Social and spatial inequalities in healthcare use and health outcomes among people living with dementia in England

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy (or other degree as appropriate)

by James Robert Watson

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James Robert Watson

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Abstract

Introduction

The number of people living with dementia (PLWD) continues to rise. PLWD from disadvantaged groups are more likely to experience delayed or incorrect diagnoses, suboptimal care, transitions into nursing care, lower quality of life and increased mortality risk. Big data can support understanding of inequalities in among PLWD and identify solutions for narrowing these inequalities. The aims of this PhD project were to: (i) synthesise evidence of inequalities from existing research using routine and cohort datasets, and identify gaps in the current literature. In identifying research gaps from this synthesis, the PhD thesis then aimed to: employ big data to identify variations among PLWD in (ii) their use of different types of primary and secondary healthcare services, (iii) risk of mortality, and (iv) experience of different temporal patterns in primary and secondary healthcare use in the five-years after dementia diagnoses, and the risk of subsequent mortality.

Methods

To address the aims of this PhD, three quantitative research studies and a systematic review were conducted. A systematic review synthesised evidence of dementia inequalities from research using routinely-collected data and identified gaps in the existing research. The gaps in the literature led to the development of three quantitative research papers utilising big data. Clinical Practice Research Datalink (CPRD) data included ~120 million healthcare contacts for over 142,300 people diagnosed with dementia in England between 2002-2016, examining geographic and socio-economic inequalities. Regression models evidenced the simultaneous impact of explanatory factors on mortality risk and healthcare use. Finally,

clusters of PLWD were created based on healthcare use trajectories post-diagnosis. Cox proportional hazards regression evidenced variation in subsequent mortality across clusters.

Results

Findings highlight numerous inequalities for PLWD. The systematic review showed differences in care transitions, care quality, dementia progression and survival, associated with demographic, geographic and socio-economic factors. Quantitative studies demonstrated variations in mortality risk and healthcare use, associated with age, sex, ethnicity, deprivation and geography. Specifically, men, older PLWD and PLWD from more deprived areas experience greater risk of mortality, and men, people from White ethnicity groups and PLWD from more deprived and rural areas were more likely to encounter healthcare use associated with poor health outcomes. Additionally, four distinct trajectories in healthcare use were noted in early- and late-onset populations. Variation in mortality risk was associated with different patterns in healthcare use.

Discussion

This PhD sought to address gaps in the dementia care inequalities literature. By using big data this PhD identifies the simultaneous impact of multiple social and spatial factors in healthcare use and mortality risk among PLWD. Novel evidence also demonstrates temporal patterns in healthcare use among PLWD, and the impact of healthcare trajectories on subsequent mortality. This PhD demonstrates geographic and socio-economic inequalities in dementia, and the extent to which mortality risk varies based on healthcare pathways. Some subpopulations encounter suboptimal care and worse health outcomes, exacerbated by an underfunded and understaffed health and social care system. Our findings highlight the need for health and social care to view care among PLWD as heterogenous, and the benefits of involving PLWD and carers in their own care decisions. Promoting better and more accessible and consistent care for PLWD requires identification of initial, and changing needs. Identification of need, and person-centred care can illuminate the specific needs of

the individual and make care more appropriate and accessible to the individual, which has the potential to narrow inequalities in how PLWD experience care and health outcomes. Future research should explore more factors of inequalities, comprehensive care trajectories, develop international collaborations and employ data science to support decision-making.

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List of Abbreviations

A&E	Accident & Emergency
AChEI	Acetylcholinesterase inhibitor
ADPR	Alzheimer's Disease Patient Registry
BIC	Bayesian Information Criterion
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CFAS	Cognitive Function and Ageing Studies
CI	Confidence Interval(s)
CPH	Cox Proportional Hazards
CPRD	Clinical Practice Research Datalink
CRIS	Clinical Record Interactive Search
EHR	Electronic Health Record
ELSA	English Longitudinal Study of Ageing
GP	General Practice(s)
HDR	Hospital Discharge Register
HR	Hazard Ratio(s)
IIR	Incidence Rate Ratio(s)
ILTC	Institutional Long-Term Care
IMD	Indices of Multiple Deprivation
LogLik	Log-Likelihood
MADRC	Massachusetts Alzheimer's Disease Research Center
MEDALZ	Medication Use and Alzheimer's Disease
NACC	National Alzheimer’s Coordinating Center
NHS	National Health Service
NIH	National institutes of Health
NIHR	National Institute for Health Research
NLCS	National Longitudinal Caregiver Study
ONS	Office for national Statistics
OR	Odds Ratio(s)
PLWD	People Living With Dementia
PPIE	Public and Patient Involvement and Engagement
PR	Population Register
ReDiGi	Registry of Dementia of Girona
RR	Relative Risk
RTPC	RightTimePlaceCare
SATS	Swedish Alzheimer Treatment Study
SLAM	South London Maudsley
SveDem	Swedish Dementia Registry
THIN	The Health Improvement Network
UK	United Kingdom
US	United States

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1. Chapter 1: Introduction

1.1. Background

Dementia is an umbrella term for a group of syndromes associated with impaired cognitive function and progressive neurocognitive decline (NHS, 2020). Some symptoms are more common among people living with dementia (PLWD) and can impact their day-to-day functioning. These include both instrumental activities of daily living (IADL) - such as household tasks, meal preparation and adherence to medications – and basic activities of daily living (ADL) – such as bathing and dressing oneself (Giebel, Sutcliffe and Challis, 2015). There are subtypes of dementia which have additional or differential symptomatology (NHS, 2022 (2)). Alzheimer's Disease is the most prevalent subtype of dementia and often exhibits memory loss and difficulties in social situations, particularly in unfamiliar environments (NHS, 2020). Symptoms of dementia can be less or more severe depending on the subtype, especially in the early stages. Vascular dementia can include muscle weakness, short-term paralysis and difficulties with movement, mood and understanding (NHS, 2020 (2)). Dementia with Lewy bodies can present with impairment in vision and perception, motor difficulties, difficulties in speech and speed of thinking, and hallucinations, unsteadiness and sleep disturbances (NHS, 2020 (3)). Frontotemporal dementia can present with behavioural changes – including inappropriate or less-empathetic behaviour (NHS, 2020 (4)). As dementia progresses, the number and severity of symptoms can increase. More acute issues with memory, communication and mobility, combined with the potential for greater behavioural changes and issues with maintaining ones' health can present greater needs in ADLs and IADLs for PLWD (Alzheimer's Society, 2021). Dementia currently has no cure and treatment is aimed at managing and delaying the symptoms and impacts of dementia (NHS, 2021), making timely and effective diagnosis, treatment and support vital (Alzheimer's Society, 2021 (2)).

There are approximately 944,000 PLWD in the UK (Dementia Statistics Hub, Alzheimer's Society, 2022). Having accounted for less than 4% of all deaths in the UK in 2005, dementia was the primary cause of one in every ten deaths in 2021 (Dementia Statistics Hub, Alzheimer's Society, 2022). In part due to an ageing UK population (Alzheimer's Society, 2022), the prevalence of dementia is set to continue to rise, with forecasts suggesting that there will be more than 1 million PLWD by 2024, and by 2040 that figure is expected to reach 1.4 million (Dementia Statistics Hub, Alzheimer's Research UK, 2022 (2)). The largest proportional increase in the number of PLWD is expected to be among those with more severe symptoms, and therefore more acute needs (Wittenberg et al., 2020). Due to the increasing number of PLWD, and a greater proportion of PLWD having more acute needs as a result of the severity of their condition, the cost of providing health and social care to PLWD is projected to increase threefold by 2030 (Andersen et al., 2003; Wittenberg et al., 2020).

In 2015, the government published '*The Prime Minister's Challenge on Dementia*'. This paper stated the government saw dementia as a public health priority and they would deliver on specific targets by 2020 (Department of Health and Social Care, 2015). These targets have not been delivered on, and even prior to the end of the target period one review illustrated that professionals felt some commitments would not be delivered (British Geriatrics Society, 2018). Public health authorities, GPs, and the wider health and social care workforce were not adequately funded to provide the length and breadth of support needed to improve the situation for PLWD (British Geriatrics Society, 2018). Since these Government commitments, reform of an unfair system and greater funding have not been delivered. Instead, care for PLWD has stagnated, and with greater demand, services are under growing pressures (Local Government, 2021; UK Parliament, 2021). The intensive and specific support needs for PLWD were amplified during the COVID-19 pandemic and the impact of the pandemic has not been fully alleviated (Alzheimer's Society, 2020(1); Giebel et al., 2021; Numbers and Brodaty, 2021). Health and social care services are

stretched, and a lack of resources and staffing are resulting in a system struggling to meet growing demands from an increasingly ageing population (Alzheimer's Society, 2022). A new 10-year dementia plan was announced by the UK Government in 2022, with further commitments to funding dementia care and research (Department of Health and Social Care, 2022). However, Governmental changes have meant the plan remains inactive, and once again professionals and experts feel this funding would fall short of that required to significantly impact care for PLWD (Alzheimer's Society, 2022; Alzheimer's Society, 2023).

Lack of funding results in suboptimal service delivery and inadequate staffing, which has an impact on the level and quality of care PLWD receive (Alzheimer's Society, 2022). Government inaction will impact the UK population of PLWD, but different groups in society are more likely to be unequally affected and experience poorer health as a result (UK Dementia Research Institute, 2022). Health inequalities are the *'avoidable differences in health outcomes between groups or populations'* (Office for Health Improvement & Disparities, 2022). In the Marmot review in 2010, large swathes of health inequalities were noted across the life course, highlighting the impact of the wider, social determinants of health (Institute of Health Equity, 2010). The wider determinants of health refer to the distribution of access and availability of resources which enable positive health (Institute of Health Equity, 2010).

The demographic, geographic, socio-economic and wider determinants of health do not exist in silos. They are often cumulative and multifactorial (The King's Fund, 2022). When studying these wider determinants of health, we therefore need to consider frameworks which make explicit the multiple and interacting nature of the drivers of inequalities. One important framework that underpins the thinking in this thesis is intersectionality. With roots in Black Feminist literature, intersectionality makes explicit the multiple interacting dimensions for how structural issues produce injustices in health (Agenor, 2020). The presence of intersectionality has been evidenced in dementia, particularly when identifying gaps in the experiences of PLWD (Dilworth-Anderson, Moon and Aranda, 2020; Roes et al.,

2022), and when evidencing the social exclusion and subsequent impacts on the use of services and health outcomes (Adames et al., 2020; Archibald, Innes and Murphy, 2004; Harari and Lee, 2022). As such, it is important to be cognizant of the intersectional nature of factors that can impact health, health and social care access, and health outcomes (Archibald, Innes and Murphy, 2004). While this thesis was unable to fully implement a truly intersectional analysis, this framework is key for justifying the need to consider a multitude of axes of inequality in the analyses.

Some social groups are less likely to have access, or have limited availability, to green spaces, job market or quality education for example, that can enable good quality health (Dahlgren and Whitehead, 1991). Those more likely to be disadvantaged are more likely to experience poorer relative health and health outcomes (The King's Fund, 2021). Health and health outcome inequalities exist by sex, whether a person lives in an urban or rural area, those from more socio-economically deprived areas or with lower incomes, and people from minoritised ethnic groups (Institute of Health Equity, 2020; The King's Fund, 2022).

There are inequalities in many outcomes in dementia. From the outset, PLWD may encounter issues in accessing a dementia diagnosis (Ahmad et al., 2010; Mukadam et al., 2013; Vohra et al., 2021). They may also face inequalities once they receive their dementia diagnosis, in terms of their access to health and social care (Giebel et al., 2021), and in their likelihood of experiencing poor health outcomes (Wu et al., 2018). There are variations in the health of PLWD, the quality of the health and social care they encounter, and their risk of worse health outcomes, as a result of demographic, geographic and socio-economic characteristics (UK Dementia Research Institute, 2022). For example, people living in areas of greater deprivation and from minoritised ethnic backgrounds are more likely to have dementia, but are less likely to receive an official diagnosis (Gamble et al., 2022; Tsamakis et al., 2021). Getting a dementia diagnosis is a gateway to accessing care and treatment (Morgan et al., 2009), but delays, misdiagnoses of dementia subtypes, particularly among some communities lead to a lack of access to the treatment and support they would benefit

from (Bradford et al., 2010; Leist, 2017; Robinson, Tang and Taylor, 2015). As a result, those communities who tend to face barriers in accessing a diagnosis are less likely to receive timely treatment to maintain their cognition and manage their general health (Cooper et al., 2016; Lin et al., 2021).

Even after receiving a dementia diagnosis, some groups receive less frequent and poorer quality care, and experience greater barriers to treatment. Level of deprivation, ethnicity, gender and other socio-economic factors impact the level and quality of treatment and support received in dementia (Cooper et al., 2016; Giebel et al., 2021; Kenning et al., 2017; Sourial et al., 2020; Wu et al., 2018). A lack of early care and treatment will result in a lack of support and management of symptoms remaining unresolved (Bradford et al., 2009). This can increase the likelihood of dementia progressing rapidly (Moise, Schwarzinger and Um, 2004). More advanced dementia and more frequent symptoms put significant pressure on care at home, and may increase the need for acute care and support. Increased care needs and suboptimal treatment can place greater pressure on unpaid carers and care at home, resulting in avoidable, emergency healthcare use (de Vugt and Verhey, 2013; Sommerlad et al., 2019), transitions into formal care settings, and increased risk of death (Reeves et al., 2023). Existing inequalities in the level and quality of care, support and treatment are likely to widen due to the growing need coinciding with shortfalls in local and national government service funding and provision (Giebel et al., 2021; Grand et al., 2011; Hu et al., 2022).

The number of PLWD increasing in the UK, particularly among those with more severe symptomatology and greater day-to-day needs. Coupled with a lack of funding and services struggling to meet current demand, this is only likely to exacerbate inequalities, and as such, it is essential we understand the situation now, to ease current and negate future inequalities among PLWD. There is a body of research exploring inequalities or disparities in the health and social care use and health outcome among PLWD (Bambra et al., 2010; Cookson et al., 2016). There has also been a substantial amount of research using cohort or secondary datasets to explore inequalities in general health and in different health conditions (Institute

of Health Equity, 2010), with some investigating those among PLWD (Cooper et al., 2017; Wu et al., 2018). However, there has seemingly been no synthesis of the literature identifying research employing routine or cohort data to explore demographic, geographic or socio-economic inequalities in the care and health outcomes of PLWD. The existing literature – highlighted in the systematic review – identifies the gaps in the literature that currently exist. Firstly, there is a lack of research encompassing a range of demographic, geographic or socio-economic variables as factors associated with inequalities. Secondly, existing research does not simultaneously investigate the use of a range of different healthcare services. Finally, existing research tends to frame contact with healthcare as one-off, unrelated events, rather than as a cumulative, inherently interlinked series of events.

The focus of this PhD was to demonstrate the potential of secondary data to identify inequalities in service use and health outcomes among PLWD. Secondary datasets can be classed as big data if incorporating one or more of the three key concepts of what defines big data: volume, velocity and variety (Russom, 2011). The three Vs refer to the size of the data (Volume), the exponential growth in the data (Velocity) or different types of data or opportunities for analysis of the data (Variety) (Russom, 2011). Large databases of routinely-collected data such as electronic health records can be classed as big data, and can provide the basis for research to examine health inequalities (Dash et al., 2019). Big data has been used extensively to explore health and health inequalities (Pastorino et al., 2019; WHO, 2022) and continues to provide great benefits to research and the people research seeks to benefit, but not extensively in dementia research. Big data of larger populations can provide better representation of societal groups often under-represented in data and research (Redwood and Gill, 2013). Research encompassing larger populations can enable greater representation of the experience of ethnic minority groups, those from more deprived areas, and provide better comparison of experience between geographic regions (Zhang et al., 2017). There is estimated to be 944,000 people in the UK living with dementia, but figures from Public Health England estimate that as of 2022, only 62.0% of PLWD aged 65 and over

in England had an official recorded diagnosis (Public Health England, 2023). There are also relatively few people with early-onset dementia, so a larger sample population can allow for a more representative analysis of the experience of early-onset dementia. As such, representation in routinely-collected datasets could be somewhat limited. Using big data of large populations can enable greater representation of both people with early- and late-onset. From Clinical Practice Research Datalink (CPRD), this thesis employed large volumes of electronic health records – primary healthcare contacts and linked secondary healthcare contacts - for a large population of PLWD. CPRD has previously been used to investigate health, healthcare and inequalities (Hawkins et al., 2012; Head et al., 2021), but not extensively in research among populations of PLWD. The linked data of EHR from CPRD will be used to explore and describe variations in healthcare use and health outcomes among different social and spatial groups of PLWD in England. With that said, it is important to understand how we can employ such large volumes of secondary data in dementia to represent the wider experience of the breadth of people with dementia. We need to understand how existing research has employed large volumes of secondary data to examine inequalities among PLWD, as well as identifying the gaps in the research. I can then focus on research areas with limited knowledge. Using big data, I can explore the simultaneous impact geographic and socio-economic factors may have on contact with different types of healthcare, and risk of mortality post-diagnosis. This will be done initially through a series of association-based regression analyses of demographic, geographic and socio-economic factors and different outcome measures. The first outcomes measure is mortality risk (based on the presence, or not, of a date of death in CPRD data), secondly the frequency or likelihood of using three types of primary healthcare (GP observations, dementia medications and non-dementia medications) and secondary healthcare (A&E attendances, emergency hospital admissions and elective hospital admissions) services. Finally, members of the sample population(s) will be clustered into groups, based on temporal patterns in their use of primary and secondary healthcare services in the first five

full years after dementia diagnosis. Regression analyses will then examine the association between membership to the different healthcare use cluster, and subsequent mortality risk.

Due to the existing evidence, the gaps in the literature and the growing need to evidence inequalities among PLWD, a set of aims were developed. To effectively support PLWD, informal carers, and health and social care staff, I need to understand the current picture of demographic, geographic and socio-economic inequalities in the healthcare use and health outcomes among PLWD. From this knowledge, I can identify policy changes and potential changes to health and social care practice which can improve care for PLWD, and reduce the potential future inequalities. These recommendations also aim to highlight inequalities in service access and quality, and health outcomes, with the direct intention of improving the situation for the social and spatial groups of PLWD already encountering poor care and outcomes.

Aims

The focus of this PhD project was to examine how electronic health records can be used to identify inequalities in service use and health outcomes among PLWD, as a means to identifying areas of potential policy and practice change to aid care, support and health outcome benefits for PLWD. In order to fulfil the intent of this PhD project, four sequential aims were developed:

1.1.1. Aims:

1. Explore the potential of routinely collected data for investigating dementia inequalities
2. Examine potential inequalities in healthcare use among PLWD
3. Examine potential inequalities in health outcomes (e.g. mortality risk) among PLWD
4. Identify variations in healthcare use and its impact on health outcomes.

The first aim provides a rationale from which the subsequent research within this PhD came. A systematic review will demonstrate how existing research has used routine datasets to understand demographic, geographic and socio-economic variation and inequalities in the

care, treatment, health and health outcomes among PLWD. By synthesising existing research employing secondary datasets to examine socio-economic inequalities among PLWD, we can identify how health and care outcomes vary among different groups. It is also possible to highlight the limitations of the current literature and highlights gaps in the research which can be addressed through the subsequent research in this PhD project.

The second and third aims contribute to improving our understanding on the nature and extent of social inequalities in dementia outcomes. Analyses will consider how both the level of contact with healthcare services and the risk of worse health outcomes (e.g., mortality) vary between different social and spatial groups. The fourth aim will extend this work through introducing a longitudinal element towards how inequalities were characterised in aims two and three. It will identify the different temporal trajectories in the level of contact PLWD have with different types of primary and secondary healthcare, and how they relate to health outcomes. This is important to do since it can begin to highlight the importance of healthcare as a sequence of linked events, rather than a series of individual, one-off contacts.

1.2. Thesis structure

There are six chapters in this thesis, sequential in order with each generating the evidence to proceed with the next. The thesis follows the 'thesis by publication' route, representing a collection of published and drafted papers with additional written narrative in-between. The second chapter is a systematic review exploring how existing research has used routine data to investigate geographic and socio-economic inequalities among PLWD. As the first of four research papers from this PhD thesis, this review draws together the global evidence of variations among PLWD, from diagnosis, through their trajectory - including health and social care use - to survival and mortality risk. From here we can illustrate which inequalities exist and which groups within society are most likely to have poor health and health outcomes, and experience poor health and social care contacts. Having drawn together the available research on the topic, it is then possible to demonstrate any gaps in the existing literature on

inequalities in dementia. As a result, it is possible to know how primary research - using routine data and quantitative methods - can start to fill the spaces in the existing knowledge.

The next chapters present three quantitative analyses informed from the review. The research papers presented in chapters three, four and five all utilised Clinical Practice Research Datalink (CPRD) primary healthcare use data. Data linkage allowed access to records of these patients' secondary healthcare use and their anonymised patient-level geographic and socio-economic variables. Chapter three investigates how primary healthcare use and medications, geography and socio-economic factors can impact mortality risk among PLWD post-diagnosis. Employing large-scale, secondary datasets this paper examines the variation in risk of mortality among 142,340 people with either early- and late-onset dementia based on how much they access GP care, where they live and access GP care, and their demographic and socio-economic background. This paper produced a novel analysis incorporating a multitude of social and spatial variables as both factors for mortality risk and as potential confounders. The paper also highlights the potential for further research employing CPRD healthcare use data to explore social and spatial inequalities in other outcomes among PLWD, including use of primary and secondary healthcare services.

Chapter four examines the impact of these explanatory factors on the frequency or likelihood of using six different types of primary and secondary healthcare. This paper highlighted social and spatial variations in GP contacts, medications for both dementia and non-dementia medications, their use of A&E and both emergency and elective admissions to hospital. With limited previous exploration of variations in the use of multiple healthcare services by the same population, this study provides novel evidence. This is important given the number of demographic, geographic and socio-economic factors incorporated as factors for inequalities in the rates of likelihood of using different healthcare services. This study also gives narrative context to the potential reasons why some groups in society may encounter primary and secondary healthcare services more or less than others. This study also illuminated potential avenues of future research, again using CPRD data. Healthcare use is

not a series of one-off events, they are inherently linked and are sequential, with each having the potential to impact the occurrence and frequency of subsequent healthcare use.

