for women than men.

Gender was as a factor in care transitions in several studies, revealing differences in the likelihood of transitions to nursing care. Stevnsborg et al.[35] found women were significantly more likely to be diagnosed with dementia whilst living in nursing care, and Smith et al.[7] discovered that men with dementia were significantly less likely to be admitted to nursing care generally. However, in the final 2 years of life, a greater proportion of men with dementia had care transitions, with a higher median number of transitions than women.[16] The timing of transitions in disease progression was also found to differ by gender. Neumann et al.[40] found Alzheimer's disease severity to progress at a faster rate for men, with men being more likely to transition to nursing care if they had severe Alzheimer's disease. Women, however, were more likely to be admitted to nursing care with mild Alzheimer's, indicating they would enter institutional care earlier in their disease progression.

Knapp et al.[35] investigated ethnicity as a factor in care transitions, finding people of Caribbean/African and East/South Asian ethnicities to be significantly less likely to be admitted to institutional care (hospital or nursing home). In Denmark, Stevnsborg et al.[48] compared native-born, Western and non-Western immigrant dementia populations, discovering non-Western immigrants were significantly less likely to be living in a nursing home when receiving their dementia diagnosis.

3.5 | Anti-dementia medication

Eighteen studies investigated diagnostics and use of anti-dementia medications, with nine analysing socio-economic variables as factors in likelihood of anti-dementia drug initiation.

TABLE 1 Summary characteristics of included papers

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Aaltonen et al.[16]	2012	Finland	Dementia	Age Gender	Care transitions: Difference in likelihood of transitions in care in last 2 years of life by accommodation (all; at home at baseline; in residential care)	Finnish National Registers
Bunn et al.[17]	2016	UK	Dementia	None	Health and social care interactions: People with dementia using hospital services in previous 4 weeks and in previous 12 months.	CFAS I and II
Calvo-Perxas et al.[18]	2012	Spain	Alzheimer's disease, vascular dementia, other secondary dementias, frontotemporal dementias, Parkinsonian syndromes, dementia with Lewy bodies, not specified dementias	Age Gender Marital status Education Residence	Diagnostics and medications: Prescription and consumption of antipsychotic drugs for various dementia subtypes.	Registry of Dementia of Girona (ReDiGi)
Calvo-Perxas et al.[19]	2014	Spain	Alzheimer's disease	Age Gender Education Marital status Residence	Diagnostics and medications: Use of antipsychotics and other medications for the treatment of symptoms in Alzheimer's disease.	Registry of Dementia of Girona (ReDiGi)
Cermakova et al.[3]	2017	Sweden	Alzheimer's disease	Age Gender Residence	Diagnostics and medications: Use of antipsychotics in Alzheimer's disease.	SveDem
Connolly et al.[20]	2012	England	Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia, other dementia, unspecified type dementia	Age Gender Residence	Health and social care interactions: People with dementia receiving their annual dementia review, recorded discussions with carers and review of their social care Diagnostics and medications: Prescription and review of antipsychotics	GP register (quality outcomes framework)

(Continues)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Cooper et al.[4]	2016	UK	Dementia	Age Gender Deprivation geography	Diagnostics and medications: Anti-dementia drug initiation rates.	The Health Improvement Network (THIN)
Cooper et al.[12]	2017	UK	Dementia	Age Gender Deprivation	Diagnostics and medications: Prescribing and initiation of psychotropic, hypnotics and anxiolytics medications Health and social care interactions: Likelihood of surgical consultations, blood pressure monitoring, weight monitoring and annual dementia reviews	The Health Improvement Network (THIN)
Donegan et al.[21]	2017	UK	Dementia, Alzheimer's disease	Age Gender	Diagnostics and medications: Prescription of anti-dementia drugs in clinical practice research datalink (CPRD) sample of people with dementia.	Clinical Practice Research Datalink (CPRD)
Eriksson et al.[22]	2014	Sweden	Alzheimer's disease	Age Gender	Diagnostics and medications: Prescription of anti-dementia medications and difference in diagnostics used in early and late onset Alzheimer's disease	SveDem
Fereshtehnejad et al.[23]	2014	Sweden	Dementia with Lewy bodies, Alzheimer's disease	Age Gender	Diagnostics and medications: Prescription of various anti-dementia/medications for people with dementia with Lewy bodies (DLB) and Alzheimer's disease.	SveDem and Swedish Patient Registry
Fereshtehnejad et al.[24]	2015	Sweden; Denmark	Early and late onset, Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease with dementia	Age Gender Residence Geography	Diagnostics and medications: Differences in prescription of anti-dementia medications. Differences in use of diagnostics for people with dementia. Health and social care interactions: 6 indicators of care quality identified and analysed.	SveDem and Danish Dementia Registry
Fillenbaum et al.[25]	2001	US	Alzheimer's disease	Age Gender Ethnicity Education Marital status Residence Geography	Health and social care interactions: Outpatient visits based on residence (home or long-term care); cost of outpatient visits.	Consortium to Establish a Registry for Alzheimer's Disease (CERAD)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Fong et al.[26]	2012	US	Alzheimer's disease	Age Gender Ethnicity Education	Health and social care interactions: Adverse outcomes for people with dementia who were: hospitalised with delirium, hospitalised without delirium and not hospitalised: (1) death; (2) institutionalised; (3) cognitive decline; (4) any adverse outcome	Massachusetts Alzheimer's Disease Research Center (MADRC) patient registry
Frahm-Falkenberg et al.[27]	2016	Denmark	Alzheimer's disease, vascular dementia, dementia not otherwise specified	Age Gender Marital status	Health and social care interactions: Cost and use of healthcare before and after dementia diagnosis for 'patients' and partners versus controls without dementia	Danish Patient Registry
Gillette-Guyonnet et al.[28]	2011	France	Alzheimer's disease	Age Gender Education Residence Caregiver variables	Disease progression, mortality and survival: MMSE score change over years to end of study/mortality Diagnostics and medications: Use of Alzheimer's disease medications throughout Health and social care interactions: Rate of institutionalisation	REALFR cohort
Gustavsson et al.[29]	2009	England	Alzheimer's disease, dementia with Lewy bodies	None	Health and social care interactions: Rates of institutionalisation into full-time care for those using ChEI	Oxford Study
Hackett et al.[30]	2019	England	Dementia	Age Gender Education Deprivation	Health and social care interactions: Monthly interactions with family as a factor in occurrence of depressive symptoms among people with dementia.	English Longitudinal Study for Ageing (ELSA)
Hartz et al.[31]	2012	Germany	Alzheimer's disease	None	Diagnostics and medications: Societal savings based on anti-dementia medications.Anti-dementia medications impact on caregivers' QALYs.	Consortium to Establish a registry for Alzheimer's disease (CERAD)
Huang et al.[32]	1994	US	Alzheimer's disease	Age Gender Education	Disease progression, mortality and survival: Survival rates for different living arrangements and availability of caregiver(s).	South Carolina Statewide Alzheimer's Disease and Related Disorders Registry

(Continues)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Johnell et al.[33]	2013	Sweden	Alzheimer's disease, mixed Alzheimer's disease/Vascular dementia, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease dementia, unspecified dementia, other dementia	Age, Gender, Residence, Cohabitation	Diagnostics and medications: Anti-dementia medication use in dementia subtypes.	SveDem
Kahle-Wrobleski et al.[34]	2017	France, Germany, England	Alzheimer's disease	Age, Gender, Cohabitation, Caregiver variables	Disease progression, mortality and survival: Change in independence levels by disease severity impacts of various factors on progression of illness.	GERAS
Knapp et al.[35]	2016	England	Alzheimer's disease	Age, Gender, Ethnicity, Caregiver variables, Cohabitation	Care transitions: Probability of care home admission and socio-economic and other factors impact; and their associated costs. Health and social care interactions: Probability of hospital inpatient admissions and mental health inpatient admissions, with influential factors and associated costs.	South London Maudsley NHS Foundation Trust (SLAM) and Clinical Record Interactive Search (CRIS)
Korhonen et al.[36]	2018	Finland	Dementia	Age, Marital status, Deprivation	Care transitions: Probability of movement into long-term institutional care. Comparing those who died from dementia versus other causes and those who survived to the end of the study period	Finnish Death Register and national care registers
Miller et al.[37]	1998	US	Alzheimer's disease	Age, Gender, Marital status, Education	Care transitions: Risk factors associated with time to nursing home admission.	Consortium to Establish a Registry for Alzheimer's Disease (CERAD)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Moore et al.[38]	2001	US, Puerto Rico	Alzheimer's disease, vascular dementia	Age Ethnicity Education Marital status Caregiver variables	Informal care costs: Broken-down into four aspects: Value of caregiving times, caregivers' lost income, out-of-pocket expenditures for formal caregiving services, and caregivers' excess healthcare costs.	National Longitudinal Caregiver Study (NLCS)
Murman et al.[39]	2002	US	Alzheimer's disease, dementia with Parkinsonism, Huntington disease	Age Gender Ethnicity Education Marital status Caregiver variables	Health and social care interactions: Over 3.5 years: Use, time spent in and frequency of use of long-term care, hospital care and paid home care.	Michigan Alzheimer's Disease Research Center (MADRC) registry
Neumann et al.[40]	2001	US	Alzheimer's disease	Age Gender	Care transitions: Annual probability of care home transition. Annual probability of movement in severity of Alzheimer's disease.	Consortium to Establish a Registry for Alzheimer's Disease (CERAD)
Peterson et al.[6]	2008	US	Alzheimer's disease	Age Gender Education Marital status	Disease progression, mortality and survival: Survival in nursing homes: Socio-economic characteristics as predictive factors of survival with dementia.	Consortium to Establish a Registry for Alzheimer's Disease (CERAD)
Pujades-Rodrgiuez et al.[41]	2018	England	Alzheimer's disease, vascular dementia, rare dementias	Age Gender	Disease progression, mortality and survival: 10 years and lifetime risk split by age and gender (for all and Alzheimer's disease). Dementia versus non-dementia mortality rates	Clinical Practice Research Datalink (CPRD)

(Continues)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Ramsey et al.[42]	2018	US	Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, other dementias	Age; Gender; Ethnicity; Education; Residence; Cohabitation	Diagnostics and medications: Inappropriate prescription of medications in dementia subtypes	National Alzheimer's Coordinating Center (NACC)
Rattinger et al.[43]	2016	US	Alzheimer's disease, vascular dementia (without AD), other dementia	Age; Gender; Ethnicity	Informal care costs: Changes in informal care costs over time and due to illness progression.	Cache country study on memory in Ageing
Rudolph et al.[44]	2010	US	Alzheimer's disease	Age; Gender; Ethnicity; Education; Marital status	Health and social care interactions: Risk factors for hospitalisation; frequency and number of hospitalisations, days in hospital per year and primary diagnoses for hospitalisation for people with dementia	Massachusetts Alzheimer's Disease Research Center (MADRC) patient registry
Scalmana et al.[45]	2013	Italy	Alzheimer's disease, vascular dementia, mixed dementia, frontotemporal dementia, Lewy body dementia, Parkinson's dementia, other dementias	Age; Gender; Education; Caregiver variables	Health and social care interactions: Number of population using different social care services. Factors associated with use of services	Unità valutativa Alzheimer
Sheng et al.[46]	2009	Hong Kong	Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mild-cognitive impairment, undetermined dementia, other irreversible dementia	Age; Gender; Education; Residence; Caregiver variables	Diagnostics and medications: Brain imaging and lab tests by subtype of dementia. Care transitions: Residence at first versus final visit in studyFamilial informal care availability at first and final visit in study. Health and social care interactions: Use of home help, meal delivery and other services.	Memory clinic data