The fifth chapter goes on to explore temporal patterns in primary and secondary healthcare use among PLWD, something with extremely limited exploration in previous research. Employing over 80 million electronic health records for PLWD, we employed novel temporal clustering methods to identify groups of PLWD who experience similar patterns in their use of GP services, dementia and non-dementia medication, and an all-encompassing secondary healthcare use variable. Defining the populations of people with early- and late-onset dementia, we were able to demonstrate groups of PLWD with similar temporal patterns in the use of healthcare. Once clusters were generated, it was possible to explore the social and spatial constituency of each, to highlight inequalities in the likelihood of experiencing different healthcare pathways by social and spatial factors. Finally, this study went on to demonstrate that PLWD who experience certain healthcare pathways had a greater risk of subsequent mortality. The methods employed in this study and the findings generated, are novel, particularly in dementia inequalities research, but also highlighted potential areas of future research to build on this paper.

Chapter six is the Discussion chapter, bringing together the evidence generated from this thesis, how these findings sit within the existing research, giving a narrative and wider, social context to how and why these results came about. The final chapter highlights the findings across the thesis, generating evidence-based recommendations to inform both policy and practice. Recommendations are raised with a view to improving the situation for PLWD, informal carers, health and social care services and staff, and to reduce inequalities which may be encountered more acutely by some geographic or social groups.

1.3. Publications and Contributions

At point of thesis submission (March 2023), I have published three of my PhD chapters, and submitted a fourth and final one to a journal (currently undergoing peer review).

Chapter 1: **Introduction.** James Watson wrote this chapter. Asangaedem Akpan, Clarissa Giebel and Mark Green offered revision contributions.

Chapter 2: **Systematic Review.** James Watson was the lead author, producing the search strategy, extracting relevant research papers and findings related to the review topic. James Watson also synthesising the research evidence, developing findings and themes from the encompassed literature, developing the narrative discussion, conclusions, and both practice and future research recommendations. Asangaedem Akpan, Clarissa Giebel, Fran Darlington Pollock and Mark Green co-authored the chapter contributing revisions. James Watson and Clarissa Giebel produced the study design and acted as reviewers of the research papers to be included. This paper was published in the International Journal of Geriatric Psychiatry:

> Watson J, Giebel C, Green M, Darlington-Pollock F and Akpan A. Use of routine and cohort data globally in exploring dementia care pathways and inequalities: A systematic review. *International journal of geriatric psychiatry*. 2021;**36**(2), pp. 252. doi: 10.1002/gps.5419

Chapter 3: **Research study 1.** James Watson was the lead author, produced the study design, formatting, cleaning and development of data and variables needed for analysis. James Watson cleaned the data, formatted variables needed for analysis, and conducted the analysis, producing and enacting code for descriptive and statistical analysis, as well as producing the synthesised findings narrative discussion, conclusions and recommendations. Mark Green and Fran Darlington Pollock offered contributions to study design and data formatting. Asangaedem Akpan, Clarissa Giebel, Fran Darlington Pollock and Mark Green co-authored the chapter contributing revisions. James Watson and a public advisor discussed the findings, discussions and recommendations to apply a real-world lens to the paper. the narrative around the findings and discussion. This paper was published in the International Journal of Environmental Research in Public Health:

Watson J, Darlington-Pollock F, Green M, Giebel C, Akpan A. The Impact of Demographic, Socio-Economic and Geographic Factors on Mortality Risk among People Living with Dementia in England (2002-2016). *Int J Environ Res Public Health*. 2021 Dec 20;18(24):13405. doi: 10.3390/ijerph182413405

Chapter 4: **Research study 2.** James Watson was the lead author and produced the study design. James Watson cleaned and formatted the data and variables, selected analytical methods, wrote and enacted the code for descriptive and statistical analyses, synthesised findings and produced the discussion narrative, draw conclusions and recommendations for policy, practice and future research. Mark Green and Fran Darlington Pollock offered contributions to study design and data formatting. Asangaedem Akpan, Clarissa Giebel, Fran Darlington Pollock and Mark Green co-authored the chapter contributing revisions. James Watson and a public advisor discussed the findings, discussions and recommendations to apply a real-world lens to the paper. This paper was published in Aging and Mental Health:

Watson J, Green MA, Giebel C, Darlington-Pollock F, Akpan A. Social and spatial inequalities in healthcare use among people living with dementia in England (2002-2016). *Aging Ment Health*. 2022 Aug 12:1-12. doi: 10.1080/13607863.2022.2107176

Chapter 5: Research study 3. James Watson was the lead author. James Watson and Mark Green generated the study design and choice of analytical methods. James Watson cleaned and formatted data ready for analysis, wrote the code to enact descriptive and statistical analyses, synthesised findings, produced the narrative discussion and developed the conclusions recommendations for future research, and both policy and practice. Asangaedem Akpan, Clarissa Giebel and Mark Green offered contributions to revised versions of the paper. James Watson and a public advisor discussed the findings, discussions and recommendations to apply a real-world lens to the paper. James Watson and a public advisor discussed the study design to understand the applicability of the

potential research prior to analysis. This paper has recently been submitted to a research journal and the authors are awaiting response.

Chapter 6: James Watson wrote this chapter. Asangaedem Akpan, Clarissa Giebel and Mark Green offered revision contributions.

1.4. Dissemination and Public and Patient Involvement and Engagement (PPIE)

During the PhD project I have co-authored one further paper and hosted, taken part in and contributed to many public and patient involvement events these are detailed by type below.

1.4.1. Public Involvement and Engagement

- During my PhD I discussed my research and wider work with public advisor(s). Without involvement from those with practical, lived experience, there is a risk that the true and entire picture of my findings and recommendations would be limited and biased to the researchers' perspective. I discussed my research with both a former carer of a family member living with dementia, and a current carer for a family member with dementia who was also worked in healthcare. Engaging with people with real-world experience of providing care to PLWD was invaluable. Meeting with public advisors helped me understand my findings and generate narrative around those findings, based on not only the existing literature, but also from the wider perspective of carers and the PLWD they cared for.

1.4.2. Conference presentations:

- Poster flash presentation of Chapter 2 paper *'Systematic Review: Use of routine and cohort data to explore inequalities in dementia'* at the United Kingdom Society for Biomaterials, Future Leaders Joint CDT Virtual Conference, June 2020.
- Oral presentation of Chapter 3 paper *'The Impact of Demographic, Socio-Economic and Geographic Factors on Mortality Risk among People Living with Dementia in*

England (2002–2016)' at the 19th International Medical Geography Symposium at the University of Edinburgh, June 2022.

- Oral presentation of Chapter 4 paper '*Social and spatial inequalities in healthcare use among people living with dementia in England (2002-2016)*' at the 4th Liverpool Dementia and Ageing Research Conference, in Liverpool, October 2022.
- Poster presentation of Chapter 4 paper *'Social and spatial inequalities in healthcare use among people living with dementia in England (2002-2016)'* at the 33rd Alzheimer Europe conference in Bucharest Romania, October 2022.
- Oral presentation of Chapter 3 paper: *'The Impact of Demographic, Socio-Economic and Geographic Factors on Mortality Risk among People Living with Dementia in England (2002–2016)'* at PopFest (hosted by The University of Florence in combination with British Society for Population Studies), October 2022.

1.4.3. Workshops:

- North West Quantitative Methods/North West Social Science Doctoral Training Partnership *'Stakeholder engagement in data science research'* workshop. I co-designed and co-hosted a workshop bringing together data scientists across several North West Universities to discuss the importance of stakeholder involvement in data science research, and the role of co-production in data science (February 2022).
- *'People, Practice, Data and Dementia'*. I designed and co-hosted a workshop, bringing together carers of PLWD as lived experts, academic researchers and health and social care clinicians to discuss the potential of data to support person-centred care decision-making for PLWD (March 2021).

1.4.4. Blogs, Podcasts, Seminars and Webinars:

- Three blog posts for the National Institute for Health Research (NIHR) Dementia Researcher. Firstly, discussing my PhD and how the project aims to improve care for PLWD (October 2019). Secondly, discussing my PhD project, the aims and my

systematic review (April 2020). Thirdly, a post discussing the challenges and benefits of carrying out a PhD project during the COVID-19 pandemic (February 2021).

- Blog post for University of Liverpool's *'Becoming an Expert'*, discussing my PhD and my hopes for impacting positive change using my research (August 2022).
- Webinar hosted by the NIHR Dementia Researcher, in which I gave a presentation on how to conduct a systematic review, online, June 2020.

1.5. Why I did this PhD?

I applied for this PhD project because I have wanted to work in research for a long time. Having worked for over a decade in Local Government Public Health, I became the lead analyst on mental health, the health of older people and dementia and this PhD project piqued my interest given the subject matter. Dementia, health inequalities and the wider determinants of health not only aligned with my knowledge and expertise, but they are areas of health research I am passionate about. I want to make a real-world difference if I can in my work and this PhD was a route towards achieving this goal. I feel that engaging with PLWD, their carers, clinicians, social care workers, researchers and others, I feel I can be a part of something tangible that improves the lives and care of PLWD and carers now and in the future. I could also see the potential of the project to push me to develop my ability to conduct research. Dementia, particularly inequalities in the care health and support of PLWD is a topic area I have a great passion for and I continue to see it as my career path.

2. Chapter 2: Systematic Review: Use of routine and cohort data to explore inequalities in dementia

Originally published in the International Journal of Geriatric Psychiatry:

Watson J, Giebel C, Green M, Darlington-Pollock F and Akpan A. Use of routine and cohort data globally in exploring dementia care pathways and inequalities: A systematic review. *International journal of geriatric psychiatry*. 2021;**36**(2), pp. 252. doi: 10.1002/gps.5419

Abstract

Aims

The aim of this systematic review was to evaluate studies which employed routine and cohort data sets to understand socio-economic, geographic and demographic 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.

2.1. Introduction

The number of people diagnosed with dementia in the UK 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 living with dementia (PLWD) to double and the reflected cost of care to increase threefold (Wittenberg et al., 2019). 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 (Government Office for Science, 2016).

Health inequalities are *'avoidable differences in health outcomes between groups or populations'* (Office for Health Improvement & Disparities, 2022). Marmot's 2010 review demonstrated the impact that wider, social determinants of health can have (Institute of Health Equity, 2010). These wider determinants refer to the distribution of access and availability of resources which enable positive health (Institute of Health Equity, 2010). 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. The prevalence of dementia varies based on geography. People from rural areas have been shown to be more likely to be living with dementia, and between different countries and regions within countries, there are wide variations in dementia prevalence (Russ et al., 2012). Previous research has highlighted differences between PLWD living in rural and urban areas, including in their access and use of primary healthcare, frequency of hospital admissions, length of stay in hospital, use of medications and mortality risk (Arsenault-Lapierre et al., 2023). Variations in healthcare use have also been found by geographic location, with frequency of secondary healthcare use varying between regions of the country, due to variation in finances and inconsistencies in care delivery (Eyles et al., 2021). A greater demand on services in some areas, coupled with disparate funding and staffing of health and social care services, means the experience of PLWD from different geographic will vary greatly (IFS, 2022), , making it vital that inequalities

by geographic area are explored. Socio-economic status (Cermakova et al., 2017; Cooper et al., 2016; Verbeek et al., 2015) and place of residence (Peterson et al., 2008; Smith et al., 2001) also influence access to a diagnosis, and aspects of care, treatment and the support a PLWD 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 (Ogden, 2017). People who are unable to afford their own care will endure worse outcomes relative to more affluent PLWD (Cooper et al., 2016; Wu et al., 2018). 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 PLWD.

Routine datasets in dementia – such as the National Alzheimer's Coordinating Center (NACC) in the United States and SveDem in Sweden - are large databases containing standardised clinical and service interaction records for PLWD. 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 datasets, such as those focusing 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 PLWD.

The aim of this systematic review was to evaluate studies which employed routine and cohort datasets to understand demographic, geographic and socio-economic inequalities in dementia care pathways. The review did not intend to explore the degree or level to which biological and or social factors, impact any existing inequalities. Existing systematic reviews have explored specific socio-economic inequalities in dementia care pathways, including age, ethnicity, gender, deprivation and country of residence (Bone al., 2019; Cooper et al., 2010; Cooper et al., Mukadam et al., 2011; Mukadam et al., 2013). However, this is the first to explore how routine datasets 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 PLWD 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 for PLWD and their carers, and attempt to reduce related inequalities in care.

2.2. Methods

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

2.2.1. Search Strategy

We searched the Cochrane Central Register of Controlled Trials (CENTRAL), 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. These terms were searched for anywhere in the text, including the keywords. 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.

2.2.2. Inclusion criteria

The population used in the studies had to be dementia-specific and PLWD need to have received a documented diagnosis of dementia. Only English language papers, published since 01/01/1990, looking at the use of routine or cohort data to quantitatively explore issues of care pathways and care utilisation in PLWD and their family carers were included.

2.2.3. Exclusion criteria

Papers published in any language other than English, published before 01/01/1990, 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, e.g. dementia and mild cognitive impairment were also excluded.

2.2.4. 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.

2.2.5. Data extraction

To process the literature to conduct the data synthesis, relevant findings were taken from the final research, including demonstrating the potential demographic, geographic or socio-economic factor(s) each investigated, as related to 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.

2.2.6. Data Synthesis

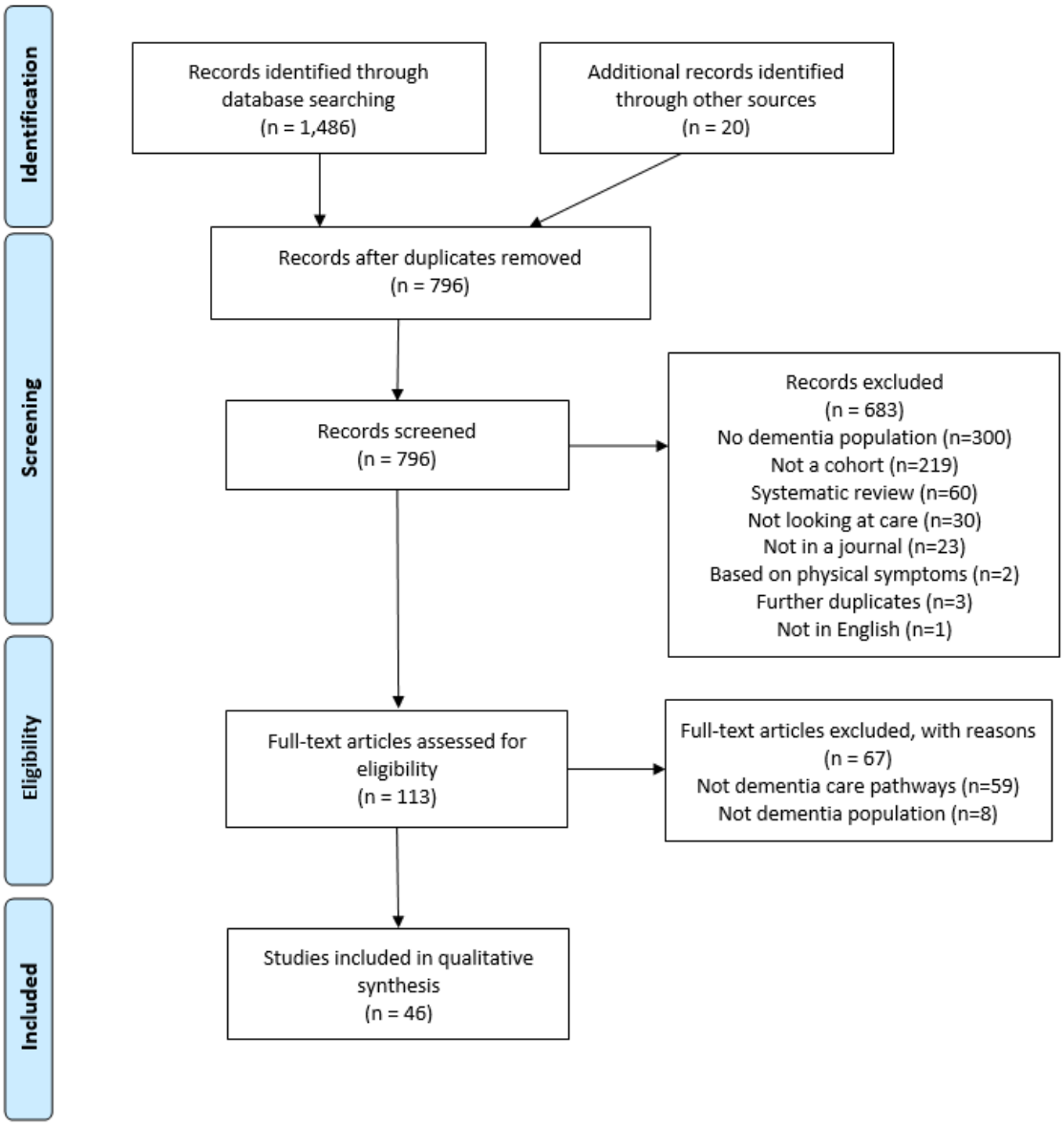
A narrative summary of the evidence taken from the final included papers was conducted. This process involves drawing out specific findings from quantitative papers when a meta-analysis is not feasible (Campbell et al., 2018). The papers generated from the search of electronic databases returned few studies which were similar, either in their outcome measure(s), or their independent, explanatory variables. In pooling estimates for the

association between a causal factor and an outcome(s), using heterogenous variables can present issues, potentially generating misleading findings (Higgins et al., 2022). With so few studies to pool from, and subsequently small sample populations for the effects of explanatory factors on some outcomes variables, this prevents the potential for a good quality meta-analysis. A systematic review allows us to gather all of the empirical evidence related to a specific research question, and deliver a narrative synthesis of these findings, which was most appropriate given the nature of the included papers. 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, anti-dementia medications, health and social care interactions, disease progression, mortality, survival.

2.3. Results

2.3.1. Search Outcomes

We identified 1,506 studies via database (n=1,486) and grey literature searches (n=20), 796 of which remained once duplicate records were removed (see Figure 2.1 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. 67 papers were removed leaving a total of 46 studies which met the defined inclusion criteria.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Figure 2.1: Systematic Review Search Strategy

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.

2.3.2. Characteristics of included studies

Table 2.1 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 datasets, 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.

Table 2.1: Summary characteristics of included papers

Author	**Year Published**	**Country**	**Dementia Population**	**Socio-economic variables**	**Pathway: Outcomes**	**Routine Dataset(s) Used** *(sample size)*
Aaltonen et al.	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 (*70,366)*
Bunn et al.	2016	UK	Dementia	None	**Health and social care interactions:** People living with dementia using hospital services in previous 4 weeks and in previous 12 months.	CFAS I and II (*117)*
Calvo-Perxas et al.	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	**Medications:** Prescription and consumption of antipsychotic drugs for various dementia subtypes.	Registry of Dementia of Girona (ReDiGi) (*1,894)*
Calvo-Perxas et al.	2014	Spain	Alzheimer's Disease	Age Gender Education Marital Status Residence	**Medications:** Use of antipsychotics and other medications for the treatment of symptoms in Alzheimer's Disease.	Registry of Dementia of Girona (ReDiGi) (*1,894)*
Cermakova et al.	2017	Sweden	Alzheimer's disease	Age Gender Residence	**Medications:** Use of antipsychotics in Alzheimer's Disease.	SveDem (*26,163)*
Connolly et al.	2012	England	Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy Bodies, Frontotemporal dementia, Other	Age Gender Residence	**Health and social care interactions:** People living with dementia receiving their annual dementia review, recorded discussions with carers and review of their social care. **Medications:** Prescription and review of antipsychotics.	GP register (Quality Outcomes Framework) (*994)*

			dementia, Unspecified type dementia			
Cooper et al	2016	UK	Dementia	Age Gender Deprivation Geography	**Medications:** Anti-dementia drug initiation rates.	The Health Improvement Network (THIN) (*77,045)*
Cooper et al.	2017	UK	Dementia	Age Gender Deprivation	**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) (*68,061)*
Donegan et al.	2017	UK	Dementia, Alzheimer's disease	Age Gender	**Medications:** Prescription of antidementia drugs in Clinical Practice Research Datalink (CPRD) sample of people living with dementia.	Clinical Practice Research Datalink (CPRD) (*128,249)*
Eriksson et al.	2014	Sweden	Alzheimer's Disease	Age Gender	**Medications:** Prescription of anti-dementia medications and difference in diagnostics used in Early and Late onset Alzheimer's Disease	SveDem (*5,052)*
Fereshtehnejad et al.	2014	Sweden	Dementia with Lewy Bodies, Alzheimer's disease	Age Gender	**Medications:** Prescription of various anti-dementia/medications for people living with dementia with Lewy Bodies (DLB) and Alzheimer's Disease.	SveDem and Swedish patient registry (*9,795)*
Fereshtehnejad et al.	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	**Medications:** Differences in prescription of anti-dementia medications. Differences in use of diagnostics for people living with dementia. **Health and social care interactions:** 6 indicators of care quality identified and analysed.	SveDem and Danish Dementia Registry (*26,205)*
Fillenbaum et al.	2001	US	Alzheimer's disease	Age Gender Ethnicity Education Marital Status	**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) (*388)*

				Residence Geography		
Fong et al.	2012	US	Alzheimer's disease	Age Gender Ethnicity Education	**Health and social care interactions:** Adverse outcomes for people living 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.	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 vs. controls without dementia.	Danish patient registry (*771)*
Gillette-Guyonnet et al.	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. **Medications:** Use of Alzheimer's Disease medications throughout. **Health and social care interactions:** Rate of institutionalisation.	REAL.FR cohort (*686)*
Gustavsson et al.	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 (*852)*
Hackett et al.	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 living with dementia.	English Longitudinal Study for Ageing (ELSA) (*4,171)*
Hartz et al.	2012	Germany	Alzheimer's disease	None	**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) (2,700*)*
Huang et al.	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 (*722)*
Johnell et al.	2013	Sweden	Alzheimer's disease, Mixed Alzheimer's Disease/Vascular Dementia,	Age Gender Residence Cohabitation	**Medications:** Anti-dementia medication use in dementia subtypes.	SveDem (*7,570)*

			Vascular dementia, Dementia with Lewy Bodies, Frontotemporal dementia, Parkinson's disease dementia, Unspecified dementia, Other dementia			
Kahle-Wrobleski et al.	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 (*1,495)*
Knapp et al.	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) (*3,075)*
Korhonen et al.	2018	Finland	Dementia	Age Marital Status Deprivation	**Care transitions:** Probability of movement into long-term institutional care. Comparing those who died from dementia vs. other causes and those who survived to the end of the study period.	Finnish Death Register and national care registers (*187,657)*
Miller et al.	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) (*639)*
Moore et al.	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 health care costs.	National Longitudinal Caregiver Study (NLCS) (*2,043)*
Murman et al.	2002	US	Alzheimer's disease,	Age Gender	**Health and social care interactions:**	Michigan Alzheimer's Disease Research

			Dementia with Parkinsonism, Huntington disease	Ethnicity Education Marital status Caregiver variables	Over 3.5 years: use, time spent in and frequency of use of Long-Term Care, hospital care and paid home care.	Center (MADRC) registry (*267)*
Neumann et al.	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) (*345)*
Peterson et al.	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) (*890)*
Pujades-Rodgriguez et al.	2018	England	Alzheimer's disease, Vascular dementia, rare dementias	Age Gender	**Disease progression, mortality and survival:** 10 year and lifetime risk split by age and gender (for all and Alzheimer's Disease) Dementia vs. non-dementia mortality rates.	Clinical Practice Research Datalink (CPRD) (*47,386)*
Ramsey et al.	2018	US	Alzheimer's disease, Vascular dementia, Dementia with Lewy Bodies, Frontotemporal dementia, Other dementias	Age Gender Ethnicity Education Residence Cohabitation	**Medications:** Inappropriate prescription of medications in dementia subtypes.	National Alzheimer's Coordinating Center (NACC) (*2,448)*
Rattinger et al.	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 (*287)*
Rudolph et al.	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 living with dementia.	Massachusetts Alzheimer's Disease Research Center (MADRC) patient registry (*827)*
Scalmana et al.	2013	Italy	Alzheimer's disease,	Age Gender	**Health and social care interactions:** Number of population using different social care services	Unità Valutativa Alzheimer (*712)*

			Vascular dementia, Mixed dementia, Frontotemporal dementia, Lewy Body dementia, Parkinson's dementia, Other dementias	Education Caregiver variables	Factors associated with use of services.	
Sheng et al.	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	**Medications:** Brain imaging and lab tests by subtype of dementia. **Care transitions:** Residence at first vs. final visit in study Familial 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 (*454)*
Smith et al.	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) (*985)*
Sommerlad et al.	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 living with dementia.	South London Maudsley NHS Foundation Trust (SLAM) and Clinical Record Interactive Search (CRIS) (*10,137)*
Stevnsborg et al.	2016	Denmark	Dementia	Age Gender Marital Status Residence	**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.	National patient registry; psychiatric central research registry; national prescription registry (*34,877)*

				Geography	**Care transitions:** Likelihood of living in a nursing home when diagnosed with dementia for Danish-born, Western immigrants and Non-Western immigrants.	
Taipale et al.	2014	Finland	Alzheimer's disease	Age Gender	**Medications:** Factors associated with discontinuation of AChEI therapy.	MEDALZ-2005 (medication use and Alzheimer's Disease) (*6,858)*
Thorpe et al.	2016	US	Alzheimer's disease	Age Gender Ethnicity	**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 (*84,043)*
van de Vorst et al.	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 vs. general population, and patients hospitalised with dementia vs. those hospitalised with Acute Myocardial Infarction, heart failure or stroke.	Dutch Hospital Discharge Register (HDR); Dutch Population Register (PR) (*59,201)*
van de Vorst et al.	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 (*15,558)*
van de Vorst et al.	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 within 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 (*59,194)*
van Weel et al.	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 living with dementia.	NGO cohort dataset (*11,927)*
Verbeek et al.	2015	England, Estonia, Finland, France, Germany,	Dementia	Geography	**Health and social care interactions:** Factors associated with risk of recently being admitted into and institutionalised Long-Term Care.	RightTimePlaceCare (RTPC) (*2,014)*

		Netherlands, Spain, Sweden				
Wattmo et al.	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) (*880)*

†MMSE=Min-Mental State Examination; ‡ChEI=Cholinesterase Inhibitor; §QALY=Quality Adjusted life Years; ¶AChEI=Acetylcholinesterase Inhibitor

Table 2.2: Papers analysing socio-economic deprivation or geography (country of residence) as a potential factor in outcome measures for PLWD

Author	Year	Deprivation type	Analysis conducted using socio-economic variables
Cooper et al.	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.	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.	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.	2018	Indices of Multiple Deprivation quintile	**Mortality differences between those with and without dementia**: -Greater proportion of deaths in deprived areas are of people living with dementia
Sommerlad et al.	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.	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 vs. hospital
Verbeek et al.	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)

27 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 PLWD (see Table 2.2).

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.

2.3.4. Transitions to nursing care

Nine studies investigated care transitions for PLWD, primarily analysing the significance and degree to which socio-economic factors can influence the probability of moving into nursing care. Being older was associated with a significantly greater likelihood of admission to nursing care (Knapp et al., 2016; Korhonen et al., 2018; Smith et al., 2001). Stevnsborg et al. (2016) used data from three Danish health registries to demonstrate that the oldest PLWD (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. (2018) 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. (2018) found women were

significantly more likely to be diagnosed with dementia whilst living in nursing care, and Smith et al. (2001) discovered that men with dementia were significantly less likely to be admitted to nursing care generally. However, in the final two years of life, a greater proportion of men with dementia had care transitions, with a higher median number of transitions than women (Aaltonen et al., 2012). The timing of transitions in disease progression was also found to differ by gender. Neumann et al. (2001) 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. (2016) 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. (2016) 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.

2.3.5. Anti-dementia medication

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

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. (2016) found areas of greatest deprivation had significantly lower rates of anti-dementia medication initiation than the most affluent. In the UK, 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. (2014) 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. (2017) found people aged under 70 years, and ≥80 years were less likely to be prescribed anti-dementia medication than people aged 70-79 years, several studies illustrate higher initiation for older people (Donegan et al., 2017; Stevnsborg et al., 2016; Taipale et al., 2014; Thorpe et al., 2016).

Several studies demonstrated females had an increased probability of receiving antidementia medications (Cooper et al., 2017; Donegan et al., 2017; Calvo-Perxas et al., 2014; Johnell et al., 2013). However, the research available identified mixed evidence of the likelihood of having these medications discontinued (Taipale et al., 2014; Thorpe et al., 2016).

Thorpe et al. (2016) also investigated the impact of ethnicity on initiation and discontinuation of anti-dementia medication. Among Medicare beneficiaries in the US 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. (2016) found that Western and Non-Western immigrants to Denmark were significantly less likely to receive anti-dementia medications than people born in Denmark.

2.3.6. 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 (Rudolph et al., 2010), for example. It was found that PLWD living in the most socio-economically disadvantaged areas had a significantly higher risk of emergency hospital admission, and significantly lower probability of elective admissions (Sommerlad et al., 2019).

Evidence varies on the exact impact that ethnicity can have on admissions to hospital for PLWD (Knapp et al., 2016; Sommerlad et al., 2019; Fillenbaum et al., 2001). 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 PLWD were at greater risk of hospitalisation (Knapp et al., 2016; Rudolph et al., 2010; Fillenbaum et al., 2001). 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 (Knapp et al., 2016) and elective admissions (Sommerlad et al, 2019). However, among PLWD, 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. (2017) 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. (2013) discovered that for PLWD, younger people had a longer delay in accessing Home-Help Services.

Care quality can also be impacted by socio-economic factors. Connolly et al. (2012) 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. (2013) discovered that people with less education were less likely to access health and social care services.

2.3.7. Disease progression, mortality and survival

Nine studies investigated direct outcomes and illness progression for PLWD, with seven studies focusing 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 (2001). Women and those who were younger when receiving a dementia diagnosis were shown to have better

survival (Peterson et al., 2008; Huang et al., 1994), with older people and men at greater risk of dying (Van de Vorst et al., 2015; Van de Vorst et al., 2016).

Greater support is indicative of better survival, long-term independence and condition maintenance among PLWD. As well as noting that less education is associated with poorer survival for PLWD, Huang et al. (1994) 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 (2008), 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 PLWD maintaining their dependence at the level at seen at study start (Kahle-Wrobleski et al., 2017).

Pujades-Rodriguez et al. (2018) compared people with and without dementia in retrospective analyses of mortality records. They illustrated PLWD were more likely to live in deprived areas. Van de Vorst et al. (2015; 2016) identified mortality risk as significantly higher for PLWD living in the most socio-economically disadvantaged areas.

2.3.8. 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 2.3) 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 7-10. 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.

Table 2.3: Quality rating checklist and applied scores

		Quality rating checklist points†,‡														Total	Applied checklist points
Author	**Year**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**		
Aaltonen et al.	2012	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Calvo-Perxas et al.	2014	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Connolly et al.	2012	1	1	1	1	0	na	1	1	1	0	1	na	na	1	9	11
Cooper et al.	2016	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Cooper et al.	2017	1	1	na	1	0	na	1	1	1	1	1	na	na	1	9	10
Donegan et al.	2017	0	1	na	1	0	na	1	0	1	0	1	na	na	0	5	10
Fillenbaum et al.	2001	0	1	na	1	0	na	1	1	1	1	1	na	na	1	8	10
Huang et al.	1994	1	1	na	1	0	na	1	0	1	0	1	na	na	1	7	10
Johnell et al.	2013	1	1	na	1	0	na	1	1	1	1	1	na	na	1	9	10
Kahle-Wrobleski et al.	2017	1	1	na	1	0	1	1	1	1	1	1	na	na	0	9	11
Knapp et al.	2016	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11
Korhonen et al.	2018	1	1	na	1	0	na	1	1	1	0	1	na	na	1	8	10
Miller et al.	1998	1	1	na	1	0	1	1	1	1	1	1	na	na	0	9	11
Neumann et al.	2001	1	1	na	1	0	1	1	1	1	0	1	na	na	0	8	11
Peterson et al.	2008	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Pujades-Rodgriguez et al.	2018	1	1	na	1	0	0	1	0	1	1	1	na	na	0	7	11
Rudolph et al.	2010	1	1	na	1	0	1	1	0	1	0	1	na	na	1	8	11
Scalmana et al.	2013	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11
Smith et al.	2001	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Sommerlad et al.	2019	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Stevnsborg et al.	2016	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Taipale et al.	2014	1	1	na	1	0	0	1	0	1	0	1	na	na	1	7	11
Thorpe et al.	2016	1	1	na	1	0	1	1	na	1	0	1	na	na	1	8	10
van de Vorst et al.	2015	1	1	na	1	0	1	1	na	1	0	1	na	na	0	7	10
van de Vorst et al.	2016	0	1	na	1	0	1	1	1	1	0	1	na	na	1	8	11
Verbeek et al.	2015	1	1	na	1	0	1	1	1	1	1	1	na	na	1	10	11
Wattmo et al.	2013	1	1	na	1	0	1	1	1	1	0	1	na	na	1	9	11

†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)?

‡ '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

2.4. Discussion

This is the first systematic review evaluating and synthesising the use of routine and cohort datasets to investigate demographic, geographic and socio-economic inequalities in dementia 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 (Connolly et al., 2011). 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 (Kelly and Stove, 2014). With greater unmet needs (Cooper et al., 2016), 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 PLWD 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 documented diagnosis of dementia. Although people from BAME groups are more likely to have dementia, they are less likely to be diagnosed (Mukadam et al., 2013; Pham et al., 2018) and are therefore underrepresented in services (Giebel et al., 2015), and may therefore be 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 (Giebel et al., 2015; Kenning et al., 2017; Memon et al., 2016; Parveen and Oyebode et al., 2018). 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 PLWD.

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 (Protheroe, Nutbeam and Rowlands, 2009). 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 PLWD and their carers.

We found that women with dementia tend to access care and treatment services earlier and more frequently than their male counterparts. Women also enter Institutional Long-Term Care (ILTC) earlier than men and require less urgent healthcare than men. Earlier entrance into ILTC could indicate differential access to both informal care and societal gender-based expectations of women in the caregiving role (Miller, 1990). Men are more likely to have access to informal care through their spouses and therefore more likely to stay at home longer (Sharma, Chakrabarti and Grover, 2016; Sutcliffe et al., 2016). Although staying at home is associated with better outcomes, men are more likely to exhibit behavioural symptoms of dementia particularly later in their trajectory (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012). In conjunction with the added caregiving pressure this may place on women (Sutcliffe et al., 2016) this can present more acute and critical need, resulting in the increased use of emergency healthcare and later care transitions we noted among men. Greater use of emergency healthcare, less use of primary healthcare and treatments, and later transitions in

care are all factors associated with poorer health outcomes, including increased risk of mortality noted from the literature in this review (Aneshensel et al., 2000; Bartlett et al., 2016).

We have identified older PLWD are more likely to live alone. PLWD 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 (Zwaanswij et al., 2013; Broese van Groenou, Marjolein and De Boer, 2016), greater comorbidities and frailty (Bunn et al., 2014; Nelis et al., 2019), poor prognosis from elective hospital treatments (Kassahun, 2018) and heightened dementia severity, lead to older PLWD being more likely to spend longer in hospital and encounter poorer outcomes (George, long and Vincent, 2013).

We find that greater caregiver burden and less support increase emergency healthcare use and ILTC. PLWD in ILTC have poorer primary healthcare experiences and worse survival. Carers feel a sense of duty (Brodaty and Donkin, 2019) and take on great responsibility (Wanless, 2016). However, with substantial caregiver burden, PLWD are less likely to use services that can aid longevity of care at home (Cotrell, 1999) leading to extensive informal home care becoming unfeasible, resulting in greater ILTC and urgent healthcare use.

Being able to manage and care for PLWD at home is critical to the sustainability of the health and social care system (Ogden, 2017). Lack of informal care, or having informal caregivers with greater burden can generate adverse outcomes for PLWD. We have highlighted that both are factors which differ for men and women with dementia and for older PLWD. Better communication from primary care of what to expect when providing informal care for PLWD, and increased community care provision (Dawson et al., 2015) 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.

2.4.1. Limitations

We have generated a detailed synthesis of the literature available for various socio-economic factors in dementia care pathways. However, 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 UK, 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 account for the variance in experiences of PLWD and future research should look to widen the outcomes considered.

Our search strategy used few terms to generate the list of literature, but many iterations of the search strategy were conducted before the final one was selected. Initial searches using a wider list of search terms, including terms such as Alzheimer, returned either very few, or too many results. Using such search results would have either under-represented the available research, or presented an unmanageable and unfeasible amount of research to review which was unrelated to the topic. Although the breadth of socio-economic factors and outcome measures investigated highlights the scale of literature found in relation to the topic, there is a paucity of research looking at specific outcomes for PLWD and carers. From the literature search, there was no research investigating socio-economic factors in outcomes for informal carers. It is important to note the impact of caregiver variables, specifically caregiver burden on care pathways, illness progression and health outcomes for PLWD. This is an area that needs greater exploration. Age and gender were consistently investigated, but socio-economic deprivation level, ethnicity, immigration status and level of education were found sporadically. This emphasises a need to explore the capturing of such information in greater

detail in the existing routine datasets, and improving research investigating such factors in care for PLWD.

2.4.2. 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 PLWD, improve the availability of culturally appropriate services, and to provide services to PLWD who are not in the position of being able to call on informal care from family or friends.

2.5. Research developments from Chapter 2

Chapter 2, the systematic review highlighted some key areas which have seen limited exploration. Although socio-economic and demographic factors have been used in research examining inequalities among PLWD, they have not been investigated simultaneously. Demographic and socio-economic factors associated with outcomes among PLWD have been explored somewhat sporadically, with only one or two incorporated in any one analysis and a limited look at potential confounders. Geographic factors have seen limited applications as a factor associated with differential care or outcomes among PLWD. The inclusion of geographic factors is important, but research has tended to examine differences and similarities between different countries, with little exploration of differences within countries. This gap in the literature highlights the need to not only explore geography *within* countries as a factor for potential differences in healthcare use and mortality risk, but also to examine variation in these outcomes measures simultaneously with a multitude of demographic, geographic and socio-economic variables. The systematic review also demonstrates that research has not tended to explore healthcare use as a holistic, interlinked series of events. Instead existing literature tends to observe one area, or part of the pathway for a person with dementia, such as diagnosis, treatment, care transitions, or health outcomes, such as survival or mortality risk. From the systematic review, it was evident that exploration of social and spatial variation in the risk of multiple outcomes was required, starting with mortality risk in Chapter 3.

3. Chapter 3: The Impact of Demographic, Socio-Economic and Geographic Factors on Mortality Risk among People Living with Dementia in England (2002–2016)

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Watson J, Darlington-Pollock F, Green M, Giebel C, Akpan A. The Impact of Demographic, Socio-Economic and Geographic Factors on Mortality Risk among People Living with Dementia in England (2002-2016). *Int J Environ Res Public Health*. 2021 Dec 20;18(24):13405. doi: 10.3390/ijerph182413405

Abstract

Introduction

Increasing numbers of people living with dementia (PLWD), and a pressured health and social care system, will exacerbate inequalities in mortality for PLWD. There is a dearth of research examining multiple factors in mortality risk among PLWD, including application of large administrative datasets to investigate these issues.

Methods

This study explored mortality risk variation among people diagnosed with dementia between 2002-2016, based on: age, sex, ethnicity, deprivation, geography and general practice (GP) contacts. Data were derived from electronic health records from a cohort of Clinical Practice Research Datalink GP patients in England (n = 142,340). Cox proportional hazards regression modelled mortality risk separately for people with early- and later- onset dementia.

Results

Few social inequalities were observed in early-onset dementia; men had greater risk of mortality. For both early-onset and later-onset, higher rates of GP observations were associated with increased mortality risk. For later-onset only, dementia medications were associated with increased mortality risk. Social inequalities were evident in later-onset dementia. Accounting for other explanatory factors, Black and Mixed/Other ethnicity groups had lower mortality risk, more deprived areas had greater mortality risk, and higher mortality was observed in North East, South Central and South West GP regions.

Conclusions

This study provides novel evidence of the extent of mortality risk inequalities among PLWD. Variance in mortality risk was observed by social, demographic and geographic factors, and frequency of GP contact. Findings illustrate need for greater person-centred care discussions, prioritising tackling inequalities among PLWD. Future research should explore more outcomes for PLWD, and more explanatory factors of health outcomes.

3.1. Introduction

There are inequalities in mortality for PLWD by various socio-economic and geographic factors (Van de Vorst et al., 2016; Korhonen et al., 2020). People from the most disadvantaged socio-economic groups are most likely to have unmet care needs and experience poorer health outcomes (Wu et al., 2018). Government policy has prioritised narrowing inequalities in access to dementia diagnosis, post-diagnostic support, treatment, and health and social outcomes (Department of Health and Social Care, 2016).

PLWD are more likely than the general population to have comorbidities, and as their condition progresses, a greater need for support with activities of daily living. Increased care need, care home closures and fewer care home places, and social care funding changes, means PLWD with comorbidities are more reliant on informal carers (Bennett et al., 2018). PLWD pay more out-of-pocket for social care (Alzheimer's Research UK, 2020) and use healthcare services more than those without dementia (Shepherd et al., 2019). Increased use of acute and unplanned healthcare is associated with greater financial cost to services and poorer outcomes for PLWD (Briggs et al., 2017; Van de Vorst et al., 2015). However, current UK health and social care funding is strained, with a reliance on the individual to fund, and the third sector to provide a substantial proportion of dementia services (Ogden, 2017). Appropriate health and social care can slow dementia progression, improve outcomes, benefit informal carers and maintain independence for PLWD (Handley et al., 2017; de Vugt and Verhey, 2013). UK strategies and policy recommendations are not reflected in service provision, and recent government commitments to increase dementia funding have not been enacted (Local Government Association, 2017).

The number of PLWD in the UK is estimated to increase from ~920,000 in 2020, to over 1 million by 2024. The reflected financial health and social care cost is anticipated to increase threefold (Wittenberg et al., 2015). The majority of PLWD are aged 65 and over, and the greatest increase will be among those with severe dementia, who often have the greatest needs (for support with routine daily activities), poorest prognosis (Wittenberg et al., 2015)

and greatest service costs (Andersen et al., 2003). As dementia progresses, and health deteriorates, PLWD are likely to need greater levels of healthcare involvement, both in relation to dementia, and comorbidities (Van de Vorst et al., 2019). A further shift towards an older population and increased numbers of PLWD, more severe symptomology and poorer health will result in greater mortality risk (Van de Vorst et al., 2016). These factors will impact some social groups more acutely, particularly older PLWD (Watson et al., 2021). Without additional funding and support, dementia services struggling to cope with current demand - and further impacted by the COVID-19 pandemic (Giebel et al., 2021) - are unlikely to be able to effectively care for and treat increased numbers of PLWD (Alzheimer's Society, 2020). Increased demand for healthcare will exacerbate issues with care and treatment, which will likely have a disproportionate impact (Government Office for Science, 2016), resulting in worse outcomes, including poorer survival and greater mortality (Cooper et al., 2016). Due to inequalities in service availability, access and quality of care, the most disadvantaged will likely be impacted disproportionately (Nuffield Trust, 2021).

In order to address current inequalities, and prevent inequalities widening due to increased demand and struggling services, we need to employ administrative data to better support improved decision-making. Mortality is a definitive outcome, which can illustrate both ill-health and effectiveness of care and symptom management throughout the trajectory of an illness (Van De Vorst et al., 2019; Rait et al., 2010). During times of restricted funding and service availability, inequalities in mortality and differences in life expectancy across social groups widen (Daly and Allen, 2016). As such, it is critical we explore current inequalities as a matter of course to understanding how we can negate the differences experiences by people as a result of belonging to specific social groups. Electronic health records (EHR) can be employed to identify healthcare use and outcomes among specified, large patient groups, which may not be possible through other means (Casey et al., 2016; Manca, 2015). Though EHRs have been used to evidence mortality risk variation among PLWD, there have been limitations in their use. There is not a great deal of research evidencing a multitude of social,

demographic and geographic inequalities in mortality risk among PLWD, or accounting for multiple demographic, geographic or socio-economic variables as potential confounding factors in mortality risk variation (Watson et al., 2021). With policy-makers and service commissioners increasingly aware of the need for patients' social context in their experience of a disease, there is an urgent need to better employ EHRs to evidence variation in outcomes for PLWD. This study addresses these evidence gaps.