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
Smith et al.[7]	2001	US	Alzheimer's disease, vascular dementia, mixed dementia, other dementias	Age, Gender, Education, Marital status, Residence	Care transitions: Time to nursing home placement. Factors that can impact on nursing home placement.	National Institute on Aging funded Alzheimer's Disease Patient Registry (ADPR)
Sommerlad et al.[47]	2019	England	Alzheimer's disease, vascular dementia, dementia with Lewy bodies, other dementia, unspecified dementia	Age, Gender, Ethnicity, Marital status	Health and social care interactions: Predictive factors associated with probability of emergency and elective hospital admissions for people with dementia	South London Maudsley NHS Foundation Trust (SLAM) and Clinical Record Interactive Search (CRIS)
Stevnsborg et al.[48]	2016	Denmark	Dementia	Age, Gender, Marital status, Residence, Geography	Diagnostics and medications: Socio-economic factors in receiving anti-dementia medication after a diagnosis of dementia, for Danish-born, Western immigrants and non-Western immigrants living in Denmark. Care transitions: Likelihood of living in a nursing home when diagnosed with dementia for Danish-born, Western immigrants and non-Western immigrants	National patient registry; psychiatric central research registry; national prescription registry
Taipale et al.[49]	2014	Finland	Alzheimer's disease	Age, Gender	Diagnostics and medications: Factors associated with discontinuation of AChEI therapy	MEDALZ-2005 (medication use and Alzheimer's disease)
Thorpe et al.[50]	2016	US	Alzheimer's disease	Age, Gender, Ethnicity	Diagnostics and medications: Initiation and discontinuation of anti-dementia drugs.Rate of discontinuation and likelihood of initiation of anti-dementia drugs (for new users of AChEI) by ethnicity	Medicare
van de Vorst et al.[51]	2015	Netherlands	Alzheimer's disease, vascular dementia, other dementia	Age, Gender	Disease progression, mortality and survival: 1 and 5-year age-specific and sex-specific mortality risk for patients with dementia visiting a day clinic versus general population, and patients hospitalised with dementia versus those hospitalised with acute Myocardial infarction, heart failure or stroke	Dutch Hospital Discharge Register (HDR); Dutch Population Register (PR)

(Continues)

TABLE 1 (Continued)

Author	Year published	Country	Dementia population	Socio-economic variables	Pathway: Outcomes	Routine data set(s) used
van de Vorst et al.[52]	2016	Netherlands	Alzheimer's disease, vascular dementia	Age Gender Deprivation	Disease progression, mortality and survival: 1 and 5-year mortality risk for men and women stratified by age, income and setting of care (hospital, day clinic). 1 and 5-year mortality risk based on tertile of household income	Dutch Hospital Discharge Register (HDR); Dutch Population Register (PR); National Cause of Death Register; Regional Income Survey
van de Vorst et al.[53]	2019	Netherlands	Alzheimer's disease, Vascular dementia	Age Gender Geography	Disease progression, mortality and survival: 1 and 3-year mortality risk for patients visiting a first day clinic or first admission to hospital with dementia Health and social care interactions: Risk of hospital readmission with a year for patients visiting a first day clinic or first admission to hospital with dementia.	Dutch hospital discharge register (HDR); Dutch population register (PR); national Cause of death register
van Weel et al.[54]	2019	Australia	Dementia	Cohabitation Deprivation Language	Health and social care interactions: Use of home care services, receiving nursing interventions, admitted to hospital, other service use and care outcomes for people with dementia	NGO cohort data set
Verbeek et al.[5]	2015	England, Estonia, Finland, France, Germany, Netherlands, Spain, Sweden	Dementia	Geography	Health and social care interactions: Factors associated with risk of recently being admitted into and institutionalised long-term care	RightTimePlaceCare (RTPC)
Wattmo et al.[55]	2013	Sweden	Alzheimer's disease	Age Gender Education Cohabitation	Health and social care interactions: Time taken from commencement of ChEI treatment to receiving home help services and the amount of such services received.	Swedish Alzheimer Treatment Study (SATS)

Abbreviations: AChEI, acetylcholinesterase inhibitor; ChEI, cholinesterase inhibitor; MMSE, Mini–Mental State Examination; QALY, quality-adjusted life years.

TABLE 2 Papers analysing socio-economic deprivation or geography (county of residence) as a potential factor in outcome measures for people with dementia

Author	Year	Deprivation type	Analysis conducted using socio-economic variables
Cooper et al.[4]	2016	Townsend score quintiles; Country of residence	**Initiation of anti-dementia drugs**: -Compared to England → Northern Ireland significantly more, and Wales significantly less likely initiate anti-dementia drugs -Anti-dementia drug initiation → greatest in most affluent areas -Anti-dementia drug initiation → reduction with each quintile to most deprived
Cooper et al.[12]	2017	Townsend score quintiles	**Prescription prevalence for antipsychotics, hypnotics and anxiolytics**: -Most deprived areas → lowest prescription prevalence, but not s significantly so
Korhonen et al.[36]	2018	Household income quintile	**Probability of institutional LTC in 8 years before death/end of study**: -For men, increasing deprivation → increased institutionalisation in long-term care
Pujades-Rodgriguez et al.[41]	2018	Indices of multiple deprivation quintile	**Mortality differences between those with and without dementia**: -Greater proportion of deaths in deprived areas are of people with dementia
Sommerlad et al.[47]	2019	Indices of multiple deprivation decile	**Association of factors with hospital admissions a year after dementia diagnosis**: -Greater deprivation → increased risk of emergency admissions and reduced risk of elective admissions
van de Vorst et al.[52]	2016	Disposable household income tertile	**1 and 5-year mortality risk for people with a first hospitalisation or day clinic visit for dementia**: -Greater deprivation → increased mortality risk for men and women-deprivation and mortality more likely when visiting a day clinic versus hospital
Verbeek et al.[5]	2015	Country of residence	**Risk factors for recent admission to institutional long-term nursing care**: -Higher dependence for activities of daily living → increased move to long-term care in all countries -Lower caregiver burden → lower admissions to long-term care all countries (not Spain) -Having an informal carer who was a spouse → less admissions to long-term care all countries (not Estonia, France)

Socio-economic deprivation and country of residence were shown to impact the likelihood of receiving anti-dementia medication. Using UK primary care records, Cooper et al.[4] found areas of greatest deprivation had significantly lower rates of anti-dementia medication initiation than the most affluent. In the United Kingdom, there was a stepped-effect with each quintile from the most affluent quintile—which had the highest initiation—to the most deprived—which had the lowest initiation.