The aim of this study is to examine the extent to which demographic, socioeconomic, geographic and healthcare factors are associated with mortality for PLWD, using large-scale, longitudinal EHRs.

3.2. Materials and Methods

3.2.1. Data Access and Ethical Approval

Clinical Practice Research Datalink (CPRD) collects anonymised EHR from ~2000 general practices (GPs) across the UK, with ~16 million registered patients included, representing 25% of the UK's population. GPs apply to CPRD to register for their data to be collected, resulting in potential uneven geographic coverage. CPRD has been employed previously to investigate socio-economic and demographic factors in variation in care of physical and mental health conditions (Chan et al., 2019; Hawkins et al., 2012). Data access was granted by CPRD and use of CPRD Aurum for research purposes approved by the University of Liverpool Research Ethics board (Reference: 7922). The CPRD Aurum database contains routinely-collected, longitudinal EHRs from CPRD-registered GPs, providing records of patient-GP contacts and some socio-economic and geographic variables. For reference, in this paper, a "patient-GP contact" is a single record of a discussion between or regarding a patient - whether that be face-to-face or otherwise—or record of a medication prescribed to a patient - whether that be an initial medication or repeat prescription.

3.2.2. Outcome Variable

Mortality, is a binary outcome variable, based on whether the individual within the sample population has a date of death stated within the CPRD data.

3.2.3. Explanatory Variables

CPRD Aurum contains three primary datasets for patients' contacts with their GP: consultations, observations and drug issue (medication) records (CPRD, 2021). Observation records include clinical measurements, symptoms, laboratory results or diagnoses, and multiple observation records can occur at a single consultation. Consultation records do not contain such granularity, so observation records were selected for analysis. Drug issue records contain medications prescribed. Dementia-specific medications include prescriptions for four drugs advised for use by the NHS for PLWD (NHS, 2020): Donepezil, Galantamine, Rivastigmine and Memantine. Non-dementia medications refer to all remaining drugs prescribed to the sample population. Rates per year of three patient-GP contacts types were calculated: dementia medications, non-dementia medications and observations.

Date of diagnosis is not specified in CPRD. Previous research using CPRD calculated date of diagnosis as the first GP observation record with the condition under investigation specified (Kuan et al., 2019). We defined date of diagnosis as the date of the individuals' first dementia-specific observation, based on the any of the following diagnosis terms noted: "dementia", "Alzheimer", "cogniti", or "memory". These terms relate to specific codes entered into the GP system and reflect a patient presentation to GP. Using this date as date of diagnosis will both standardise diagnosis date across the sample population, and define the first date at which a dementia-specific event was observable within an individuals' GP records. Diagnosis date was set as 'year 0' for each person in the study. We include only patient-GP contact records after the date of diagnosis.

Number of years people were present in the data were calculated by subtracting the year of their diagnosis, from the year of their final GP contact. Patient-GP contact rates were

calculated by dividing their total GP contacts by the total years of GP-contact data available. Healthcare use variables (GP observations and dementia/non-dementia medication rates) have been included to measure an individual's experiences with healthcare. Effective treatment and management of dementia and comorbidities has been illustrated to impact survival rates among PLWD (Van de Vorst et al., 2019; Watson et al., 2021). High observations may also act as a proxy for health status, since individuals who require more observations may have greater needs (rather than only reflecting effective treatment). We use these three primary healthcare use variables as explanatory factors, to identify how use of such services and medications can impact mortality risk.

Individuals' age at diagnosis and dementia onset, sex and GP region were available from their GP records. Ethnicity was available from individuals' secondary healthcare records. The 2011 GP urban/rural classification and 2019 Indices of Multiple Deprivation (IMD) quintile were available through data linkage. Inequalities in dementia and dementia outcomes have been illustrated across spatial contexts - including where somebody lives, the levels of deprivation in the area they live, and where their GP is based (Watson et al., 2021; Russ et al., 2012; Russ et al., 2016). Such variations can exist due to the social gradient in wider determinants of health, differences in local funding and service equity, the make-up of local healthcare systems and regional differences in population composition (Goddard et al., 2001; Kerpershoek et al., 2020; Marmot et al., 2020; Whitehead et al., 2006). As a result, GP region, urban/rural GP classification and IMD 2015 deprivation quintile were considered as explanatory factors for variance in mortality risk among PLWD.

3.2.4. Missing Data

Ethnicity was missing for 7421 (5.2%) people, and 276 (0.2%) people had no available IMD 2015 deprivation (Table 3.1). Statistical analyses including variables with missing data will remove those individuals with missing data.

Table 3.1. Available/missing explanatory variables data for sample population

Group	Population (n)	% Present	Missing (n)
Total sample population	142,340	-	-
With ethnicity stated	134,919	94.8%	7421
With fields present to calculate age	142,340	100%	-
With gender stated	142,340	100%	-
With IMD 2015 deprivation quintile stated	142,064	99.8%	
With general practice (GP) region stated	142,340	100%	-
With urban–rural GP classification stated	142,340	100%	-

3.2.5. Sample Population

Our analytical sample size was 142,340 people (Figure 3.2). Individuals with missing ethnicity or IMD quintile were not included regression models, with data assumed missing completely at random. We defined the sample population as patients registered at GPs in England, diagnosed with dementia between 2002–2016, with at least two years of GP follow-up data.

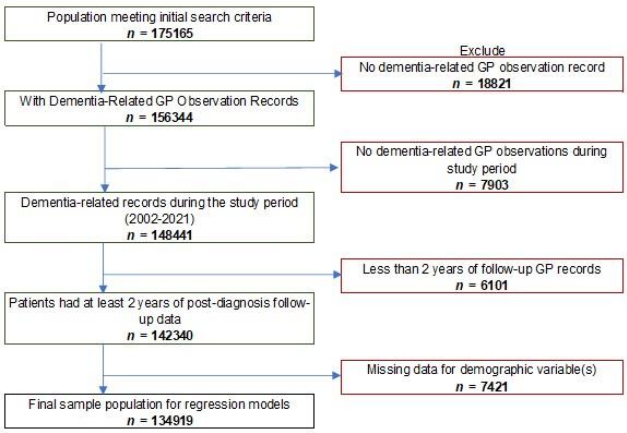

Figure 3.1. Sample population flowchart inclusion/exclusion criteria

3.2.6. Statistical Analysis

Analysis was conducted in R, with descriptive statistics calculated to summarise the dataset. Inequalities in mortality risk were examined using Cox Proportional Hazards (CPH) regression models, with Bonferroni correction applied to derived p-values to account for the potential for Type I errors when calculating multiple, simultaneous statistical tests. CPH demonstrate simultaneous impact of multiple explanatory factors on the occurrence of an event (i.e., mortality). Separate models were applied to early- and late-onset dementia, generating hazard risk values for mortality risk by explanatory factors.

3.3. Results

3.3.1. Sample Population Characteristics

Two-thirds of the sample population are female (Table 3.2), less than 4% are of non-White ethnicities, ~80% are aged 75–94 years and more live in the less deprived quintiles.

Table 3.2. Demographics of UK dementia population vs. sample population

Demographic	Study Cohort		UK[1]
	n	%	%
Sex			
Female	94,060	66.1%	65.0%
Male	48,280	33.9%	35.0%
Age Group			
Under45	104	0.1%	0.2%
45–54	870	0.6%	0.5%
55–64	4237	3.0%	4.5%
65–74	20,516	14.4%	16.6%
75–84	63,236	44.4%	36.5%
85–94	49,086	34.5%	36.2%
95+	4291	3.0%	5.5%
Onset			
Early (<65)	5211	3.7%	5.2%
Late (65+)	137,129	96.3%	94.8%
Urban/Rural GP Classification			
Urban	121,612	85.4%	
Rural	20,728	14.6%	
Ethnicity			
White	129,653	96.1%	94.5%
Asian	1939	1.4%	1.5%
Black	2247	1.7%	2.7%
Mixed/Other	1080	0.8%	1.3%
Missing	*7421*	*5.2%*	
IMD 2015 Deprivation Quintile			
Quintile 1 (most deprived)	22,366	15.7%	10.7%
Quintile 2	24,932	17.5%	16.6%
Quintile 3	28,610	20.1%	20.5%
Quintile 4	32,786	23.1%	23.4%
Quintile 5 (least deprived)	33,370	23.5%	26.5%
Missing	*276*	*0.2%*	*2.4%*
GP Practice Region			
South East Coast	12,057	8.5%	17.3%
North East	7428	5.2%	5.3%
North West	25,427	17.9%	13.5%
Yorkshire And The Humber	6139	4.3%	9.9%
East Midlands	3020	2.1%	9.3%
East of England	8261	5.8%	11.8%
West Midlands	24,779	17.4%	10.2%
London	14,830	10.4%	11.0%
South Central[2]	19,584	13.8%	-
South West	20,815	14.6%	11.7%

1 UK prevalence by explanatory factors Alzheimer's Research UK [38].
2 GP regions for UK data based on GP regions from dementia prevalence estimates [39]

Older age groups and areas with increased levels of deprivation had the highest rates of mortality (Table 3.3). There were differences in mortality by geographic region; greatest mortality was in the North East (57.2%), and lowest in London (44.3%). Asian (43.6%), Black (40.0%) and Mixed/Other (41.9%) groups had lower mortality than White (51.5%).

Table 3.3. Sample population mortality and available years of data (from year of diagnosis to date of final recorded GP contact/death), by socio-economic and geographic variables

Group	Died	% Died	Total Data Years	Data Years Per Patient	Total Patients
Sex					
Female	47,655	50.7%	1,037,575	11.03	94,060
Male	25,114	52.0%	545,912	11.31	48,280
Dementia Onset					
Early-Onset	1727	33.1%	59,550	11.43	5211
Late-Onset	71,042	51.8%	1,523,937	11.11	137,129
Urban/Rural GP Classification					
Urban	62,120	51.1%	1,355,230	11.14	121,612
Rural	10,649	51.4%	228,257	11.01	20,728
Age Group					
Under45	29	27.9%	1133	10.89	104
45–54	278	32.0%	9564	10.99	870
55–64	1420	33.5%	48,853	11.53	4237
65–74	8001	39.0%	242,220	11.81	20,516
75–84	30,652	48.5%	720,722	11.40	63,236
85–94	29,234	59.6%	518,774	10.57	49,086
95+	3155	73.5%	42,221	9.84	4291
Ethnicity Group					
White	66,817	51.5%	1,443,890	11.14	129,653
Asian	845	43.6%	23,629	12.19	1939
Black	899	40.0%	26,023	11.58	2247
Mixed/Other	453	41.9%	12,114	11.22	1080
IMD 2015 Deprivation Quintile					
Quintile 1: Most Deprived	11,853	53.0%	244,494	10.93	22,366
Quintile 2	12,687	50.9%	274,378	11.01	24,932
Quintile 3	14,841	51.9%	319,408	11.16	28,610
Quintile 4	16,851	51.4%	364,830	11.13	32,786
Quintile 5: Least Deprived	16,404	49.2%	377,391	11.31	33,370
GP Region					
South East Coast	5816	48.2%	136,116	11.29	12,057
North East	4252	57.2%	85,681	11.53	7428
North West	13,418	52.8%	289,817	11.40	25,427
Yorkshire And The Humber	3082	50.2%	68,595	11.17	6139
East Midlands	1410	46.7%	32,825	10.87	3020
East of England	4135	50.1%	91,006	11.02	8261
West Midlands	12,307	49.7%	275,161	11.10	24,779
London	6573	44.3%	165,344	11.15	14,830
South Central	10,695	54.6%	215,802	11.02	19,584
South West	11081	53.2%	223,140	10.72	20,815

3.3.2. Mortality Inequalities in Early-Onset Dementia

Regression analyses found few factors had a significant impact on mortality risk among those with early-onset dementia (Table 3.4). Accounting for covariates (age at diagnosis, ethnicity, IMD 2015 deprivation quintile, urban-rural GP classification, GP region and patient-GP contact rates), men had significantly greater mortality risk than women and, higher rates of GP observations were significantly associated with greater mortality risk.

Table 3.4. Fully-adjusted for covariates[1]. Cox proportional hazards model for sample population with early- and late-onset dementia, by explanatory factors

Group	Early-Onset Dementia				Late-Onset Dementia			
	HR	95% CI	Adjusted p-value		HR	95% CI	Adjusted p-value	
Sex								
Female	1.00				1.00			
Male	1.24 **	(1.09–1.41)	0.032	*	1.11 ***	(1.09–1.14)	0.000	***
Age								
Age At Diagnosis	1.00	(0.99–1.01)	1.000		1.04 ***	(1.04–1.05)	0.000	***
Ethnicity								
White	1.00				1.00			
Asian	0.64	(0.39–1.02)	1.000		0.80 ***	(0.72–0.89)	0.095	
Black	0.88	(0.54–1.43)	1.000		0.71 ***	(0.64–0.79)	0.000	***
Mixed/Other	1.18	(0.53–2.66)	1.000		0.74 ***	(0.65–0.86)	0.004	**
IMD 2015 deprivation quintile								
Quintile 5: Least Deprived	1.00				1.00			
Quintile 4	1.18	(0.97–1.45)	1.000		1.08 ***	(1.04–1.11)	0.012	*
Quintile 3	1.09	(0.88–1.35)	1.000		1.07 ***	(1.03–1.11)	0.000	***
Quintile 2	1.10	(0.89–1.38)	1.000		1.09 ***	(1.05–1.13)	0.055	
Quintile 1: Most Deprived	1.06	(0.85–1.34)	1.000		1.20 ***	(1.15–1.24)	0.000	***
Urban/Rural GP Classification								
Urban	1.00				1.00			
Rural	0.96	(0.78–1.16)	1.000		1.01	(0.97–1.04)	1.000	
GP Region								
South East Coast	1.00				1.00			
North East	0.96	(0.65–1.43)	1.000		1.10 **	(1.03–1.16)	0.000	***
North West	1.09	(0.81–1.48)	1.000		1.04	(0.99–1.09)	0.000	***
Yorkshire And The Humber	1.22	(0.80–1.87)	1.000		1.06	(0.99–1.13)	0.962	
East Midlands	0.97	(0.60–1.57)	1.000		1.03	(0.94–1.13)	1.000	
East of England	0.96	(0.63–1.47)	1.000		1.06	(0.99–1.13)	1.000	
West Midlands	0.88	(0.64–1.22)	1.000		1.03	(0.98–1.08)	1.000	
London	1.09	(0.77–1.52)	1.000		0.95	(0.90–1.00)	1.000	
South Central	1.39 *	(1.02–1.88)	0.727		1.23 ***	(1.17–1.29)	0.000	***
South West	1.30	(0.95–1.78)	1.000		1.17 ***	(1.11–1.23)	0.000	***
Patient-GP Contact rates per year/100								
Observations	1.67 ***	(1.44–1.92)	0.000	***	1.94 ***	(1.91–1.97)	0.000	***
Dementia Medications	6.44 **	(1.73–23.69)	0.112		21.48 ***	(17.62–26.19)	0.000	***
Non-Dementia Medications	0.86 *	(0.78–0.98)	0.613		0.84 ***	(0.82–0.85)	1.000	

*[1]Covariates accounted for: age, sex, ethnicity, deprivation quintile, urban/rural GP, GP region and healthcare contacts; 2 Adjusted p-values for from Cox proportional hazards with Bonferroni adjustments applied; significance level codes: *** 0.001 (99.9%); ** 0.01 (99%); * 0.05 (95%); Note: reference group for each explanatory factor in italics.*

3.3.3. Mortality Inequalities in Late-Onset Dementia

Regression analysis for late-onset dementia found distinct, significant demographic inequalities. When accounting for covariates (Table 3.4), men had significantly greater mortality risk than women. Age was significantly, positively associated with mortality risk, with each year of age associated with 4% (hazard risk (HR): 1.04; confidence Intervals: 1.04–1.05) greater likelihood of dying in the study. Significant variance in mortality risk was found among ethnic groups, with PLWD of Black ethnic groups having a 29% lower risk of mortality than White ethnicity groups (HR: 0.71; 0.64–0.79) and Mixed/Other (HR: 0.75; 0.65–0.86) people having lower mortality risk than White people.

Deprivation was also significantly associated with mortality risk. Compared to the least deprived quintile (Quintile 5), each quintile had significantly increased mortality risk with a dose-response relationship; the most deprived quintile (Quintile 1) had a 20% increased risk of mortality (HR: 1.20; 1.15–1.24) compared to the least deprived. Significant differences were found across geographic regions. Compared to the South East Coast region, mortality risk was greater in the South Central (HR: 1.23; 1.17–1.29), South West (HR: 1.17; 1.11–1.23), North East (HR: 1.10; 1.03–1.16).

Rates of GP observations and dementia medications were also associated with significantly greater risk of mortality among people living with late-onset dementia.

3.4. Discussion

3.4.1. Key Findings

This study presents one of the first to apply large EHRs in exploring numerous causes of inequalities in dementia-related mortality. In early- and late-onset dementia, increasing rates of GP observation contacts - and for late-onset, dementia medications - are associated with increased mortality risk. In late-onset, men had higher mortality risk than women, those from Black ethnicity groups had lower mortality risk than White ethnicity groups, and those living in the most deprived areas had greatest mortality risk compared to those from the least

deprived areas. Additionally, compared to the South East Coast GP region, people registered with GPs in North East, South Central and South West GP regions, had higher mortality risk.

3.4.2. Research Context

Existing research examines the impact of few social, demographic or geographic factors in mortality risk among PLWD (Van de Vorst et al., 2016; Korhonen et al., 2020; Co et al., 2021). Yet none focus on multiple risk factors or investigate healthcare contacts as explanatory factors in health outcomes for PLWD. Despite continuing evidence of dementia care inequalities (Watson et al., 2021) and UK Strategies prioritising narrowing inequalities (Department of Health and Social Care, 2016), issues persist, and have been exacerbated throughout the COVID-19 pandemic (Alzheimer's Society, 2020(2)). Our findings progress previous research, highlighting social, demographic, geographic and healthcare inequalities in mortality risk, accounting for a greater range of explanatory factors.

We noted that in late-onset dementia, living in the most deprived areas was associated with a 20% greater risk of mortality compared to living in the least deprived areas. There are multiple factors that could have a detrimental impact on outcomes for PLWD in more deprived areas, which can occur before they are diagnosed and have a cumulative impact throughout their dementia pathway (Jitlal et al., 2021; Marden et al., 2017). In areas of greatest deprivation, there are more diagnosed and undiagnosed PLWD (Pujades-Rodriguez et al., 2018). With lower rates of early diagnosis for PLWD from more deprived areas, there are fewer treatment options, and dementia has progressed whilst they have remained undiagnosed (Bradford et al., 2009). People from the most deprived areas receive less, and inadequate care and treatment (Nuffield Trust, 2021; Cooper et al., 2017). In dementia, this leads to later diagnosis, with PLWD from deprived areas more likely to experience faster disease progression, use emergency healthcare with more severe symptoms (Sommerlad et al., 2019), have shorter survival and greater mortality risk (Van de Vorst et al., 2019).

People registered with North East, South Central and South East GPs had greater mortality risk. The North East - along with higher prevalence of poor health (UK Parliament, 2016) and lowest life expectancy in England (Corris et al., 2020) - contains some of the most socio-economically deprived areas in England (Ministry of Housing, Communities and Local Government, 2019), likely contributing to higher mortality risk for. Greater dementia mortality risk in South Central and South East regions is reflective of demographic and systemic factors. The South of England tends to be more affluent, with greater life expectancy (ONS, 2020). However, pockets of deprivation may be hidden in regional analyses. Greater mortality risk for older PLWD was observed, and White people had higher mortality risk than other ethnicities. With increased mortality risk observed in GP regions with varied levels of deprivation, mortality risk may be more likely a result of the regions' population composition, rather than the geographic region itself. The South Central and South East regions are older and less ethnically diverse (Local Government Association, 2021). An older population, with reduced mobility and further to travel to access care, will have less frequent healthcare contact, limited treatment options, faster disease progression, and greater risk of negative health outcomes (Innes et al., 2020; Szymczynska et al., 2011).

This study demonstrated that PLWD from ethnic minority groups had a lower risk of mortality than PLWD from White ethnicity groups. These findings are reflective of the lower life expectancy and mortality risk among people from White ethnicity groups in the wider UK population (Gruer et al., 2016; ONS, 2020). They are also similar to findings from previous studies of mortality risk among PLWD from different ethnicity groups (Lewis et al., 2018; Mueller et al., 2017). PLWD from White ethnicity groups tend to access healthcare services more frequently, and encounter better quality care and treatment (Tsamakis et al., 2021). As such, this finding would seem to demonstrate that the mortality risk differences seen between PLWD of White ethnicity and from Black and Mixed/Other ethnicity groups is not necessarily due to inherent social inequalities, or differences in their access to or quality of the health and social care services they encounter. However, there are some cultural and

demographic differences which may play a part in the variation in mortality risk between ethnicity groups in this study. The demography of ethnic minority groups in the UK is younger than that of White ethnicity groups (ONS, 2018), and in conjunction with cultural differences in care expectation, this may mean PLWD from ethnic minority groups are more likely to have a wider group of younger relatives who can provide care at home (Parveen and Oyebode, 2018). People with dementia from ethnic minority groups are also more likely to be diagnosed when they are younger (Mukadam et al., 2023) when their condition may be more manageable at home. Care at home can support better short- and long-term health outcomes, including reduced risk of mortality, which may be a factor in reduced mortality risk among PLWD from ethnic minority groups.

3.4.3. Implications for Policy, Practice and Research

This study illustrates that increasing frequency of patient-GP contact and dementia medications are associated with greater mortality risk among PLWD. We suggest caution in interpreting this finding. Towards the end of life, PLWD are more likely to display more severe dementia symptomatology and a greater number and more severe comorbidities, which can increase GP contact and the number of medications prescribed (Bunn et al., 2014). Greater continuity of GP care for PLWD has been shown to reduce the risk of inappropriate medications and the risk of emergency admissions to hospital (Delgado et al., 2020). However, it should also be noted that different medications are required for dementia subtypes (O'Brien et al., 2017). Incorrect diagnoses and the increased levels of comorbidities among PLWD (Bunn et al., 2014) can increase the potential for inappropriate medications and risk of poor health outcomes (Delgado et al., 2020). More acute need and greater numbers of medications can result in differential patterns in primary healthcare use, and increased secondary healthcare contact which can heighten mortality risk in dementia (Banerjee, 2009; Goddard et all., 2016; Fogg et al., 2017). These findings illustrate how vital continuity of care, and correct treatment for dementia and comorbidities is to maintaining quality of life and longer-term survival are for PLWD (Griffith et al., 2016; Rees et al., 2020).

Further evidence is required to understand the direction of causality in the association between increased GP contact and dementia medications, and mortality risk.

There is a growing need to improve understanding of health inequalities for PLWD (Glikich et al., 2018). This study illustrates the potential and importance of using existing EHRs to explore health inequalities. Further use of EHRs to evidence inequalities in various outcomes for PLWD can benefit policy-makers, service commissioners and providers and clinicians. Developing further on this study, future research should develop understanding of variation in primary and secondary healthcare use among PLWD. Exploring numerous dementia-specific, and non-dementia healthcare contact types is important to identify inequalities in the need and use of healthcare services among PLWD. Future research can extend this work through examining the healthcare pathways, and temporal service use changes among PLWD. For example, by clustering PLWD based on type and frequency of use of different healthcare services, one can identify social, demographic and geographic groups most likely to need and use different services. This can help us to explain why inequalities exist, building on more descriptive work exploring the extent of inequalities. Additionally, EHRs can be used to identify care pathways, helping to illuminate patterns in care usage and associations with positive or negative outcomes. Knowledge of the pathways more likely to elicit positive outcomes can guide future service provision and care decision-making.

3.4.4. Limitations

There are potential explanatory factors of outcome inequalities for PLWD which are not available through CPRD. There is a need to improve data collection for PLWD; routine data of EHRs should be more inclusionary and representative, aiming to be more complete in existing metrics and expanding social, demographic and geographic metrics recorded. There are issues around the representativeness of the sample population within CPRD. Although the population in our study is relatively representative of the UK dementia population for most social and demographic variables—as seen in Tables 2 and 3 —there are differences

between the GP region of the sample population compared to the UK dementia population. Over/under-representation of certain regions may introduce selection bias into our analyses, which may limit the generalisability of our findings (especially the inequalities by region we identify). CPRD holds only data from GPs who have registered to send their practice data to CPRD. If those GPs engaging with data sharing are not random and socially/geographically patterned, this may contribute to the bias in our data. This study used static, at point-of-entry, GP-based geographic variables as explanatory factors of variation in mortality risk among PLWD. Although deprivation was based on individuals' home postcode, location of residence and any change of residence through postcode data is not available via CPRD data, as data is anonymised at source and confidentiality of data is paramount. Using GP-based geographic variables, encompassing large regions of England does however bring a potential limitation. Geographic variables covering large areas, can mask the nuance and variation in numerous factors that exist within regions. Though some areas – such as the North East or North West may have greater deprivations, there are large pockets of wealth. Although we accounted for deprivation in analyses, catch-all GP regions don't necessarily enable as nuanced analyses as could be represented by more exact locations of sample populations' residence, particularly with no data on change of GP or residence over the study period. Future research should seek to understand, at a lower geographic level, changes in the location of residence, as well as movements in primary care provider.

Given the nature of the condition, date of dementia diagnosis is difficult to define. Though screening and testing can indicate dementia symptomology, there is a reliance on clinical judgement during healthcare interactions (Brodaty et al., 1994. Lack of GP confidence in diagnosing, or lack of knowledge of dementia in primary care may result in issues around dementia diagnosis, resulting in issues with defining dementia date of diagnosis (Phillips et al., 2012). There nature of dementia presents difficulties in defining an exact date of diagnosis from health records. Methods to test for symptoms are not always applied consistently and the system relies on clinical judgement (Chithiramohan et al., 2019; Creavin

et al., 2017; Lin et al., 2015). Healthcare provision and a stretched primary care system can result in diagnosis issues, which are more likely to impact the already disadvantaged (Phillips et al., 2012). With people from minority ethnic backgrounds, or from socio-economically deprived areas less likely to receive a diagnosis (Connolly et al., 2011; Pham et al., 2018), this could introduce a degree of selection bias to our findings. There is currently no way to negate this, however in standardising date of diagnosis in the sample population, adds a greater degree of precision.

Evidence points to greater prevalence of diagnosed and undiagnosed dementia among some minority ethnic groups (Pham et al., 2018), and in areas of greatest deprivation (Connolly et al., 2011). Furthermore, less reliance on formal care for PLWD among some communities (Williams et al., 2019), inadequate collection of socio-economic and demographic information and historic under-representation in EHRs and research among some communities (Hindorff et al., 2018), means true prevalence among certain population groups may not be discovered (Klinger et al., 2015). Severity or stage of dementia was not available from the CPRD data, and no comorbidities index or variable indicating health status, or healthcare need was included within the analyses. This may be a factor in some of the findings coming from this paper, specifically with men tending to have greater comorbidities and need (Gambassi et al., 1999), and people from White ethnicity groups having greater access to, and quality of healthcare than PLWD from other ethnicity groups (Duran-Kirac et al., 2021). Potential lack of representation in CPRD, and identifier of general need as a result of comorbidities may impact potential findings and conclusions.

For the sample population, there are fewer dementia medication records (~2.5% of all recorded patient-GP) than GP observation or non-dementia medication records. In early- and late-onset dementia there are fewer than 2.4 and 2.9 dementia medication records per patient year respectively. This may help explain wider confidence intervals for dementia medication contacts as an explanatory factor for mortality risk in the sample population.

3.4.5. Conclusions

Findings from this study suggest substantial differential mortality risk among PLWD, due to demographic, social and geographic factors, and use of primary healthcare. These findings have ramifications for future research and services. Reducing inequalities in mortality for PLWD requires systemic, societal and cultural measures. In areas of greatest deprivation, expansion of health and social care provision, alongside improved links between primary healthcare and post-diagnostic support, can make services more accessible. Additionally, commitment to person-centred care discussions are essential, with pragmatic inclusion of medicative and non-medicative treatments. Better access to, and support in using health technologies, alongside improved transport infrastructure can enable more equitable service access for remote and older populations. Future research should explore more health and social outcomes for PLWD. This study was the first to incorporate numerous socio-economic and geographic factors, and healthcare contacts as factors in mortality risk among PLWD. Future research should include broader healthcare contact types, and socio-economic and geographic characteristics as explanatory factors of health outcomes for PLWD.

3.5. Research developments from Chapter 3

Along with the gaps in the literature identified by the systematic review – a lack of research on multiple parts of the pathway for people living with dementia, using multiple explanatory factors – further potential avenues for research were highlighted from the research in Chapter 3. Mortality is a definitive variable for a time-to-event analysis among PWLD and having a singular focus on mortality does not encompass the range of lived experiences of PLWD beyond their diagnosis. Exploring the experience between diagnosis and an end point such as mortality is critical in understanding differential care needs and how healthcare use can impact other outcomes. This led to the generation of the research idea that forms Chapter 4 – an exploration of social and spatial variations in the use of multiple types of primary and secondary healthcare. This study focused on healthcare usage since (i) literature has showed, both for dementia and other conditions, that there are large inequalities in who accesses and uses different types of healthcare, and (ii) any inequalities are potentially modifiable through improving access which could tackle inequalities. In the preceding paper, we highlighted that differential rates of use of primary healthcare services can impact the risk of mortality among people living with dementia. However, it is important to understand how socio-economic and geographic factors may impact the frequency or likelihood of using different types of healthcare. Exploring the frequency or likelihood of using a variety of both primary and secondary healthcare services can create a bigger picture of how inequalities could be more ingrained and reflect to use greater need among certain socio-economic or geographic groups.

4. Chapter 4: Social and spatial inequalities in healthcare use among people living with dementia in England (2002-2016)

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Abstract

Objectives

Healthcare services for people living with dementia (PLWD) are stretched, and government promises of increased funding remain undelivered. With the UK dementia population to surpass 1 million by 2024, and dementia care costs predicted to almost treble by 2040, it is essential we understand differences in healthcare use among PLWD. This study aimed to explore social and spatial variations in healthcare use among people diagnosed with dementia (2002–2016).

Methods

Data were derived from Electronic Health Records of Clinical Practice Research Datalink GP patients in England (n = 142,302). To standardise healthcare contacts, rates of healthcare contacts per year were calculated for three primary (GP observations and medications) and three secondary healthcare types [Accident & Emergency (A&E) attendances and, emergency and elective hospital admissions]. Fully-adjusted generalised linear regression models were used to identify healthcare use variation by social and spatial groups. Twelve

models were generated, one for each healthcare type in early- and late-onset populations separately.

Results

This study highlights numerous social and spatial variations in healthcare use among PLWD. Among PLWD, several groups tended to have healthcare service use more closely associated with negative outcomes, including a greater likelihood of A&E attendances and emergency and elective hospital admissions. These groups include: men, people from White ethnicity groups and people from more deprived and rural areas.

Conclusions

Systemic and social measures are needed to reduce variations in healthcare use inequalities in PWLD. These include greater healthcare continuity, health checks and medicines reviews, culturally appropriate services, better and more accessible treatment and improved infrastructure.

4.1. Introduction

Among PLWD, inequalities exist in the availability and quality of healthcare (Cooper et al., 2017; Wu et al., 2018) and in the likelihood of negative health and social outcomes (Korhonen et al., 2020, van de Vorst et al., 2016; Watson et al., 2020). PLWD from disadvantaged areas and socio-economic groups experience greater unmet care needs, and have poorer health outcomes (Giebel et al., 2021; Wu et al., 2018). Recent government policy has prioritised reducing inequalities in accessing dementia diagnosis, support, treatment and resultant outcomes. However, commitments to increased funding to support services remain unfulfilled (Department of Health and Social Care, 2016; Local Government Association, 2021). Both health and social care are vital for PLWD and their carers to live well in the community or in a care home after a diagnosis, and continued lack of funding of both, and neglect of the social care system (King's Fund, 2018), has resulted in an increased use of avoidable healthcare services (Alzheimer's Society, 2018; NICE, 2018).

The majority of PLWD are aged 65 years and over, and are more likely to have comorbidities than the general population (Griffith et al., 2016). The number of PLWD in the UK is expected to increase from an estimated 920,000 currently to over 1 million by 2024 (Wittenberg et al., 2019). The greatest increase will be among those with severe dementia symptomatology, with acute everyday support needs (Bennett et al., 2018). With increased and more acute need among PLWD, the cost of providing health and social care to PLWD is set to almost than treble by 2040 (Wittenberg et al., 2019). Increasing numbers of PLWD and more acute need, alongside sustained funding shortfalls will likely exacerbate inequalities in the accessibility and quality of healthcare, health outcomes and the frequency and cost of avoidable healthcare use.

Avoidable, unplanned healthcare use, including A&E attendances, hospital admissions and readmissions, is greater among PLWD than the general population (Voss et al., 2017). Among PLWD, there are differences in the likelihood of using potentially avoidable healthcare, by socio-economic and demographic groups, including by gender, age, levels of

deprivation and rurality (Thorpe et al., 2010; Husaini et al., 2015; Shepherd et al., 2019; Watson et al., 2020). There are also social and spatial differences in the use of primary healthcare among PLWD, including the quality and frequency of dementia medications and, adequate care and treatment reviews (Cooper et al., 2017; Giebel et al., 2021; Lu et al., 2021). Avoidable healthcare use is associated with more severe dementia, faster deterioration, poorer quality of life, increased mortality risk and greater cost to the healthcare system (Briggs et al., 2017; Reynish et al., 2017; Sager et al., 1996; Tropea et al., 2017; van de Vorst et al., 2015). Although early diagnosis and effective treatment can reduce avoidable healthcare use and associated negative outcomes (Alzheimer's Society, 2021; Watson et al., 2021), a lack of funding for formal services and greater and more acute need among PLWD will likely exacerbate avoidable healthcare use, leading to more proliferate negative health outcomes for PLWD with elevated costs to healthcare services. Some socio-economic groups and geographic areas are more likely to experience a lack of sufficient care, including those from more remote or historically underserved communities (Rahman et al., 2020; Thorpe et al., 2020; Watson et al., 2020). Funding issues, increased numbers of PLWD and more acute need is likely to widen existing inequalities, meaning those already experiencing poorer care, treatment and health outcomes will be affected more greatly.

It is therefore essential we understand the spatial and social contexts that influence the healthcare experiences of PLWD, to identify and address their resulting inequalities (Pearce, Mitchell and Shortt, 2015). We define inequality here to mean observable differences between societal groups. We are describing the extent of these differences, and therefore we do not take an equity approach, however, inequalities often reflect unjust and unfair processes that lead to certain social groups to have better health than others. While some argue that inequalities reflect differences in need, these differences in need are often socially rooted as well. In our paper we select social and spatial factors that have been identified by the UK Government as unjust and use them as social markers for measuring inequalities. Providing a picture of differential need and quality and, avoidable service use based on

spatial factors, can help with policy decisions to reduce pressure and financial burden on services and potentially address improved wellbeing for PLWD (Dummer, 2008; Rice and Smith, 2001).

To reduce current and future inequalities among PLWD, we need to support better service delivery and healthcare decision-making. Electronic Healthcare Records (EHRs) can be used to identify healthcare use among large cohorts of patients with a specified health condition, such as dementia (Casey et al., 2016). EHRs have been employed previously to evidence inequalities in health outcomes, although their use has been somewhat limited (Watson et al., 2020; Watson et al., 2021). Understanding which services PLWD are in contact with, by social and spatial variables, can demonstrate differences associated with healthcare utilisation. There are gaps in the existing literature, with a lack of research encompassing more than one or two demographic, geographic or socio-economic variables associated with differential use of healthcare services, or incorporating the use of a variety of both primary and secondary healthcare services as outcome measures (Watson et al., 2020). Also, we are not aware of previous research exploring spatial variations in healthcare use among PLWD. To begin to understand how we can go about reducing inequalities in healthcare use and health outcomes, and improve the situation for PLWD, it is important to address these key gaps.

The aim of this study was to examine the extent to which social and spatial factors are associated with variations in the use of different types of primary and secondary healthcare among PLWD, using large-scale, longitudinal Electronic Health Records (EHR).

4.2. Materials and Methods

4.2.1. Data Access and Ethical Approval

Clinical Practice Research Datalink (CPRD) collect pseudo-anonymised, Electronic Health Records (EHR) from General Practices (GP) across the United Kingdom (UK). CPRD data incorporates ~16million patients registered with UK GPs representing 25% of the UK patient

population. CPRD Aurum contains routinely-collected, anonymised EHR from registered GPs, covering primary care data, including GP contacts and medications. CPRD can also provide data linkage between primary and secondary healthcare records, social and spatial variables (CPRD, 2021). Data access was granted by CPRD and use of CPRD Aurum approved by the University of Liverpool Research Ethics board (Reference: 7922).

4.2.2. Sample Population

Patients registered with CPRD GPs, who were diagnosed with dementia between 2002-2016, with at least two years of follow-up healthcare data from date of diagnosis (Figure 4.1). Our initial analytical sample size was 142,302 people.

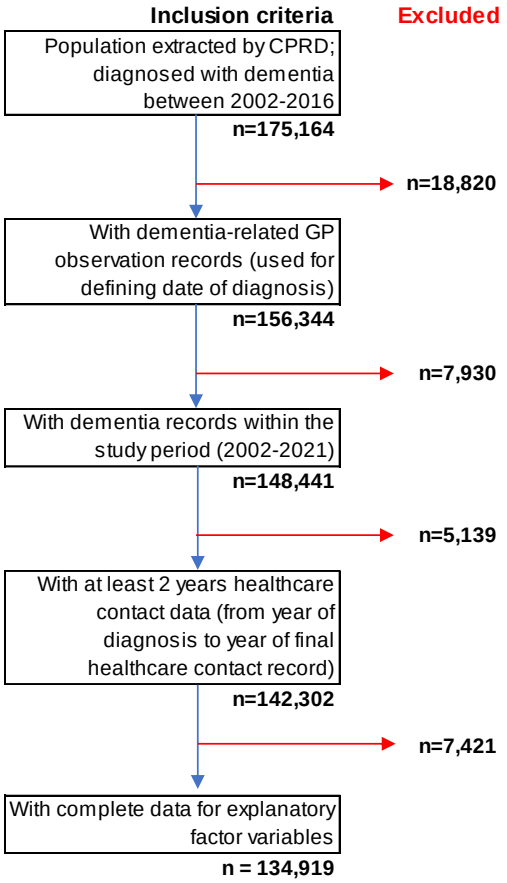


Figure 4.1: Inclusion/Exclusion criteria for sample population

4.2.3. Outcome variables

No date of dementia diagnosis is available in CPRD GP data. Dementia-specific GP observations are those which include one of the following terms as the reason the patient

presented to their GP: “dementia”, “Alzheimer”, “cogniti”, or “memory”. We calculated date of diagnosis as the date for a patient’s first dementia-specific GP observation record occurred. Healthcare contacts included in analyses are only those which occurred after this diagnosis date.

This study includes rates of six healthcare contacts per year as independent healthcare use variables as outcome measures. These include three primary healthcare use variables - GP observations, dementia medications and non-dementia medications – and three secondary healthcare use variables – A&E attendances, emergency hospital admissions and non-emergency hospital admissions. Rates for each of the six healthcare types were calculated, per year, based on years present in the data (from year of diagnosis to year of final healthcare record/year of death). In this study, a healthcare contact refers to an individual record of communication or treatment between a PLWD and a healthcare service. Healthcare contacts were standardised for each member of the sample population. Descriptions of what each of the six healthcare types refers to are given below.

GP observations are self-contained, with one record for each observation at a GP visit. Dementia-specific medications include prescriptions for four drugs advised for use by the NHS for PLWD: Donepezil, Galantamine, Rivastigmine and Memantine. Non-dementia medications refer to all remaining drugs prescribed.

A&E attendance records are self-contained, denoting individual records of a person presenting at an Accident & Emergency department. Emergency hospital admission spells are records of urgent care need and elective hospital admission spells are records of planned care. A&E attendances are generally unplanned presentations at A&E or urgent care, and hospital admissions involve a clinical decision to admit the patient as they are deemed to require further care, treatment and observation.

4.2.4. Explanatory variables

This study encompasses multiple variables as potential explanatory factors of variation in healthcare use among PLWD. Available from CPRD GP data, we included patients' age at diagnosis, sex and GP region, and from patient secondary healthcare records, ethnicity. From age at diagnosis, we defined whether patients had early-onset (aged under 65 years) or late-onset dementia (aged 65 years+). People with early-onset dementia are more likely to have rarer forms of dementia than in late-onset (DementiaUK, 2022; Gupta, Fiertag and Warner, 2018), which can present additional symptomatology (Giebel et al., 2020). Together with the need for greater support with day-to-day activities, such as washing or preparing food, rare dementias can present varied symptoms which can have a greater impact on health and cognition (Gerritsen et al., 2019; Koedam et al., 2010; Smits et al., 2014). The differential impact on cognition and physical capabilities, along with family, social and employment dynamics mean people with early- and late-onset dementia will likely have differing needs (Alzheimer's Society, 2020). 2015 Indices of Multiple Deprivation (IMD) quintile and GP urban/rural classification was available via data linkage using patients' GP ID. This study includes these explanatory factors for healthcare use among PLWD, as research illustrates differential provision and quality of healthcare, and health outcomes for PLWD by age (continuous), sex, ethnicity and deprivation, and by spatial factors including level of urbanity/rurality (Rahman et al., 2020; Watson et al., 2020, Watson et al., 2021; Wu et al., 2020).

4.2.5. Missing Data

Our analytical sample size was 142,340 people. However, ethnicity data for 7,421 (5.2%) and IMD 2015 quintile data for 276 (0.2%) was missing data. As such these individuals were not included in regression analyses (Figure 1). Research has demonstrated that there is under-diagnosis of dementia, and under-representation of some population groups healthcare services, data and research, particularly people from minority ethnicity groups and more deprived areas (Cooper et al., 2010; Gilmore-Bykovskyi et al., 2019; Mukadam et

al., 2023). This means that missing data for explanatory factors cannot be assumed missing at random.

4.2.6. Statistical analysis

The sample population was stratified into two groups based on age of onset of dementia diagnosis. Descriptive statistics of the sample populations' social and spatial factors were calculated. Frequency counts and rates per year of the six healthcare types were calculated. Explanatory factors were included in fully-adjusted, generalised linear regression models, highlighting variation in healthcare use. A mixture of Binomial and Poisson generalised linear regression models were used. Those healthcare types with sufficient numbers – in which more than half of the population came into contact with the healthcare service - of contacts were analysed using Poisson regression, based on rates per patient year. People come into contact with secondary healthcare services a lot less frequently than they do with primary care services. With so many of the sample population potentially having 0, or very few secondary healthcare contacts, Poisson models would likely generate under-dispersion. As such, if less than half of the sample population came into contact with a specific healthcare service type, binomial regression models were used, testing the impact of explanatory factors on whether the person did or did not use the type of healthcare. Within regression models, explanatory factors were included as dependent variables, with the rates/occurrence of healthcare contacts the independent variable(s).

Early-onset: Binomial regression models were used for analysis of associations between explanatory factors and likelihood of using dementia medications, A&E attendances and, elective and emergency hospital admissions. Poisson regression models were used to test for associations between explanatory factors and frequency of for GP observations and non-dementia medications.

Late-onset: Binomial regression models were used for A&E attendances and, elective and emergency hospital admissions. Poisson regression models were used for GP observations, dementia and, non-dementia medications.