Taipale et al.[49] discovered that among people with Alzheimer's disease using acetylcholinesterase inhibitors (AChEI), older people were at a higher risk of AChEI discontinuation. However, evidence is somewhat conflicting regarding the impact of age on anti-dementia medication initiation. Although Cooper et al.[12] found people aged under 70 years, and ≥80 years were less likely to be prescribed

anti-dementia medication than people aged 7-79 years, several studies illustrate higher initiation for older people.[21,48–50]

Several studies demonstrated females had an increased probability of receiving anti-dementia medications.[12,19,21,33] However, the research available identified mixed evidence of the likelihood of having these medications discontinued.[49,50]

Thorpe et al.[50] also investigated the impact of ethnicity on initiation and discontinuation of anti-dementia medication. Among Medicare beneficiaries in the United States who were non-users of anti-dementia medications at the beginning, Hispanic people were significantly more likely to initiate use than any other ethnicity, with Black and Hispanic ethnicities significantly more likely to have their anti-dementia medications discontinued. Being 'non-native' to a country can also have an impact on the likelihood of receiving

medications. Stevnsborg et al.[48] found that Western and non-Western immigrants to Denmark were significantly less likely to receive anti-dementia medications than people born in Denmark.

3.6 | Health and social care interaction

Of 17 studies exploring health and social care interactions, eight involved socio-economic variables. The greater number of socio-economic risk factors somebody has, the greater their likelihood of hospitalisation,[44] for example. It was found that PwD living in the most socio-economically disadvantaged areas had a significantly higher risk of emergency hospital admission, and significantly lower probability of elective admissions.[47]

Evidence varies on the exact impact that ethnicity can have on admissions to hospital for PwD.[25,35,47] However, the variance in findings may be reflective of the country in which the studies were carried out, and their relevant health and social care systems.

Older PwD were at greater risk of hospitalisation.[25,35,44] However, the type of admissions demonstrates that they may be at greater risk of *emergency* hospital admissions, but a significantly reduced risk of both mental health inpatient[35] and elective admissions.[47] However, among PwD, those who are older (aged ≥80 years) and younger have a reduced probability of coming into contact with health and social care services in a more elective capacity. Cooper et al.[12] identified people aged under 70 years as less likely to come into contact with healthcare—even for annual dementia reviews—and those aged 80 and over were less likely to receive surgical consultations or weight monitoring checks. Furthermore, Wattmo et al.[55] discovered that for PwD, younger people had a longer delay in accessing home help services.

Care quality can also be impacted by socio-economic factors. Connolly et al.[20] found people living in the community had greater quality annual dementia reviews and overall care than those living in care homes, and Scalmana et al.[45] discovered that people with less education were less likely to access health and social care services.

3.7 | Disease progression, mortality and survival

Nine studies investigated direct outcomes and illness progression for PwD, with seven studies focussing on socio-economic factors.

Both age and gender were found to correlate with disease progression and mortality risk. Older people and men with Alzheimer's disease transitioned at a faster rate.[40] Women and those who were younger when receiving a dementia diagnosis were shown to have better survival,[6,32] with older people and men at greater risk of dying.[51,52]

Greater support is indicative of better survival, long-term independence and condition maintenance among PwD. As well as noting that less education is associated with poorer survival for PwD, Huang et al.[32] identified living in the community with a caregiver or in institutional care acted as a protective factor for survival among

people with Alzheimer's disease. Survival was worse for people living in a nursing home compared to those living at home,[6] living in the community with a caregiver or in institutional care acted as a protective factor for people with Alzheimer's disease and living with others and having multiple carers led to a greater likelihood of a PwD maintaining their dependence at the level at seen at study start.[34]

Pujades-Rodriguez et al.[41] compared people with and without dementia in retrospective analyses of mortality records. They illustrated PwD were more likely to live in deprived areas. Van de Vorst et al.[51,52] identified mortality risk as significantly higher for PwD living in the most socio-economically disadvantaged areas.

3.8 | Study quality

Using the NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies, some of the 14-points used to assess quality were not applicable (Table 3) and so had a maximum potential score of 10 or 11. One paper received a quality rating of 5 (out of 10), but the remainder received a rating of between 7 and 10. Thus, the studies included in this review are of moderate to high quality. As a whole, they were clear in their objectives and findings and tended to describe and deliver robust research methods.

4 | DISCUSSION

This is the first systematic review evaluating the use of routine and cohort data sets to investigate inequalities in dementia care pathways. Findings from this review highlight the advantage of using national longitudinal databases to explore inequalities in dementia care across the globe, highlighting numerous gaps and current inequalities in care which need to be addressed.

The most socio-economically deprived areas have higher rates of undiagnosed dementia.[56] Deprivation can be reflective of wider, social and structural factors, such as income, employment, housing and transport. GP practices from such areas are more likely to only have one GP and therefore have less time to identify, diagnose and manage dementia.[57] With greater unmet needs,[4] people from deprived areas are more likely to present to emergency healthcare services later in their disease trajectory when their condition is less manageable, resulting in poorer management and treatment. Inequality in primary care provision needs to be addressed, and promoting earlier identification and diagnosis of dementia needs to be prioritised as a means to enabling support for PwD in more disadvantaged areas.