Early- and late-onset populations were analysed separately, with a total of 12 fully-adjusted models run to indicate differential use of each healthcare type by explanatory variables. Analyses were conducted in R. Poisson regression models return Incidence Rate Ratios (IIR), and Binomial regression models return Odds Ratios (OR), both with 95% confidence intervals. OR gives us the relative difference to the reference group in the odds of an outcome, whereas IRR provides a ratio of the difference in the rate of the outcome compared to the reference group.

For categorical variables included as explanatory factors of an outcome in regression analyses, we are required to specify a level as our reference group, against which each of the other levels are compared. As a continuous variable in both early- and late-onset models, age at diagnosis did not require this. However, in our analyses, our reference groups for gender (women), ethnicity (White), urban-rural GP classification (Urban) are based on the level with the largest population size. For IMD 2015 deprivation quintile (Ministry of Housing, Communities & Local Government), we used the least deprived quintile (Quintile 5) as our reference group, to demonstrate the impact of increasing levels of deprivation on outcomes. For GP region, the North East was chosen as our reference group. In our descriptive analysis the North East was shown to have higher rates per year of most healthcare types than other regions, and so gave the most pragmatic choice for reference group.

4.3. Results

4.3.1. Sample population

Of the 142,302 population PLWD (Table 4.1), approximately two-thirds were female, less than 4% were of Asian, Black or Mixed/Other ethnicity groups, and a greater proportion resided in less deprived areas. Less than 4% of the sample population had early-onset dementia, with the majority (78.9%) aged between 75-94 years. Approximately 1 in 7 were registered with GPs in urban areas and greater numbers were registered with GPs in the North West, West Midlands, South West and South-Central regions. Thirty-three PLWD had

neither IMD quintile, or ethnicity (<0.01%) available, 7,388 (5.2%) had no stated ethnicity, and a further 243 (<0.2%), no IMD quintile stated. Data are not included in regression models and due to the inherent under-representation of some groups in society in diagnosis, healthcare services, data and research, these data cannot be assumed missing at random.

Table 4.1: Demographic characteristics of sample population vs. UK dementia population

Explanatory factor	***Sample Population***		***UK[3]***
	n	***%***	***%***
Onset/Age Group			
Early-Onset	52101	3.7%	5.2%
Under45	104	0.1%	0.2%
45-54	870	0.6%	0.5%
55-64	4236	3.0%	4.5%
Late-onset	137092	96.3%	94.8%
65-74	20514	14.4%	16.6%
75-84	63225	44.4%	36.5%
85-94	49067	34.5%	36.2%
95+	4286	3.0%	5.5%
Sex			
Female	94033	66.1%	65.0%
Male	48269	33.9%	35.0%
Ethnicity			
Asian[1]	1937	1.4%	1.5%
Black[2]	2246	1.6%	2.7%
Mixed/Other	1080	0.8%	1.3%
White	129618	91.1%	94.5%
IMD 2015 Deprivation Quintile			
Quintile 1: Most Deprived	22362	15.7%	10.7%
Quintile 2	24923	17.5%	16.6%
Quintile 3	28601	20.1%	20.5%
Quintile 4	32778	23.%	23.4%
Quintile 5: Least Deprived	33362	23.4%	26.5%
Urban-Rural GP Classification			
Urban	121586	85.4%	N/A
Rural	20719	14.6%	N/A
GP Region[4]			
North East	7428	5.2%	5.3%
North West	25422	17.9%	13.5%
Yorkshire And The Humber	6137	4.3%	9.9%
East Midlands	3020	2.1%	9.3%
East of England	8261	5.8%	11.8%
West Midlands	24769	17.4%	10.2%
London	14825	10.4%	11.0%
South Central	19579	13.8%	N/A
South East Coast	12052	8.5%	17.3%
South West	20809	14.6%	11.7%

[1]Sum of: Bangladeshi, Chinese, Indian, Other Asian and Pakistani ethnicity groups

[2]Sum of: Black African, Black Caribbean and Black other ethnicity groups

[3]Dementia Statistics hub, Alzheimer's Research UK (May 2020)

[4]Public Health England Regions include only South East/South West, not South Central

Inclusion in the study required a date of diagnosis derived from the first recorded dementia-specific GP observation record, and therefore all of the sample population had recorded GP observations. However, not all experienced each of the healthcare types. Though nearly all

had non-dementia medications (99.4%), just over half had dementia medications prescribed (53.5%). Over four in five of the sample population had A&E attendances (82.3%) and emergency hospital admissions (81.1%), but approximately only two in five had elective hospital admissions (40.3%).

4.3.2. Multivariable logistic regression: primary and secondary healthcare use

Significant differences in rates of healthcare use were noted by all explanatory factors (Figures 4.2 & 4.3 and Appendices 4.3 & 4.4). Variations were noted among those with early- (Appendices 4.1 & 4.2) and late-onset dementia (Figures 4.2 & 4.3), but more so among people living with late-onset dementia.

The Poisson models employed in the analysis of associations between social and spatial explanatory factors and healthcare use, were tested for potential over-dispersion. Over-dispersion in Poisson regression models occur when the variance value of the data is greater than the mean value of the data. This can result in bias and the overestimation of significant findings (Payne et al., 2018). Over-dispersion was noted in Poisson regression models for: early-onset models GP observations and non-dementia medications, and late-onset GP observations. To understand the extent and impact of over-dispersion in these three Poisson models and to account for potential over-dispersion I ran negative binomial regression models. Negative binomial regression models are used with over-dispersed numeric data to assess associations between explanatory factors and outcome measures (Hilbe, 2007). The coefficient values from Poisson and negative binomial regression models were compared for each of the over-dispersed models. There is broad agreement in coefficient values across Poisson and negative binomial models, which suggests that overdispersion is not a major issue. Consequently, Poisson models were used to assess associations between explanatory factors and the three aforementioned healthcare use outcome variables.

Sex

Compared to women as our reference group, men had significantly more GP observations (Early-onset: IRR: 1.077; 1.070-1.084; Late-onset: IRR: 1.136; 1.135-1.138) and non-dementia medications (Early-onset: IRR: 1.026; 1.019-1.034; Late-onset: IRR: 1.295; 1.204-1.392). Men with late-onset dementia had 11% higher odds of attending A&E than women (OR: 1.107; 1.073-1.142). Men were also more likely be admitted to hospital than women, whether as an elective (OR: 1.452; 1.418-1.487) or emergency (OR: 1.090; 1.056-1.125).

Age

Increasing age was significantly associated with greater GP observations (Early-onset: IRR: 1.002; 1.001-1.002; Late-onset: IRR: 1.003; 1.003-1.003) and non-dementia medications (Early-onset: IRR: 1.012; 1.011-1.013; Late-onset: IRR: 1.095; 1.089-1.101). The youngest (Early-onset: IRR: 0.967; 0.956-0.978) and oldest (Late-onset: IRR: 1.035; 1.034-1.036) had the most dementia medications. Among those with late-onset, each year increase in age resulted in a 2% greater likelihood of using A&E (OR: 1.020; 1.018-1.022) and emergency hospital admission spells (OR: 1.009; 1.007-1.011), but being less likely to have elective hospital admission spells (OR: 0.947; 0.945-0.949).

Ethnicity

Compared to those of White ethnic background, PLWD from Asian (Early-onset: IRR: 1.790; 1.762-1.817; Late-onset: IRR: 1.377; 1.371-1.383) and Black (Early-onset: IRR: 1.213; 1.191-1.237; Late-onset: IRR: 1.218; 1.213-1.223) ethnic groups had greater GP observations. Those with late-onset from Black ethnic groups also had significantly greater prescriptions for dementia medication (IRR: 1.167; 1.095-1.243) than those from a White ethnic background, but both people from Black (OR: 0.687; 0.611-0.775) and Asian ethnic groups (OR: 0.608; 0.542-0.683), had a significantly lower likelihood of emergency hospital admission spells. In early-onset dementia, compared to those from White ethnic groups, people from Asian (IRR: 1.607; 1.578-1.637) and Black (IRR: 1.117; 1.092-1.142) ethnic

groups had significantly higher rates of non-dementia medications, whereas PLWD from Mixed/Other ethnic groups has significantly fewer (IRR: 0.875; 0.842-0.908).

Deprivation

Compared to PLWD from the least deprived quintile (Quintile 5), those in the most deprived quintile (Quintile 1) had significantly higher rates of GP observations (Early-onset: IRR: 1.208; 1.195-1.221; Late-onset: IRR: 1.059; 1.057-1.061) and, in early-onset, had 65% higher rates of non-dementia medications (IRR: 1.648; 1.626-1.670) and, in late-onset higher rates of dementia medication prescriptions (IRR: 1.217; 1.184-1.251). In late-onset, compared to the least deprived quintile (Quintile 5), those in the most deprived quintile (Quintile 1) were significantly more likely to be admitted to hospital as an emergency (OR: 1.557; 1.474-1.644), but less likely to attend A&E (OR: 0.880; 0.835-0.926) or have elective hospital admissions (OR: 0.890; 0.856-0.926).

Urban-Rural GP Classification

Among those with early-onset dementia, people with rural GP practices had significantly fewer GP observations (IRR: 0.909; 0.900-0.919) than urban. In late-onset dementia, A&E attendances were more likely among PLWD with rural GPs (OR: 1.204; 1.156-1.253), but emergency hospital admission spells were less likely (OR: 0.820; 0.787-0.855).

GP Region

Compared to the North East GP region, PLWD registered with GPs in other regions had significantly fewer GP contacts but more non-dementia medications. In late-onset, all GP regions had significantly greater rates of prescriptions for dementia medications than the North East. Among those with late-onset, PLWD in all GP regions apart from London were more likely to attend A&E, but six of the nine regions were significantly less likely to have emergency hospital admissions than the North East.

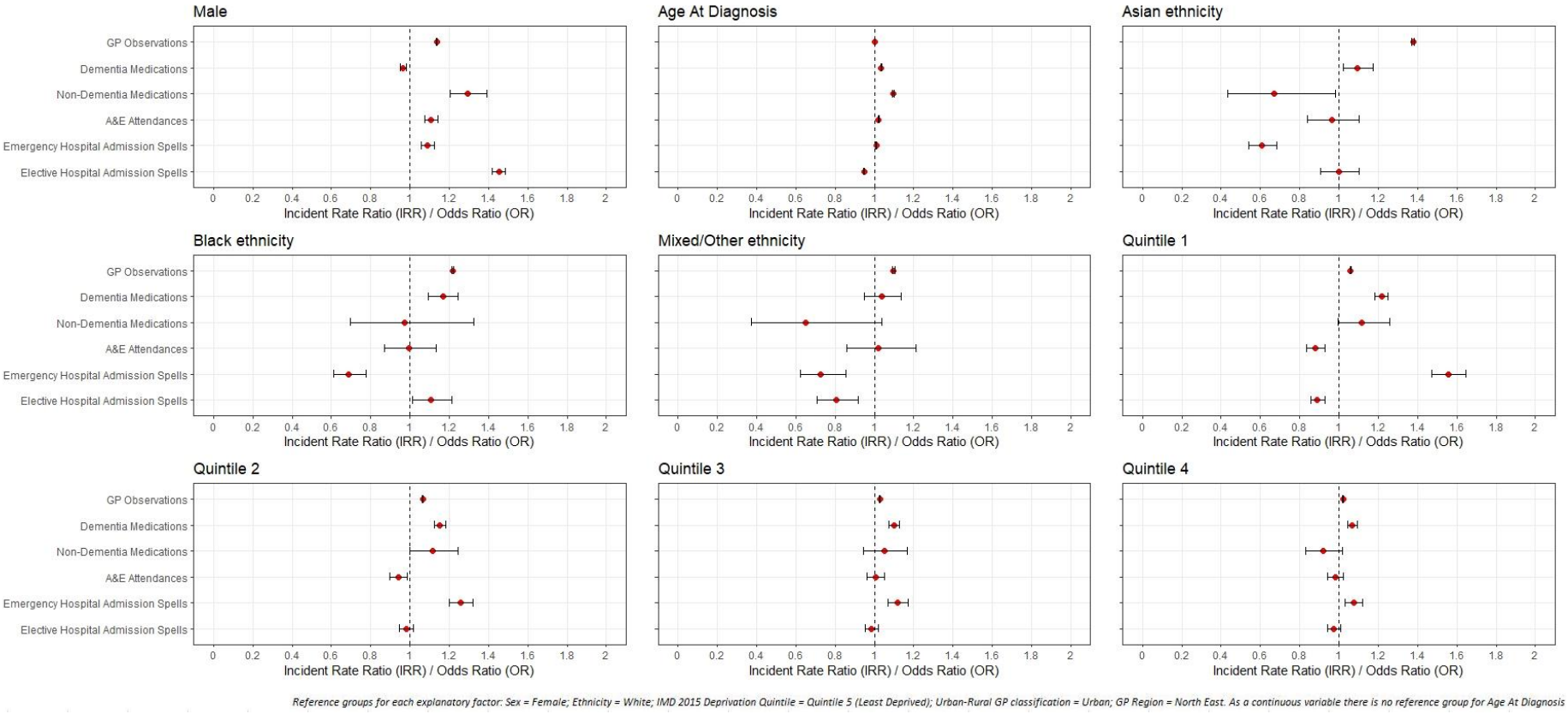


Figure 4.2: Odds Ratios (OR; for secondary healthcare) or Incidence Rate Ratios (IRR; for primary healthcare) and 95% confidence intervals for healthcare use among late-onset dementia sample population, by demographic and socio-economic factors[1]

[1] *In late-onset, Poisson regression models were used with the three types of primary healthcare (GP observations and, dementia and non-dementia medications), reporting Incidence Rate Ratios (IRR). Binomial regression models were used with the three types of secondary healthcare (A&E attendances, elective hospital admissions, and emergency hospital admissions), reporting Odds Ratios (OR).*

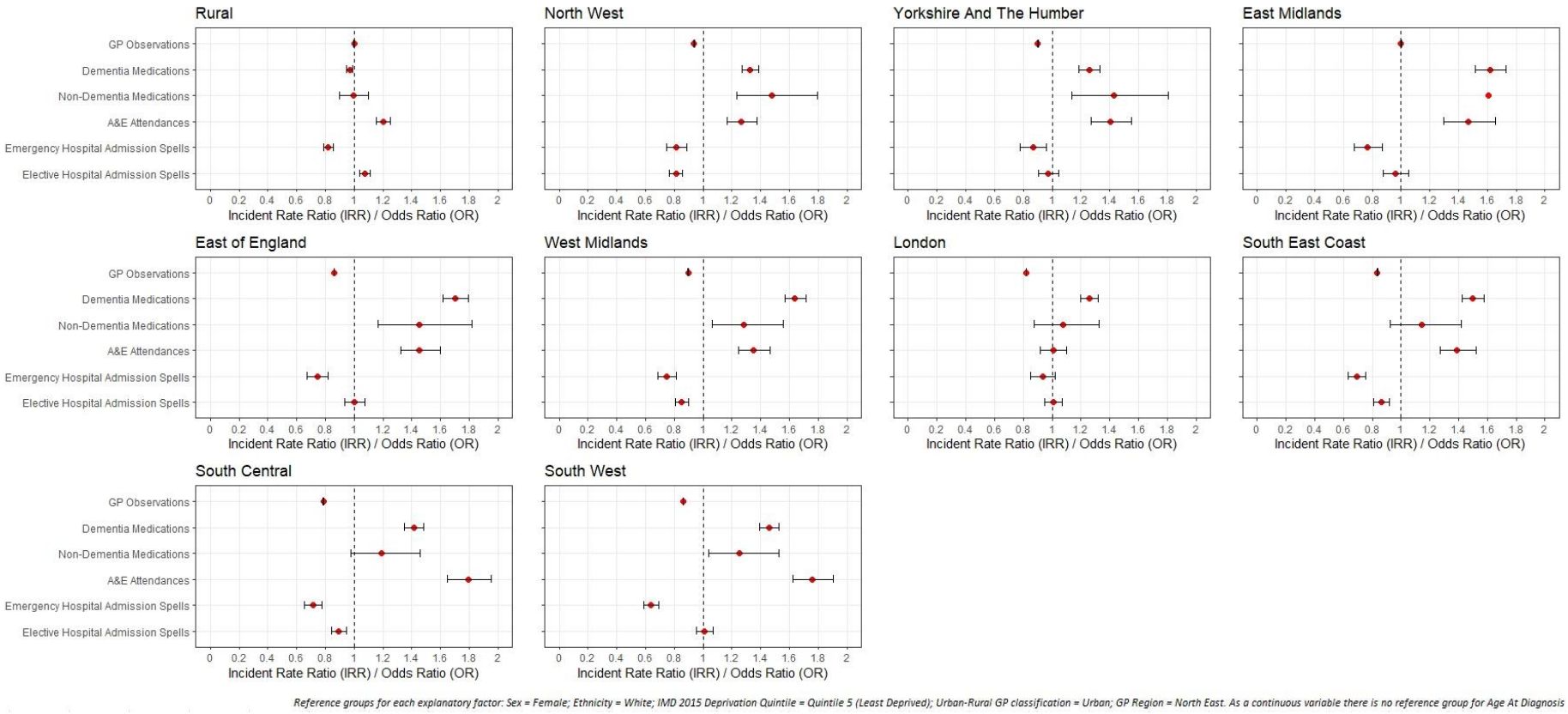


Figure 4.3: Odds Ratios (OR; for secondary healthcare) or Incidence Rate Ratios (IRR; for primary healthcare) and 95% confidence intervals for healthcare use among late-onset dementia sample population, by spatial factors

4.4. Discussion

Our study is one of the first to use large-scale EHR to document social and spatial variation in who is accessing and receiving diverse types of healthcare among PLWD. Men and older PLWD were more likely to use primary and emergency secondary healthcare. PLWD from Asian and Black ethnic groups had greater GP contact and in late-onset Dementia were less likely to have emergency hospital admissions. Increasing socioeconomic deprivation is also associated with greater GP contact, emergency hospital admissions and medications. PLWD with rural GPs had less GP contact than individuals in urban areas and though they were more likely to attend A&E, were also less likely to have emergency hospital admissions. The North East region had fewest GP contacts, varied medications and likelihood of emergency healthcare use.

We found men had more GP contact, non-dementia medications and both emergency and elective hospital admissions. Higher rates of non-dementia medications among men is a finding consistent with higher levels of severe comorbidities and severe dementia symptoms among men (Gambassi et al., 1999; Lyketsos et al., 1999; Lovheim et al., 2009; Nelis et al., 2019). Men have greater healthcare needs due to greater ill-health (Bertogg and Strauss, 2018; Sharma et al., 2016). Men with dementia also have shorter (Ono et al., 2010), but more frequent, hospital admissions than women and upon hospital discharge are more likely return to be readmitted to hospital (Bartlett et al., 2016; Watson et al., 2020).

This study reported greater use of primary healthcare, and lower risk of emergency hospital admissions, for people with late-onset dementia from ethnic minority backgrounds. The factors impacting healthcare use among PLWD from ethnic minority backgrounds is nuanced. Increased GP contact among these groups may reflect greater need for treatment due to more chronic health conditions (Price et al., 2013; Quiñones et al., 2019), as well as primary healthcare being more equitable for ethnic minorities than other forms of healthcare (King's Fund, 2021). However, our findings emphasise less need for acute healthcare among PLWD from ethnic minority backgrounds. There is lower mortality risk among PLWD

from ethnic minority backgrounds (Watson et al., 2021), a finding which may be consistent with younger demographics (insufficiently controlled for in our analysis) and reduced severity of dementia (Parveen and Oyebode, 2018). Existing research highlights the barriers in accessing quality healthcare for PLWD from ethnic minority backgrounds (Cooper et al., 2010; Lin et al., 2020; Mukadam et al., 2011; Pham et al., 2018), but with reduced severity, there is also less frequent contact with healthcare services (Duran-Kirac et al., 2022).

We found that people with late-onset dementia from the most deprived areas had higher GP observations, dementia medications and increased likelihood of using emergency healthcare. Although literature tends to show that PLWD from areas of greater deprivation receive fewer medications for dementia (Cooper et al., 2016; Vohra et al., 2021), our findings emphasise the difficulties in access to quality healthcare in more deprived areas. Access to dementia diagnosis and subsequent treatment is more difficult in more deprived areas (Hoang et al., 2021). PLWD from deprived areas are more likely to experience poorer quality primary healthcare (Watson et al., 2020; Wu et al., 2018) and receive a late or unspecified dementia diagnosis which can make effective medicative treatment, where feasible, more difficult (Connolly et al., 2011; Jitlal et al., 2021; Petersen et al., 2021). In this study, although PLWD from the most deprived areas had increased contact with a range of different types of healthcare, this may be indicative of greater and more acute need for treatment of both dementia, and other comorbidities (Browne et al., 2017; Jitlal et al., 2021; Watson et al., 2020).

Additionally, we found significant differences in experiences between urban and rural areas, suggesting the importance of spatial factors in determining healthcare experiences. In early-onset, PLWD registered with rural GPs had less contact with their GP, and those with late-onset had greater likelihood of attending A&E. Health and social care services are sparser in rural areas (Baird and Wright, 2006, Bauer et al., 2019; Giebel, 2020, National Centre for Rural health and Care, 2022) and PLWD from rural areas are more likely to live with relatives than those in urban areas (Rahman et al., 2020). Sparsity of local services may

also mean PLWD registered with rural GPs have a greater reliance on their GP to act as gatekeeper to diagnosis and treatment (Szymczynska et al., 2011). This emphasised reliance on GPs, along with few available services may result in a lack of care management and effective treatment (Bayly et al., 2020; Dal Bello-Haas et al., 2014), which can lead to a greater need for more acute, emergency healthcare, including A&E attendances.