We found evidence of inequalities in care transitions and medication use between ethnic groups. However, it is important to note that the inclusion criteria for papers in this review was for papers that included only people with a formal diagnosis of dementia. Although people from BAME groups are more likely to have dementia, they are less likely to be diagnosed[14,58] and are therefore underrepresented in services,[59] and may therefore be

TABLE 3 Quality rating checklist and applied scores

Author	Year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total	Applied checklist points
		Quality rating checklist points[a,b]															
Aaltonen et al.[16]	2012	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Calvo-Perxas et al.[19]	2014	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Connolly et al.[20]	2012	1	1	1	1	0	na	1	1	1	0	1	na	na	1	9	11
Cooper et al.[4]	2016	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Cooper et al.[12]	2017	1	1	na	1	0	na	1	1	1	1	1	na	na	1	9	10
Donegan et al.[21]	2017	0	1	na	1	0	na	1	0	1	0	1	na	na	0	5	10
Fillenbaum et al.[25]	2001	0	1	na	1	0	na	1	1	1	1	1	na	na	1	8	10
Huang et al.[32]	1994	1	1	na	1	0	na	1	0	1	0	1	na	na	1	7	10
Johnell et al.[33]	2013	1	1	na	1	0	na	1	1	1	1	1	na	na	1	9	10
Kahle-Wrobleski et al.[34]	2017	1	1	na	1	0	1	1	1	1	1	1	na	na	0	9	11
Knapp et al.[35]	2016	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11
Korhonen et al.[36]	2018	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Miller et al.[37]	1998	1	1	na	1	0	1	1	1	1	1	1	na	na	0	9	11
Neumann et al.[40]	2001	1	1	na	1	0	1	1	1	1	0	1	na	na	0	8	11
Peterson et al.[6]	2008	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Pujades-Rodriguez et al.[41]	2018	1	1	na	1	0	0	1	0	1	1	1	na	na	0	7	11
Rudolph et al.[44]	2010	1	1	na	1	0	1	1	0	1	0	1	na	na	1	8	11
Scalmana et al.[45]	2013	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11
Smith et al.[7]	2001	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Sommerlad et al.[47]	2019	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Stevnsborg et al.[48]	2016	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Taipale et al.[49]	2014	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Thorpe et al.[50]	2016	1	1	na	1	0	1	1	na	1	0	1	na	na	1	8	10
van de Vorst et al.[51]	2015	1	1	na	1	0	1	1	na	1	0	1	na	na	0	7	10
van de Vorst et al.[52]	2016	0	1	na	1	0	1	1	1	1	0	1	na	na	1	8	11
Verbeek et al.[5]	2015	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Wattmo et al.[55]	2013	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11

Abbreviations: na, not applicable; NIH, National Institutes of Health.

[a]Checklist points, NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies: **1**. Was the research question or objective in this paper clearly stated? **2**. Was the study population clearly specified and defined? **3**. Was the participation rate of eligible persons at least 50%? **4**. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants? **5**. Was a sample size justification, power description, or variance and effect estimates provided? **6**. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured? **7**. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed? **8**. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure or exposure measured as continuous variable)? **9**. Were the exposure measures (independent variables) clearly defined, valid, reliable and implemented consistently across all study participants? **10**. Was the exposure(s) assessed more than once over time? **11**. Were the outcome measures (dependent variables) clearly defined, valid, reliable and implemented consistently across all study participants? **12**. Were the outcome assessors blinded to the exposure status of participants? **13**. Was loss to follow-up after baseline 20% or less? **14**. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?

[b]na, not applicable (point on quality rating was not applicable to the research paper and so was not included in final total or maximum score; 0 = did not meet criteria, 1 = met criteria).

underrepresented in the studies included in our review. Diagnosis is a gateway to accessing care and support, compounding the disadvantage and barriers minority ethnic groups face in diagnosis and beyond.[59–62] Lack of diagnosis leads to poorer care and makes it more difficult to manage dementia, which our review highlighted. Poor, inconsistent care results in accelerated disease progression, increased dependence and shortened lives. These differences emphasise need for increased awareness of dementia and more equitable service provision. We also need to better understand how to provide culturally appropriate services for PwD.

This review highlighted that lower educational attainment resulted in less care access and poorer survival outcomes. Higher educational attainment is associated with greater health literacy, which leads to increased access to both better quality and a wider breadth of treatment and care.[63] People with lower educational attainment are less likely to know where to go, who to ask, and what treatment and care is available. They are therefore more likely to have delayed diagnosis and only receive care once their condition has worsened, resulting in faster disease progression, greater interactions with emergency and institutional care, leading to negative health and social outcomes. More needs to be done to improve health literacy. Awareness of dementia and the potential benefits of early diagnosis can help to maintain home care and independence for longer and provide a better quality of life for PwD and their carers.

We find that women receive better treatment and require less urgent care. Although they enter Institutional Long-Term Care (ILTC) earlier and use less elective healthcare and social care services, they tend to have a slower disease trajectory and better outcomes. This indicates variance in informal care provision and societal, gender-based caregiving expectations.[64] Women provide more hands-on care, experiencing a greater caregiver burden.[65,66] With men more likely to be given care at home for longer,[65,66] but more likely to exhibit more difficult behavioural symptoms,[67] a critical point may come when caring for someone at home becomes too difficult. This is reflected in greater use of urgent healthcare and later movements to ILTC for men, and their resultant poorer outcomes.

We have identified older PwD are more likely to live alone. PwD who live alone, are more often unmarried and older, require more urgent healthcare, move into ILTC, and have poorer outcomes. Maintaining independence improves survival, but a lack of informal care,[68,69] greater comorbidities and frailty,[70,71] poor prognosis from elective hospital treatments[72] and heightened dementia severity, lead to older PwD being more likely to spend longer in hospital and encounter poorer outcomes.[73]

We find that greater caregiver burden and less support increase emergency healthcare use and ILTC. PwD in ILTC have poorer primary healthcare experiences and worse survival. Carers feel a sense of duty[74] and take on great responsibility.[75] However, with substantial caregiver burden, PwD are less likely to use services that can aid longevity of care at home[76] leading to extensive informal home care becoming unfeasible, resulting in greater ILTC and urgent healthcare use.

Being able to manage and care for PwD at home is critical to the sustainability of the health and social care system.[8] Lack of informal care, or having informal caregivers with greater burden, can generate adverse outcomes for PwD. We have highlighted that both are factors which differ for men and women with dementia and for older PwD. Better communication from primary care of what to expect when providing informal care for PwD, and increased community care provision[77] could reduce caregiver strain, maintain independence at home for longer and reduce the need for emergency healthcare and ILTC. Informal carers need support and those without it, need to be cared for.

4.1 | Strengths and limitations

To our knowledge, this is the first review to identify inequalities in dementia care pathways globally through the use of routine data. We have generated a detailed synthesis of the literature available for various socio-economic factors in dementia care pathways. We have searched multiple evidence bases for available literature and have assessed the quality of all included papers, judging the value of each paper based on its quality rating as measured and agreed on by two research team members.

Some limitations of our review include that we only included English-language studies. This may reduce the likelihood of this review appraising dementia care pathways and inequalities in non-English speaking countries, and therefore the generalisability of our findings to a greater range of geographic settings. In terms of limitations of the included literature, there was limited evidence comparing countries, potentially reducing generalisability of findings across geographic areas. Further to this, the majority of studies were based in the United Kingdom, United States and mainland Europe, highlighting potential issues with applying findings to other areas, particularly 'non-Western' countries. While some studies compared and contrasted different national settings (i.e., Verbeek et al.[5]), these were all European countries. Moreover, the majority of studies investigated only one or two socio-economic outcomes, with most evidence on hospital use and ILTC. This highlights the need for greater research in all aspects of the dementia care pathway. No single measure is likely to account for the variance in experiences of PwD. Future research should look to widen the geographic scope and outcomes considered when investigating dementia care pathways and inequalities in care for PwD.

5 | CONCLUSIONS AND IMPLICATIONS

This systematic review has identified clear inequalities in current dementia care pathways across the globe, and the advantages of using existing routine and cohort data sets to explore and highlight these. Whilst there is a burgeoning literature on inequalities due to some socio-economic factors, there is a dearth of research identifying the impact of such factors in combination and the specific pathways

through which they operate. Our findings however are important to guide the production of improved care plans to ensure that everyone living with dementia and affected by the condition receives the right care at the right time. Maintaining care at home is mutually beneficial and can narrow inequalities but requires informal carers to be supported—we need to identify ways to reduce carer burden, aid care at home and improve outcomes as a result. Moreover, there is a need to provide a more equitable service to PwD, improve the availability of culturally appropriate services and to provide services to PwD who are not in the position of being able to call on informal care from family or friends.

CONFLICTS OF INTEREST

None.

DATA AVAILABILITY STATEMENT

Papers included in this systematic review were obtained via University of Liverpool library access to individual journals. No primary data were collected as part of this study.

ORCID

Clarissa Giebel (ID) https://orcid.org/0000-0002-0746-0566

REFERENCES

1. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom, 2019-2040*. London, England: Care Policy and Evaluation Centre; 2019:1-79.
2. Government Office for Science. *Future of an Ageing Population*. Oxford, England: Oxford Institute of Population Ageing; 2016:124.
3. Cermakova P, Nelson M, Secnik J, et al. Living alone with Alzheimer's disease: data from SveDem, the Swedish Dementia Registry. *J Alzheimers Dis*. 2017;58(4):1265-1272.
4. Cooper C, Lodwick R, Walters K, et al. Observational cohort study: deprivation and access to anti-dementia drugs in the UK. *Age Ageing*. 2016;45(1):148-154.
5. Verbeek H, Meyer G, Challis D, et al. Inter-country exploration of factors associated with admission to long-term institutional dementia care: evidence from the RightTimePlaceCare study. *J Adv Nurs*. 2015;71(6):1338-1350.
6. Peterson BL, Fillenbaum GG, Pieper CF, Heyman A. Home or nursing home: does place of residence affect longevity in patients with Alzheimer's disease? the experience of CERAD patients: special features: Methods. *Publ Health Nurs*. 2008;25(5):490-497.
7. Smith GE, O'Brien PC, Ivnik RJ, Kokmen E, Tangalos EG. Prospective analysis of risk factors for nursing home placement of dementia patients. *Neurology*. 2001;57(8):1467-1473.
8. Ogden J. Rising cost of dementia care risks social care funding crisis. *Prog Neurol Psychiatry*. 2017;21(1):5.
9. Wu YT, Clare L, Jones IR, et al. Inequalities in living well with dementia—the impact of deprivation on well-being, quality of life and life satisfaction: results from the improving the experience of dementia and enhancing active life study. *Int J Geriatr Psychiatry*. 2018;33(12):1736-1742.
10. Bone AE, Evans CJ, Etkind SN, et al. Factors associated with older people's emergency department attendance towards the end of life: a systematic review. *Eur J Public Health*. 2019;29(1):67-74.
11. Cooper C, Tandy AR, Balamurali TBS, Livingston G. A systematic review and meta-analysis of ethnic difference in use of dementia treatment, care and research. *J Allergy Clin Immunol*. 2010;18(3):193-203.
12. Cooper C, Lodwick R, Walters K, et al. Inequalities in receipt of mental and physical healthcare in people with dementia in the UK. *Age Ageing*. 2017;46(3):393-400.
13. 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.
14. Mukadam N, Cooper C, Livingston G. Improving access to dementia services for people from minority ethnic groups. *Curr Opin Psychiatry*. 2013;26(4):409-414.
15. Campbell M, Katikireddi SV, Sowden A, McKenzie JE, Thomson H. Improving conduct and reporting of narrative synthesis of quantitative data (ICONS-quant): protocol for a mixed methods study to develop a reporting guideline. *BMJ Open*. 2018;8(2):1-5.
16. Knapp M, Chua KC, Broadbent M, et al. Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. *BMJ Open*. 2016;6(11):1-15.
17. Korhonen K, Einio E, Leinonen T, Tarkiainen L, Martikainen P. Time-varying effects of socio-demographic and economic factors on the use of institutional long-term care before dementia-related death: a Finnish register-based study. *PLoS One*. 2018;13(6):1-16.
18. Stevnsborg L, Jensen-Dahm C, Nielsen TR, Gasse C, Waldemar G. Inequalities in access to treatment and care for patients with dementia and immigrant background: a Danish nationwide study. *J Alzheimers Dis*. 2016;54(2):505-514.
19. Aaltonen M, Rissanen P, Forma L, Raitanen J, Jylhä M. The impact of dementia on care transitions during the last two years of life. *Age Ageing*. 2012;41(1):52-57.
20. Neumann PJ, Araki SS, Arcelus A, et al. Measuring Alzheimer's disease progression with transition probabilities: estimates from CERAD. *Neurology*. 2001;57(6):957-964.
21. Taipale H, Tanskanen A, Koponen M, Tolppanen AM, Tiihonen J, Hartikainen S. Antidementia drug use among community-dwelling individuals with Alzheimer's disease in Finland: a nationwide register-based study. *Int Clin Psychopharmacol*. 2014;29(4):216-223.
22. Donegan K, Fox N, Black N, Livingston G, Banerjee S, Burns A. Trends in diagnosis and treatment for people with dementia in the UK from 2005 to 2015: a longitudinal retrospective cohort study. *Lancet Public Health*. 2017;2(3):e149-e156.
23. Thorpe CT, Fowler NR, Harrigan K, et al. Racial and ethnic differences in initiation and discontinuation of antidementia drugs by Medicare beneficiaries. *J Am Geriatr Soc*. 2016;64(9):1806-1814.
24. Calvó-Perxas L, Turró-Garriga O, Aguirregomozcorta M, et al. Psychotropic drugs in patients with Alzheimer's disease: a longitudinal study by the Registry of Dementias of Girona (ReDeGi) in Catalonia, Spain. *J Am Med Dir Assoc*. 2014;15(7):497-503.
25. Johnell K, Religa D, Eriksdotter M. Differences in drug therapy between dementia disorders in the Swedish Dementia Registry: a nationwide study of over 7,000 patients. *Dement Geriatr Cogn Disord*. 2013;35(5-6):239-248.
26. Rudolph JL, Zanin NM, Jones RN, et al. Hospitalization in community-dwelling persons with Alzheimer's disease; frequency and causes. *J Am Geriatr Soc*. 2010;58(8):1542-1548.