4.4.1. Limitations

We have included over 120 million records of primary and secondary healthcare contacts for 142,302 people diagnosed with dementia in England. We have identified social and spatial differences in the frequency and likelihood of contact with six different types of healthcare, highlighting variations in potentially avoidable service use, and healthcare use more closely associated with negative health outcomes. There are potential issues with bias and representativeness of the population being studied. Given the nature of dementia and process of diagnosis, it is difficult to pinpoint the exact date of diagnosis in health records. While there are methods to test for symptoms of dementia, they are not prevalent in primary healthcare, consistently applied, or always appropriate, and there remains a reliance on clinical judgement during healthcare contacts (Chithiramohan et al., 2019; Creavin et al., 2017; Lin et al., 2015). Lack of GP time, confidence in diagnosing, or lack of knowledge of dementia in primary care may result in issues around the diagnosis (Phillips et al., 2012). This means fewer PLWD will have an official diagnosis, which impacts some socio-economic groups more than others, our findings may not therefore be reflective of the entire population of PLWD. While we have access to socio-economic and demographic variables to allow adjustment for their influences in analyses, some population groups are under-represented through lack of dementia diagnoses, including people from an ethnic minority background and those living in more deprived areas (Connolly et al., 2011; Pham et al., 2018). This may result in selection bias being introduced in our data, including biasing the associations between our exposures and outcomes (Hindorff, Bonham and Ohno-Machado, 2018; Williams and Cooper, 2019). There is a need to improve data collection, with routine data

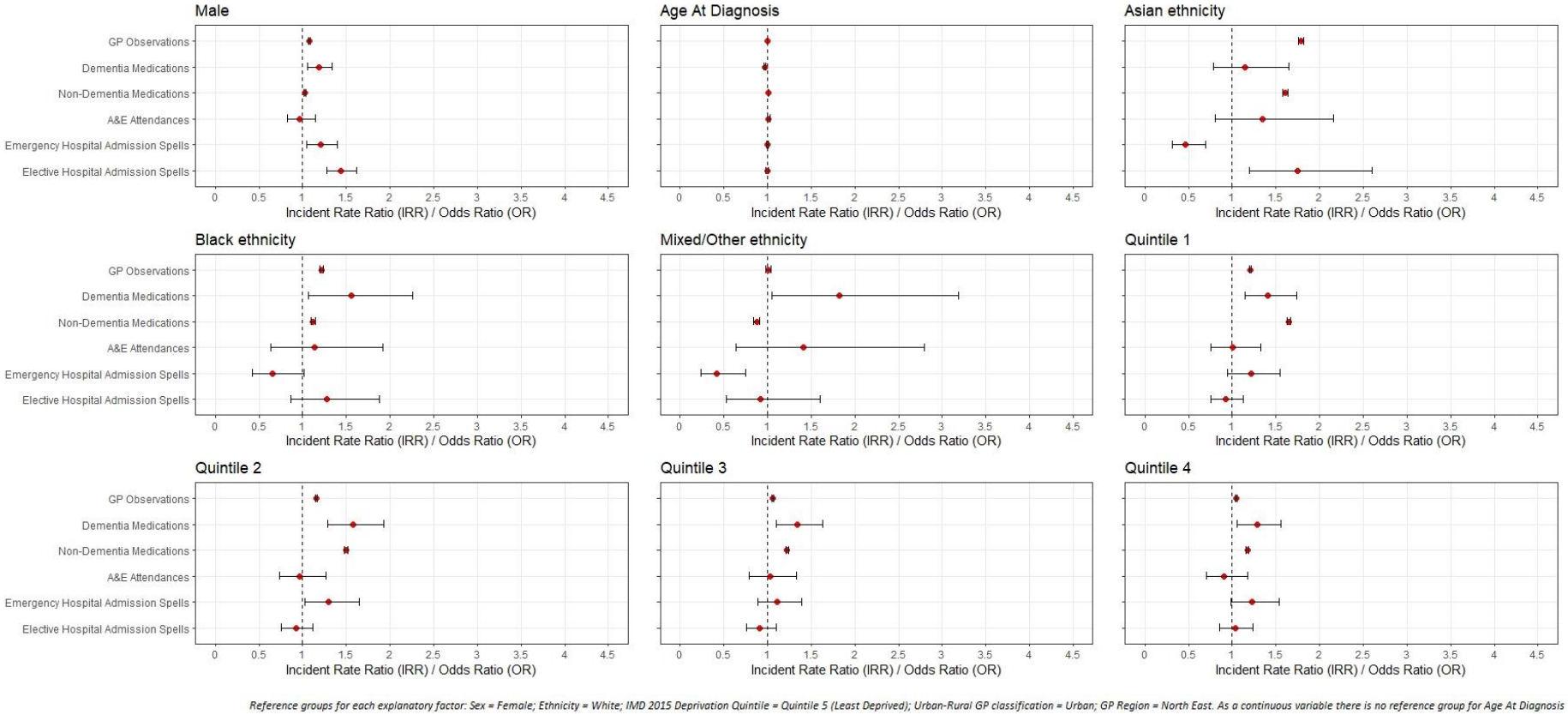
including more characteristics for PLWD, enabling research to be inclusionary and represent the population being studied. There is also a need to include greater granularity of time-variant data. This is reflected in data related to the healthcare need (i.e. comorbidity and dementia severity) and the geographic variables available. GP region and rural-urban GP classification were dependent variables tested for associations with healthcare use. However, these variables are not only based on GP location, rather than the individual's residence, but they are also a static variable based on the individual's GP at entry to the data. A lack of time-variant geographic and healthcare need variables somewhat limits the findings related to geography and will not encompass the potential nuance which could be highlighted through longitudinal data that demonstrates what changes in residence or GP can have on the healthcare use of PLWD. Future longitudinal research of this nature should aim to include time-variant data for comorbidity, dementia severity and geographic variables.

Finally, our analyses are descriptive (i.e., identifying differences by social and spatial factors) rather than interrogating explanations for why these social and spatial variations exist. This is partly a limitation of our data source since we are constrained in what data is provided on electronic health records (both about treatments/outcomes and individual's contexts). Future research should identify explanatory reasons and pathways for these associations, including the complexity linking our outcomes to measures of inequalities (e.g., provision of informal care, lack of GPs in some areas limiting care received, or disentangling whether medications are given based on need or demand). Where possible, these analyses should be extended longitudinally to explore sequences of healthcare trajectories that can consider how healthcare experiences operate holistically rather than independently (as in our analyses).

4.4.2. Conclusions

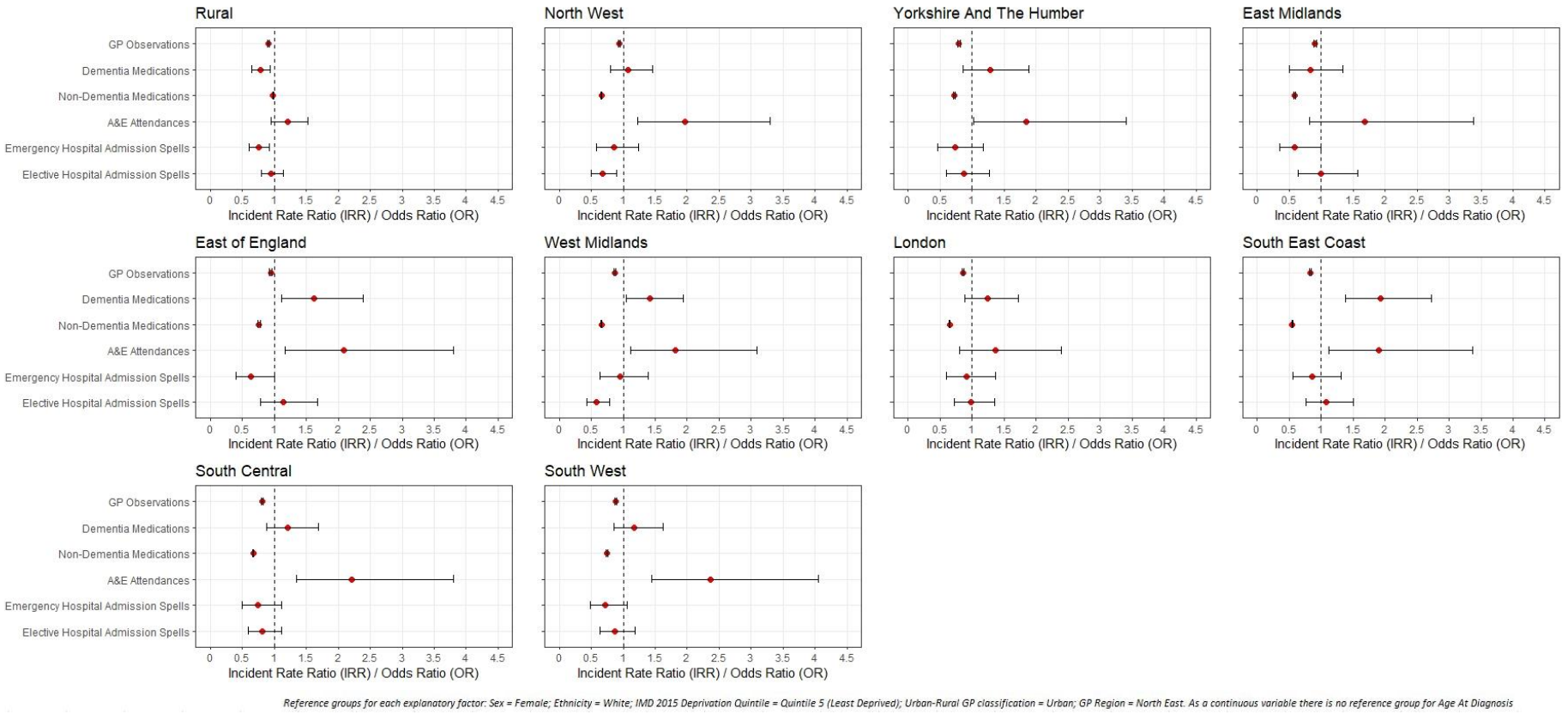
Our findings suggest there are wide social and spatial differences in the use of various healthcare services among PLWD. Early identification of dementia, as well as better care management and effective treatment, can help avoid unnecessary healthcare use associated with negative outcomes among PLWD, benefitting not only PLWD, but reducing the costs and pressure on the healthcare system (Banerjee and Wittenberg, 2009; Delgado et al., 2022; Rasmussen and Langerman, 2019). Our findings show the ongoing pressing need for clinical and public health policy aimed at promoting more equitable healthcare experiences among PLWD. This requires implementation of systemic, cultural and social measures to improve the situation for more marginalised groups (Giebel, 2020; Watson et al., 2020). Greater emphasis is required to make quality care easily accessible to people from more remote and deprived areas, and more appropriate to the communities they serve (Duran-Kirac et al., 2021; Giebel, 2020; Nebel et al., 2018). PLWD would benefit from more ubiquitous, effective management and treatment of dementia and comorbidities, in primary and specialist healthcare (Black et al., 2015). Better continuity of primary care, and stronger links between primary and social care, would allow smoother transitions and stability in changing care needs (Delgado et al., 2022).

4.5. Appendices



Appendix 4.1: Odds Ratios (OR) or Incidence Rate Ratios (IRR) and 95% confidence intervals for healthcare use in early-onset dementia sample population, by demographic/socio-economic factors[2]

[2] *In early-onset, Poisson regression models were used with GP observations and non-dementia medications, reporting Incidence Rate Ratios (IRR). Binomial regression models were used with dementia medications, A&E attendances, elective hospital admissions, and emergency hospital admissions, reporting Odds Ratios (OR).*



Appendix 4.2: Odds Ratios (OR) or Incidence Rate Ratios (IRR) and 95% confidence intervals for healthcare use in early-onset dementia sample population, by spatial factors

Appendix 4.3: Healthcare contact rates per patient year for early-onset dementia sample population, by healthcare type and explanatory factor

Explanatory Factor	***Patients***	***Patient Years***	***Healthcare contacts per patient year***				
			GP Observations	***Dementia medications***	***Non-Dementia Medications***	***A&E Attendances***	***Hospital Admission Spells***
Sex							
Female	2763	29670	51.32	3.17	39.15	0.38	0.36
Male	2447	18238	75.20	4.28	55.68	0.58	0.64
Age Group							
Under45	104	967	73.16	2.00	49.71	0.61	0.60
45-54	870	6640	70.46	3.76	50.52	0.63	0.56
55-64	4236	40301	58.45	3.60	44.51	0.42	0.45
Ethnicity							
Asian	128	978	139.10	4.65	94.03	0.57	0.62
Black	131	976	86.60	4.16	63.14	0.56	0.96
Mixed/Other	54	419	62.96	1.56	34.18	0.53	0.48
White	4517	42824	57.76	3.52	44.90	0.47	0.48
IMD 2015 Deprivation Quintile							
Quintile 1: Most Deprived	1020	7764	85.54	5.00	73.44	0.67	0.62
Quintile 2	1003	15363	38.41	2.06	3.067	0.29	0.29
Quintile 3	1073	8151	69.78	4.04	50.11	0.56	0.63
Quintile 4	1137	9073	65.80	3.91	46.81	0.48	0.49
Quintile 5: Least Deprived	957	7398	62.98	4.42	40.00	0.44	0.46
Urban-Rural GP Classification							
Urban	4528	42674	59.89	3.39	44.98	0.46	0.47
Rural	682	5234	64.63	5.23	49.25	0.42	0.46
GP Region							
North East	261	1992	87.23	8.43	90.43	0.68	0.63
North West	1027	8107	77.88	4.36	55.95	0.59	0.57
Yorkshire And The Humber	223	1595	65.60	4.64	60.05	0.70	0.73
East Midlands	139	1091	80.53	4.07	47.95	0.44	0.48
East of England	264	1887	73.04	3.56	56.85	0.50	0.59
West Midlands	882	6720	72.38	3.37	53.01	0.55	0.53
London	622	4877	78.38	4.86	53.20	0.71	0.69
South Central	714	13608	25.53	1.73	19.23	0.16	0.19
South East Coast	433	3236	63.02	2.68	41.09	0.51	0.52
South West	645	4795	70.62	4.76	57.93	0.46	0.54

Appendix 4.4: Healthcare contact rates per patient year for late-onset dementia sample population, by healthcare type and explanatory factor

Explanatory Factor	***Patients***	***Patient Years***	***Healthcare contacts per patient year***				
			GP Observations	***Dementia medications***	***Non-Dementia Medications***	***A&E Attendances***	***Hospital Admission Spells***
Sex							
Female	91270	737292	51.87	3.22	49.83	0.45	0.43
Male	45822	392926	53.24	2.92	42.63	0.44	0.51
Age Group							
65-74	20514	194397	58.03	3.71	46.57	0.40	0.45
75-84	63225	548480	54.65	3.42	49.10	0.45	0.47
85-94	49067	365512	46.53	2.48	45.39	0.47	0.45
95+	4286	21829	41.12	1.08	41.98	0.49	0.43
Ethnicity							
Asian	1809	9885	121.77	5.56	116.17	0.90	0.89
Black	2115	12548	102.11	6.47	116.96	0.91	0.98
Mixed/Other	1026	5651	91.47	6.02	91.72	0.77	0.80
White	125101	1062758	50.99	3.02	45.98	0.45	0.46
IMD 2015 Deprivation Quintile							
Quintile 1: Most Deprived	21342	202990	49.29	2.79	46.92	0.47	0.46
Quintile 2	23920	214270	50.34	2.91	46.34	0.45	0.44
Quintile 3	27528	188153	62.56	3.73	56.68	0.53	0.54
Quintile 4	31641	224941	58.90	3.50	52.20	0.48	0.50
Quintile 5: Least Deprived	32405	298422	44.45	2.82	38.72	0.35	0.38
Urban-Rural GP Classification							
Urban	117058	1025432	49.70	2.90	44.58	0.44	0.44
Rural	20034	104786	78.23	5.21	74.22	0.56	0.64
GP Region							
North East	7167	39293	92.58	8.69	104.52	0.89	0.81
North West	24395	131388	87.13	4.74	69.68	0.76	0.73
Yorkshire And The Humber	5914	110878	23.83	1.62	22.04	0.21	0.21
East Midlands	2881	14668	92.31	3.43	64.94	0.68	0.72
East of England	7997	52389	61.29	3.09	56.91	0.46	0.53
West Midlands	23887	149052	67.93	3.16	58.03	0.58	0.60
London	14203	84330	77.59	5.75	80.46	0.87	0.78
South Central	18865	377910	19.21	1.20	17.04	0.14	0.17
South East Coast	11619	63856	72.09	3.52	56.66	0.64	0.62
South West	20164	106454	18.29	5.01	78.51	0.56	0.66

4.6. Research developments from Chapter 4

The previous two papers (Chapter 3 and 4) have attempted to highlight and address one of the primary gaps in the literature identified through the systematic review. They have examined and presented, the extent to which socio-economic and geographic factors impact inequalities in the risk of mortality and the use of primary and secondary healthcare services among people living with dementia. However, this does not address another gap illustrated by the systematic review – the lack of research looking at healthcare in dementia as a cumulative pathway, rather than a series of one-off, unrelated events. This led to the design of Chapter 5, an investigation of how I can measure multiple healthcare uses together, including how their use changes over time. The following research paper involved the exploration of patterns in primary and secondary healthcare use, who is experiencing which healthcare patterns - or pathways – and differential risk of mortality that exists based on patterns in healthcare use among people living with dementia.

5. Chapter 5: Identifying longitudinal healthcare pathways and subsequent mortality for people living with dementia in England: an observational group-based trajectory analysis

Paper currently under peer review:

Watson J, Green M, Giebel C and Akpan A. Identifying longitudinal healthcare pathways and subsequent mortality for people living with dementia in England: an observational group-based trajectory analysis. Manuscript submitted for publication.

Abstract

Background

The number of people living with dementia (PLWD) continues to increase, particularly those with severe symptomatology. Severe symptoms and greater ill-health result in more acute care need. Early healthcare interventions can prove beneficial. Healthcare use has not been analysed as a holistic set of interlinked events. This study explores different healthcare pathways among PLWD, social or spatial inequalities in healthcare pathways and subsequent mortality risk.

Methods

Group-based trajectory models (GBTM) were applied to electronic healthcare records. We generated clusters of PLWD with similar five-year, post-diagnosis trajectories in rates of primary and secondary healthcare use. Potential social and spatial variations in healthcare

use clusters were examined. Cox Proportional Hazards used to explore variation in subsequent mortality risk between healthcare use clusters.

Results

Four healthcare use clusters were identified in both early- (n = 3732) and late-onset (n = 6224) dementia populations. Healthcare use variations were noted; consistent or diminishing healthcare use was associated with lower subsequent mortality risk. Increasing healthcare use was associated with increased mortality risk. Descriptive analyses indicated social and spatial variation in healthcare use cluster membership.

Conclusion

Healthcare pathways help indicate changing need, with differential healthcare use producing similar health outcomes. Care in dementia needs to be more accessible and appropriate, with care catered to specific and changing needs. Better continuity of care and greater awareness of dementia in primary can enhance prospects for PLWD. Research needs to further illuminate holistic care need for PLWD, including health and social care use, inequalities in care, health and outcomes.

5.1. Introduction

There are rising numbers of people living with dementia (PLWD) in the UK (Wittenberg et al., 2019) with over 1 million projected by 2024. The greater proportional rise is set to be among those with severe dementia and more pressing health and care needs (Bennett et al., 2018). Such trends are placing increasing demands and costs on health and social care services (Wittenberg et al., 2019). The complex nature of care needs for PLWD contributes to the high costs of providing care (Voss et al., 2017; Watson et al., 2022). Understanding the different experiences of healthcare utilisation is therefore imperative if we are to align health systems to the care that PLWD need.

Good quality health and social care can support PWLD to live well and receive care at home longer (Dawson et al., 2015; Robinson et al., 2010). Living at home for longer is associated with improved physical health outcomes. quality of life (Olsen et al., 2016) and lower mortality risk among PLWD (Delgado et al., 2022; Fox et al., 2013; de Vugt et al., 2013). Inadequate, ineffective or a lack of timely treatment can see rapid progression to more severe symptoms, requiring acute care sooner and more often (Bradford et al., 2010; Gungabissoon et al., 2020; Shepherd et al., 2019). PLWD are not only more likely to be admitted to hospital, but once they are, they are likely to stay longer in hospital and to be readmitted (Ma et al., 2019; National Institute for Health and Clinical Excellence, 2021). Hospital stays can exacerbate dementia symptoms, impact physical health, and increase the likelihood of increased mortality (Tropea et al., 2017; Yorganci et al., 2022). Issues with funding and service availability persist with many not being able to access timely diagnosis or appropriate treatment or support (Alzheimer's Society, 2021; Alzheimer's Society, 2022).

There are wide social, demographic and geographical inequalities in the frequency and quality of healthcare received, quality of life and wellbeing, likelihood of transitions to care institutions, speed of dementia progression, severity of other chronic health conditions, and risk of mortality among PWLD (Cooper et al., 2017; Watson et al., 2021; Watson et al., 2021 (2); Wu et al., 2018). It is a priority of the UK Government to address and reduce these inequalities

(Department of Health and Social Care, 2016). A lack of central funding in the UK, including a legacy of austerity which saw cuts in funding that was greater in deprived areas, has limited the level and quality of care and treatment available (Nuffield Trust, 2020). These funding issues may disproportionally impact inequalities in access to health, and social, care, widening inequalities and resulting in poorer health and health outcomes for PLWD from disadvantaged backgrounds (Giebel et al., 2021; Watson et al., 2022). This illustrates the need to understand the differential experiences of healthcare utilisation among PLWD from different social and spatial groups. Currently, there is a lack of research exploring social and spatial determinants of healthcare use among PLWD resulting in a paucity of evidence on modifiable barriers to such inequalities.

Healthcare use is often analysed by focusing on one-off healthcare events or individual types of healthcare. However, this ignores the broader context of healthcare pathways (Haenssgen and Ariana, 2017; Tabrizi and Masri, 2021). Healthcare pathways are a longitudinal sequence of linked contacts with healthcare services which can help demonstrate evolving needs and changing impacts on the health and health outcomes of an individual (Schrijvers, van Hoorn and Huiskes, 2012). Health and social care have a cumulative impact on the health, survival, quality of life and health outcomes of PLWD (Daley et al., 2022). Providing effective and good quality health and social care are vital to PLWD and their informal carers (Bökberg, Ahlström and Karlsson, 2017; Brodaty et al., 2009; Hazzan et al., 2022). This is vital as needs for PLWD increase as their condition deteriorates (Alzheimer's Society, 2021). It is beneficial to PLWD and their carers that they receive both pharmacological treatment and the variety of benefits which appropriate social care involvement can provide (Rand et al., 2021; Reilly et al., 2020). Increased social isolation - as highlighted during the COVID-19 pandemic – increases the risk of rapid deterioration in memory and motor functions (Curelaru et al., 2021; Giebel et al., 2021). Dementia can progress rapidly for some PLWD and symptoms of dementia and care need can change quickly and vary greatly over time, depending on dementia subtypes (Alzheimer's Society, 2021; Giebel et al., 2020). Dementia subtypes can impact a person's

cognitive and motor functioning differently, which can in turn has a differential effect on somebody's capability to manage finances (Giebel, Flanagan and Sutcliffe, 2019).