27. Sommerlad A, Perera G, Mueller C, et al. Hospitalisation of people with dementia: evidence from English electronic health records from 2008 to 2016. *Eur J Epidemiol.* 2019;34(6):567-577.

28. Fillenbaum G, Heyman A, Peterson BL, Pieper CF, Weiman AL. Use and cost of outpatient visits of AD patients: CERAD XXII. *Neurology.* 2001;56(12):1706-1711.

29. Wattmo C, Paulsson E, Minthon L, Londos E. A longitudinal study of risk factors for community-based home help services in Alzheimer's disease: the influence of cholinesterase inhibitor therapy. *Clin Interv Aging.* 2013;8:329-339.

30. Connolly A, Iliffe S, Gaehl E, et al. Quality of care provided to people with dementia: utilisation and quality of the annual dementia review in general practice. *Br J General Pract.* 2012;62(595):91-98.

31. Scalmana S, Di Napoli A, Franco F, et al. Use of health and social care services in a cohort of Italian dementia patients. *Funct Neurol.* 2013;28(4):265-273.

32. Huang Y, Macera CA, Cornman CB, Davis DR, Scott WK, Neff L. Survival of Alzheimer's disease patients with regard to pattern of care in South Carolina. 1988-1993, *J S C Med Assoc.* 1994;90(2):51-55.

33. Van de Vorst IE, Vaartjes I, Geerlings MI, Bots ML, Koek HL. Prognosis of patients with dementia: results from a prospective nationwide registry linkage study in the Netherlands. *BMJ Open.* 2015;5(10):e008897.

34. Van de Vorst IE, Koek HL, Stein CE, Bots ML, Vaartjes I. Socioeconomic disparities and mortality after a diagnosis of dementia: results from a nationwide registry linkage study. *Am J Epidemiol.* 2016;184(3):219-226.

35. Kahle-Wrobleski K, Andrews JS, Belger M, et al. Dependence levels as interim clinical milestones along the continuum of Alzheimer's disease: 18-month results from the GERAS Observational Study. *J Prev Alzheimers Dis.* 2017;4(2):72-80.

36. Pujades-Rodriguez M, Assi V, Gonzalez-Izquierdo A, et al. The diagnosis, burden and prognosis of dementia: a record-linkage cohort study in England. *PLoS One.* 2018;13(6):1-12.

37. Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: variations in the observed prevalence and comparisons to the expected prevalence. *Aging Mental Health.* 2011;15(8):978-984.

38. Kelly E, Stoye G. *GP Practice Size and Quality of Primary Care.* London, England: Institute for Fiscal Studies; 2014. https://www.ifs.org.uk/publications/7445

39. Pham TM, Petersen I, Walters K, et al. Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. *Clin Epidemiol.* 2018;10:949-960.

40. Giebel CM, Zubair M, Jolley D, et al. South Asian older adults with memory impairment: improving assessment and access to dementia care. *Int J Geriatr Psychiatry.* 2015;30(4):345-356.

41. 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 Psychiatry.* 2017;17(1):316.

42. Memon A, Taylor K, Mohebati LM, et al. Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *BMJ Open*, 2016;6(11):1-9.

43. Parveen S, Oyebode JR. Better health briefing 46 dementia and minority ethnic carers. 2018. http://raceequalityfoundation.org.uk/wp-content/uploads/2018/07/REF-Better-Health-463.pdf. Accessed May 2020.

44. Protheroe J, Nutbeam D, Rowlands G. Medical ethics and the healthcare rights of citizens and others. *Br J General Pract*, 2009;59(567):720-721.

45. Miller B. Gender differences in spouse caregiver strain: socialization and role explanations. *J Marriage Fam*, 1990;52(2):311-321.

46. Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family—caregivers of people with mental illnesses. *World J Psychiatry*, 2016;6(1):7.

47. Sutcliffe CL, Giebel CM, Jolley D, Challis DJ. Experience of burden in carers of people with dementia on the margins of long-term care. *Int J Geriatr Psychiatry*, 2016;31(2):101-108.

48. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. *Front Neurology*, 2012;3:1-21.

49. Zwaanswijk M, Peeters JM, van Beek APA, Meerveld JHCM, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurs J*, 2013;7:6-13.

50. Van Groenou MIB, De Boer A. Providing informal care in a changing society. *Eur J Ageing*, 2016;13(3):271-279.

51. Bunn F, Burn AM, Goodman C, et al. Comorbidity and dementia: a scoping review of the literature. *BMC Med*, 2014;12(1):192.

52. Nelis SM, Wu YT, Matthews FE, et al. The impact of co-morbidity on the quality of life of people with dementia: findings from the IDEAL study. *Age Ageing*, 2019;48(3):361-367.

53. Kassahun WT. The effects of pre-existing dementia on surgical outcomes in emergent and nonemergent general surgical procedures: assessing differences in surgical risk with dementia. *BMC Geriatr*, 2018;18(1),1-9.

54. George J, Long S, Vincent C. How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions. *J R Soc Med*, 2013;106(9):355-361.

55. Brodaty H, Donkin M. Clinical research. *Dialogues Clin Neurosci*, 2019;11(2):217-228.

56. Wanless D. *Securing Good Care for Older People: Taking a Long-term View.* London, England: King's Fund; 2016. http://www.kingsfund.org.uk/resources/publications/appendices_to.html

57. Cotrell V, Engel RJ. Living alone and depression among older Chinese immigrants. *J Gerontological Soc Work*, 1999;4372-(907140962):37-41.

58. Dawson A, Bowes A, Kelly F, Velzke K, Ward R. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics*, 2015;15(1):59.

59. Bunn F, Burn A, Goodman C, et al. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). *Health Serv Deliv Res*, 2016;4(8):1-156.

60. Calvó-Perxas L, De Eugenio RM, Marquez-Daniel F, et al. Profile and variables related to antipsychotic consumption according to dementia subtypes. *Int Psychogeriatr*, 2012;24(6):940-947.

61. Eriksson H, Fereshtehnejad S, Falahati F, Farahmand B, Religa D, Eriksdotter M. Differences in routine clinical practice between early and late onset Alzheimer's disease: data from the Swedish Dementia Registry (SveDem). *J Alzheimers Dis*, 2014;41(2):411-419.

62. Fereshtehnejad SM, Damangir S, Cermakova P, Aarsland D, Eriksdotter M, Religa D. Comorbidity profile in dementia with Lewy bodies versus Alzheimer's disease: a linkage study between the Swedish Dementia Registry and the Swedish National Patient Registry. *Alzheimers Res Ther*, 2014;6(5-8):1-14.

63. Fereshtehnejad SM, Johannsen P, Waldemar G, Eriksdotter M. Dementia diagnosis, treatment, and care in specialist clinics in two Scandinavian countries: a data comparison between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry. *J Alzheimers Dis*, 2015;48(1):229-239.

64. Fong TG, Jones RN, Marcantonio ER, et al. Adverse outcomes after hospitalization and delirium in persons with Alzheimer disease. *Ann Intern Med*, 2012;156(12):848-W296.

65. Frahm-Falkenberg S, Ibsen R, Kjellberg J, Jennum P. Health, social and economic consequences of dementias: a comparative national cohort study. *Eur J Neurology*, 2016;23(9):1400-1407.

66. Gillette-Guyonnet S, Andrieu S, Nourhashemi F, et al. Long-term progression of Alzheimer's disease in patients under antidementia drugs. *Alzheimers Dement*, 2011;7(6):579-592.

67. Gustavsson A, Van Der Putt R, Jonsson L, McShane R. Economic evaluation of cholinesterase inhibitor therapy for dementia: comparison of Alzheimer's disease and dementia with Lewy bodies. *Clin Interv Aging*, 2009;24:1072-1078.

68. Hackett RA, Steptoe A, Cadar D, Fancourt D. Social engagement before and after dementia diagnosis in the English Longitudinal Study of ageing. *PLoS One*, 2019;14(8):1-12.

69. Hartz S, Getsios D, Tao S, Blume S, Maclaine G. Evaluating the cost effectiveness of donepezil in the treatment of Alzheimer's disease in Germany using discrete event simulation. *BMC Neurol*, 2012;12(1):2.

70. Miller SC, Prohaska TR, Furner SE, Freels S, Brody JA, Levy PS. Time to nursing home admission for persons with Alzheimer's disease: the effect of health care system characteristics. *J Gerontol B Psychol Sci Soc Sci*. 1998;53(6):341-353.

71. Moore MJ, Zhu CW, Clipp EC. Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. *J Gerontol B Psychol Sci Soc Sci*. 2001;56(4):219-228.

72. Murman DL, Chen Q, Colucci PM, Colenda CC, Gelb DJ, Liang J. Comparison of healthcare utilization and direct costs in three degenerative dementias. *Am J Geriatric Psychiatry*. 2002;10(3):328-336.

73. Ramsey CM, Gnjidic D, Agogo GO, Allore H, Moga D. Longitudinal patterns of potentially inappropriate medication use following incident dementia diagnosis. *Alzheimers Dement (N Y)*. 2018;4:1-10.

74. Rattinger GB, Schwartz S, Mullins C, et al. Dementia severity and the longitudinal costs of informal care in the Cache County population. *Physiol Behav*. 2016;176(1):139-148.

75. Sheng B, Law CB, Yeung KM. Characteristics and diagnostic profile of patients seeking dementia care in a memory clinic in Hong Kong. *Int Psychogeriatr*. 2009;21(2):392-400.

76. Van de Vorst IE, Vaartjes I, Bots ML, Koek HL. Increased mortality and hospital readmission risk in patients with dementia and a history of cardiovascular disease: results from a nationwide registry linkage study. *Int J Geriatr Psychiatry*. 2019;34(3):488-496.

77. van Weel JM, Renehan E, Ervin KE, Enticott J. Home care service utilisation by people with dementia—a retrospective cohort study of community nursing data in Australia. *Health Soc Care Community*. 2019;27(3):665-675.