This illustrates how vital the need for early, and correct, diagnosis and selection of appropriate health and social care provision is. It can help maintain independence and cognition for longer, delay more severe symptoms of dementia, manage other chronic conditions and improve survival among PLWD, as well as reducing the overall economic cost to the health and social care system (Barnett et al., 2014; Rasmussen and Langerman, 2019; Robinson, Tang and Taylor, 2015; Travers, Martin-Khan and Lee, 2009; van de Vorst et al., 2016). There is a dearth of research which has investigated sequences of healthcare use for PLWD (Watson et al., 2020). There is also a lack of studies investigating the simultaneous impact of multiple socio-economic, geographic and demographic factors in healthcare pathways and their resultant health outcomes (Watson et al., 2021). Given healthcare use can play a critical role in future needs for care and health outcomes, it is vital to identify the different care pathways experienced by PLWD, and how these pathways can differentially impact health outcomes among PLWD.

Primary healthcare involvement is vital to treating dementia and other chronic conditions in PLWD and effective, consistent, holistic and person-centred primary healthcare can be central to a multifaceted support model which can help improve quality of life, maintain cognition and maintain care at home for longer, which can all enable better longer survival (Kim and Park, 2017). Levels of GP involvement and pharmacological treatment have been employed as outcomes measures in previous research (Watson et al., 2021, Watson et al., 2022), and can indicate appropriateness of ongoing care for PLWD, and the degree to which medications prescribed are appropriate to the need of PLWD (Lane et al., 2021).

Three secondary healthcare use variables have been examined as outcome measures in previous research (Watson et al., 2020): accident and emergency (A&E) attendances, emergency hospital admission spells and elective hospital admission spells. Acute hospital care, including admissions to hospital, is costly in terms of the health of the individual and

financially to the healthcare system. Hospital admissions can often occur after changes in symptomatology and care needs (Knapp et al., 2016), but can often be avoided through appropriate and effective care in the community (Yorganci et al., 2022). PLWD are more likely to spend longer in hospital when admitted (Afonso-Argilés et al., 2020), to be readmitted to hospital (Ma et al., 2019), to move into a care home once discharged from hospital (Kasteridis et al., 2016), and experience poor health outcomes following hospital admission (Tropea et al., 2017; Yorganci et al., 2022).

The aims of this novel data linkage study were to: (i) identify potentially different types of longitudinal trajectories of primary and secondary healthcare use among PWLD; (ii) examine how social and spatial inequalities persist across healthcare trajectory types; and (iii) analyse if different types of trajectories of healthcare are associated with different levels of survival in dementia.

5.2. Methods

5.2.1. Data Access and Ethical Approval

We used pseudonymised routinely collected Electronic Health Records (EHR) from Clinical Practice Research Datalink (CPRD) Aurum (CPRD, 2021). CPRD contains data for 18 million currently active patients registered with UK GPs. CPRD includes patient details and demographics, primary (GP observations and medication prescriptions) and linked secondary healthcare contacts (Accident and Emergency (A&E) attendances and hospital admission spells). Access to data for the purposes of specified research was granted by CPRD and ethical approval for the use of CPRD Aurum was provided by the University of Liverpool Research Ethics Board (Reference: 7922).

5.2.2. Sample population

Our sample population contains people registered with a CPRD-registered General Practice who received a diagnosis of dementia between the years 2002 and 2016. For inclusion in our healthcare use trajectory analyses, we restricted data to individuals with five or more

years of post-diagnosis follow-up healthcare use data. The analytical sample size for early-onset was 3735, and for late-onset dementia was 62 264. We stratified our sample population by dementia-onset, with early-onset (aged <65 years) and late-onset dementia (aged 65+) split into concurrent analyses.

Date of dementia diagnosis was not available from CPRD data. Date of dementia diagnosis has been defined as the first GP observation record for each person, in which one of the following terms were stated as the reason the patient presented to their GP: “dementia”, “Alzheimer”, “cogniti”, or “memory”. Healthcare contacts are only included for the years after the person’s year of diagnosis.

5.2.3. Outcome Variable

Mortality was our outcome measure, and mortality for members of the sample population was based on the presence of a date of death in CPRD. If there was no date of death stated, they were given as not having died during the study period. There was a maximum of 19 years of data available for members of the sample population. However, with five years of post-diagnosis healthcare use data used in healthcare trajectory clustering, subsequent mortality for members of the sample population could occur between the 1st and 14th year after the healthcare trajectory period (years 6-19 of the total study period).

In survival and mortality analysis, it is possible for data to be right-censored. That is, they leave the study before they may encounter the event of interest (mortality). In this study, it is possible that, given the long follow-up period of 14 years beyond the initial five-year healthcare trajectory period, that members of the sample population did not die, but they were lost to follow-up. This can be because they withdrew their consent for their GP to send their data to CPRD, or that they changed GP, from one which was initially registered with CPRD, to one which was not, and as such their data was no longer sent to CPRD. Right censoring can present an issue that needs to be acknowledged.

The potential issue of right censoring was addressed through analyses. Mortality risk was analysed using Cox Proportional Hazards regression, which only include the sample population as 'at-risk' of the outcome if they remain in the data. They are removed from the analyses at the point at which their data ends. They are included as having had the event in our study if they died, they are also removed from the 'at-risk' population if they did not have the event of interest, but also did not have any subsequent data. Similar can be said of Kaplan-Meier survival curves used to visually demonstrate the follow-up period, the number of people at-risk of mortality, and the population size remaining at-risk of mortality in each year of the follow-up period.

5.2.4. Healthcare Use Trajectories

Healthcare pathways are made up of multiple strands of unique healthcare service types. Here we have included four types of healthcare as trajectories for each member of the sample population:

1. *GP observations* are single records of each observation at a GP visit. Multiple observations can occur at a patient-GP consultation, with each observation related to a different matter discussed.
2. *Dementia medication prescriptions* relate to four NHS-advised drugs for treatment of dementia: Donepezil, Galantamine, Rivastigmine and Memantine.
3. *Non-dementia medications prescriptions*: refer to all other medications than the four NHS-advised medications for the treatment of dementia.
4. *Acute secondary healthcare* includes combined records for:

4.1. Accident & Emergency attendances: unplanned presentations at A&E or urgent care.

4.2. Hospital admission spells: patient requires further treatment or observation.

5.2.5. Temporal Healthcare Use

Year of diagnosis was used as year 0 and only healthcare contacts occurring in the same calendar year are included in year 0. As such, if somebody was diagnosed later in the year, the potential for healthcare contacts was reduced compared to people diagnosed earlier in

the year. Due to this potential issue, we have therefore removed year 0 healthcare contacts from any analyses, and instead healthcare contact data begins at year 1 – the first full, potential year of data for each member of the sample population.

Attrition and years of survival beyond dementia diagnosis meant it was necessary to define a time period from which the analysis would be based. To maintain integrity in the study and validity of findings we restricted healthcare records to those which occurred between the first and fifth years of post-diagnosis healthcare records. This falls in-line with dementia survival estimates. It was also pragmatic to negate the potential impact of attrition and to attain a substantial temporal trajectory of healthcare use among a representative population sub-sample. At the five-year point loss to follow-up was ~79% in early-onset and ~58% for late-onset sample populations.

5.2.6. Explanatory Factors

This study looks to describe each of the aforementioned clusters derived from GBTM, based on their composition. Identification of the socio-economic, demographic and geographic make-up of each of the clusters derived for both early- and late-onset dementia.

Previous research has identified multiple potential explanatory factors of variation in healthcare use and health outcomes for PLWD. Studies have explored a range of potential explanatory factors for differential healthcare use and mortality risk inequalities. CPRD data and data linkage provides patients': age at diagnosis, sex, ethnicity, 2015 Indices of Multiple Deprivation (IMD) quintile and GP urban/rural classification and GP region. Research has shown how variations in healthcare utilisation and health outcomes for PLWD vary across these key factors (Rahman et al., 2020; Watson et al., 2021, Watson et al., 2021 (2); Wu et al., 2020).

5.2.7. Loss-to follow-up and missing data

Loss to follow-up can occur through an individual dying or having changed to a GP who was not registered with CPRD. If a member of the sample population was lost to follow-up during

a specific year after diagnosis, we gave the number of healthcare contacts (of all four types) in the years following loss to follow-up as “NA”, as they were no longer present in the data.

Some people will have been present during a specific year after diagnosis, or throughout the time period, but did not have recorded contact(s) with one or more of the healthcare service types. In this case, they were given a value of 0 contacts for that healthcare service type(s). In this study, loss to follow-up increased beyond the populations’ 5th year post-diagnosis. As such, only people remaining in the study five years after diagnosis (5 years of complete data post-diagnosis) data were included in statistical analysis, including GBTM and subsequent cluster-survival analysis.

The original sample population for those living with early- and late-onset dementia were 5,210 and 137077 respectively. Some of the sample population had fewer than five years of post-diagnosis healthcare contact data and were therefore defined as lost to follow-up (**Appendix 5.1**). From those original sample populations, almost three quarters of those with early-onset (3,735; 71.7%) and less than half of those with late-onset (62,264; 45.5%) dementia were included in GBTM.

5.2.8. Statistical Analysis

Longitudinal datasets were created for the use of the four healthcare types, by both early- and late-onset sample populations. These datasets contained five years of full healthcare use data for each of the four healthcare types. These datasets were used to generate distinct patterns in healthcare use over the five years noted, with sample population members grouped into healthcare use clusters based on similarities in their longitudinal pattern of healthcare use.

Healthcare use clusters were generated using Group-Based Trajectory Modelling (GBTM). Clusters from GBTM receive a probability value for each member of the cluster having been correctly assigned. Each sample population member receives a value indicating the

likelihood of belonging to each of the clusters generated, having been assigned to the cluster they're deemed most likely to belong (Nagin, 2014).

GBTM as a statistical method allows for a sample population to be grouped based on similarities in temporal changes across multiple measures (Nagin et al., 2018). In this case we have employed GBTM to generate groups of PLWD based on similar patterns in their use of GP observations, dementia medications, non-dementia medication and acute secondary healthcare. GBTM is a data driven approach where the number of groups needs to be specified *a priori*.

To identify the best fitting number of groups, we ran the model for between one and ten cluster groups. We select up to 10 groups since we want to a parsimonious model that maximises variability across groups, but also minimises the complexity that each additional group brings. Model fit was then compared using Bayesian Information Criterion (BIC) and Log-likelihood (logLik) (**Appendix 5.2**), with visual trajectory plots for healthcare use trajectories for each number of cluster (k) used to aid in the number of final clusters used for mortality risk analyses. The restrictive level of computing power needed to run the models on such a large number of data points across a large population meant it was not practical to do so. To make the analyses possible, a smaller 10% random sample of the overall late-onset population was extracted to conduct GBTM, with a second 10% random sample population also taken to validate and ratify the original GBTM and subsequent outputs.

Cluster membership was then used to explore if there was any association between healthcare use patterns and subsequent mortality beyond the initial five-year period post-diagnosis. Descriptive statistics of the social and spatial composition, and subsequent mortality for each cluster were calculated. Demographic, spatial and socio-economic differences in cluster membership was analysed using multinomial logistic regression. Analysis of mortality risk across early-onset and late-onset healthcare trajectory clusters was performed using Cox Proportional Hazards regression, with presence of subsequent mortality post-five-year healthcare trajectory period (as defined in Section 5.2.3). Survival

was analysed for up to 14 years after the healthcare trajectory (years 6-19 of the study period), adjusting for age, sex, ethnicity, IMD 2015 quintile, urban-rural GP classification and GP region as confounders.

5.3. Results

5.3.1. Sample population characteristics

Within our early-onset sample population there were 3,732 people. The majority were female (2,027; 54.3%), aged 55-64 (3,061; 82.0%) and registered with urban GP (3,234; 86.7%). The majority were from White ethnicity groups (3,267; 87.5%), with Asian (95; 2.5%), Black (88; 2.4%) and Mixed/Other (40; 1.1%) ethnicity groups making up much smaller proportions of the early-onset population. There were more people registered with GPs in certain regions of the country, including the North West (763; 20.4%), South Central (516; 13.8%) and West Midlands (617; 16.5%). The population was relatively evenly spread across areas of deprivation, with 724 (19.4%) in the most deprived quintile and 683 (18.3%) in the least deprived quintile.

There were 6,224 people in the late-onset GBTM population. The majority were female (68.9%), aged 75.84 (53.1%), registered with urban GPs (85.8%). It should be noted that in the late-onset population there was more missing data for ethnicity, however the late-onset population less ethnically diverse than the early-onset, with 1.3%, 1.9% and 0.9% from Asian, Black and Mixed/Other ethnicity groups respectively. More of the late-onset population lived in areas of less deprivation, with the least and second least deprived quintiles making up a combined 47.0%. As with early-onset, some GP regions made up a much greater proportion of the population; the North West (1,178; 18.9%), South Central (843; 13.5%), South West (883; 14.2%) and West Midlands (1,040; 16.7%).

5.3.2. Attrition from sample population

There was loss to follow-up from our sample population. From the original sample of 5,210 and 137,092 people with early- and late-onset dementia respectively 3,732 (71.6%) and

62,244 (45.4%) remained once we filtered for only those with at least five years of post-diagnosis healthcare records within our dataset. With a long observation period for the event of interest (mortality) there was further attrition from the data. A 10% sample of our overall 62,244 late-onset population were included in GBTM models. From the 3,732 early- and 6,224 late-onset populations included in GBTM models, 1,126 (30.2%) and 2,548 (40.9%) had a date of death stated. Of the remaining 2,606 early-onset and 3,676 late-onset who did not die during the study period, nearly all did not have healthcare records for the entire study period; 2,595 (99.6%) early-onset and 3674 (~100%) late-onset. Data for these individuals was censored at the year of their final healthcare record(s).

We also found evidence of inequalities in attrition, which may impact how generalisable our sample population is (**Appendix 5.3**). In early-onset dementia loss to follow-up among men and those aged 45-54 were greater than their counterparts. In late-onset men, older people (aged 85-94 and 95+ years) and those from White ethnicity groups also had greater attrition than their counterparts.

5.3.3. Selection of healthcare use trajectory clusters

The selection of number of groups was data driven. Our goal was to maximise information captured by having additional groups, while minimising the complexity of more groups. For both early and late-onset populations, four-group solutions were selected as the parsimonious solution (**Appendix 5.2**). Four groups were selected through observations of a.) values of model fit, b.) a visual representation of model fit values, c.) visual representations of healthcare trajectories for each model encompassing between one and ten groups, and d.) a need for a parsimonious solution which would maximise the variability across clusters, whilst minimising the complexity brought by each additional cluster. Four groups were selected as model fit comparison (using both Bayesian Information Criterion (BIC) and loglikelihood values) showed additional groups - beyond the four-cluster model selected - only produced incremental model fit improvements. A four-group model was at the elbow point of optimal representation of healthcare use experience, with the visual

representation of healthcare trajectories for models consisting of five or more clusters, generating no significant, additional healthcare use experience in early- or late-onset dementia sample populations (**Figures 5.1 & 5.2**).

5.3.4. Defining healthcare use trajectory clusters:

i. Early-onset

With wide confidence intervals for the majority of observations, few statistically significant findings were noted in healthcare use patterns by different clusters of people with early-onset dementia. However, those statistically significant observations have been noted and the following five-year post-diagnosis healthcare trajectory groups for people living with early-onset dementia (**Figure 5.1**):

*Group 1: '**Drop-off in other chronic condition treatment**'* was comprised of 54.0% of those with early-onset. With the lowest rates of GP observations and medications at the end of the trajectory period, this group is characterised by slight reductions in GP contact and medications over the five years (trends are flat up to year 3 prior to declining).

*Group 2: '**Inefficient treatment of other chronic conditions**'* contained 37.6% of those with early-onset dementia. Group 1 was characterised by larger year-on-year increases in prescriptions for non-dementia health conditions, as well as smaller annual increases in GP observations and dementia medications.

*Group 3: '**Initial absence and delayed response**'* contains 5.1% of people with early-onset dementia. For the first three years, the group has below average values for all measures, followed by GP contact and non-dementia medications increases (and to a lesser extent dementia medications). This group had marginal increases in secondary healthcare use. This cluster had significantly greater use of all healthcare types by year five.

*Group 4: '**Ongoing review of needs**'* contained 3.3% of those with early-onset dementia. With the highest rate of all primary healthcare contacts at the start of the period, this group is characterised by falling rates to year three they level off and then increase in year five.

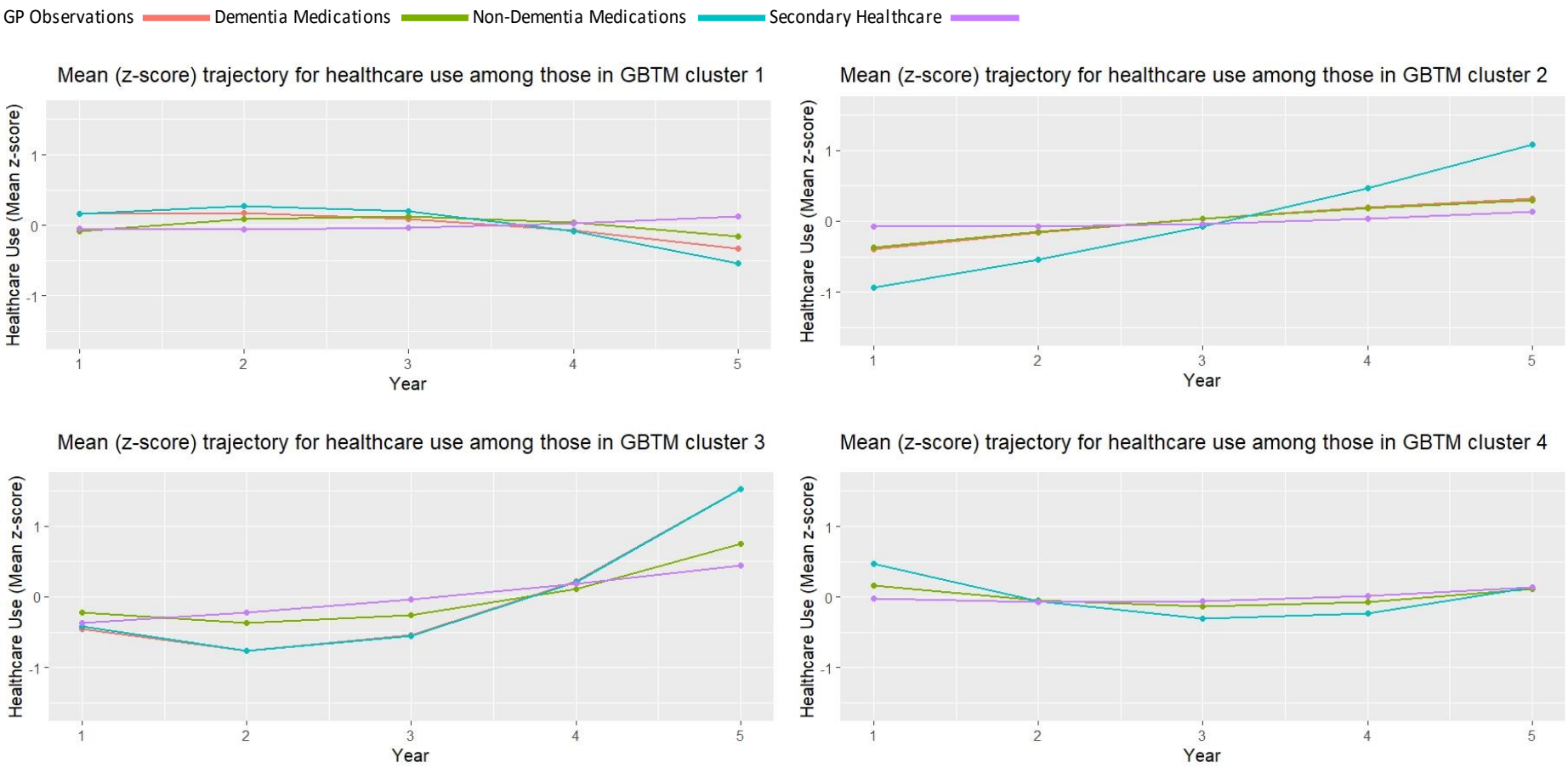


Figure 5.1: Early-onset sample population: Trajectories for mean use of each healthcare types in each group-based trajectory model (GBTM) derived cluster

ii. Late-onset

Wide confidence intervals mean very few statistically significant findings were noted in the use of different healthcare types by different clusters. However, the significant observations have been noted, and the following five-year post-diagnosis healthcare trajectory groups for people living with late-onset dementia were found (**Figure 5.2**):

Group 1: ***'Getting to grips with treatment'*** contained 44.2% of the late-onset sample population. Group 3 was characterised by small and consistent increases in each healthcare measure up to year 3 where the trend starts to level off.

Group 2: ***'Diminishing contact and medications'*** contained 38.9% of those living with late-onset dementia. This group was typified by reductions in primary healthcare and both types of medications over the five-year period.

Group 3: ***'Enduring issues in primary care'*** contained 10.5% of those living with late-onset. This group was characterised by exponential increases in GP involvement and medications. By year five, the group has the highest values across all four measures of any cluster. This cluster also had significantly lower use of all primary healthcare types in year one, but the change in use resulted in significantly high rates in year 5.

Group 4: ***'Appropriate early response to ill-health'*** contained 6.4% of the population living with late-onset dementia. This group was defined by initial high values across measures in year 1, followed by declining values over time that see it with the lowest values by year 3. In years 4 and 5, trends reverse and measures begin to increase.

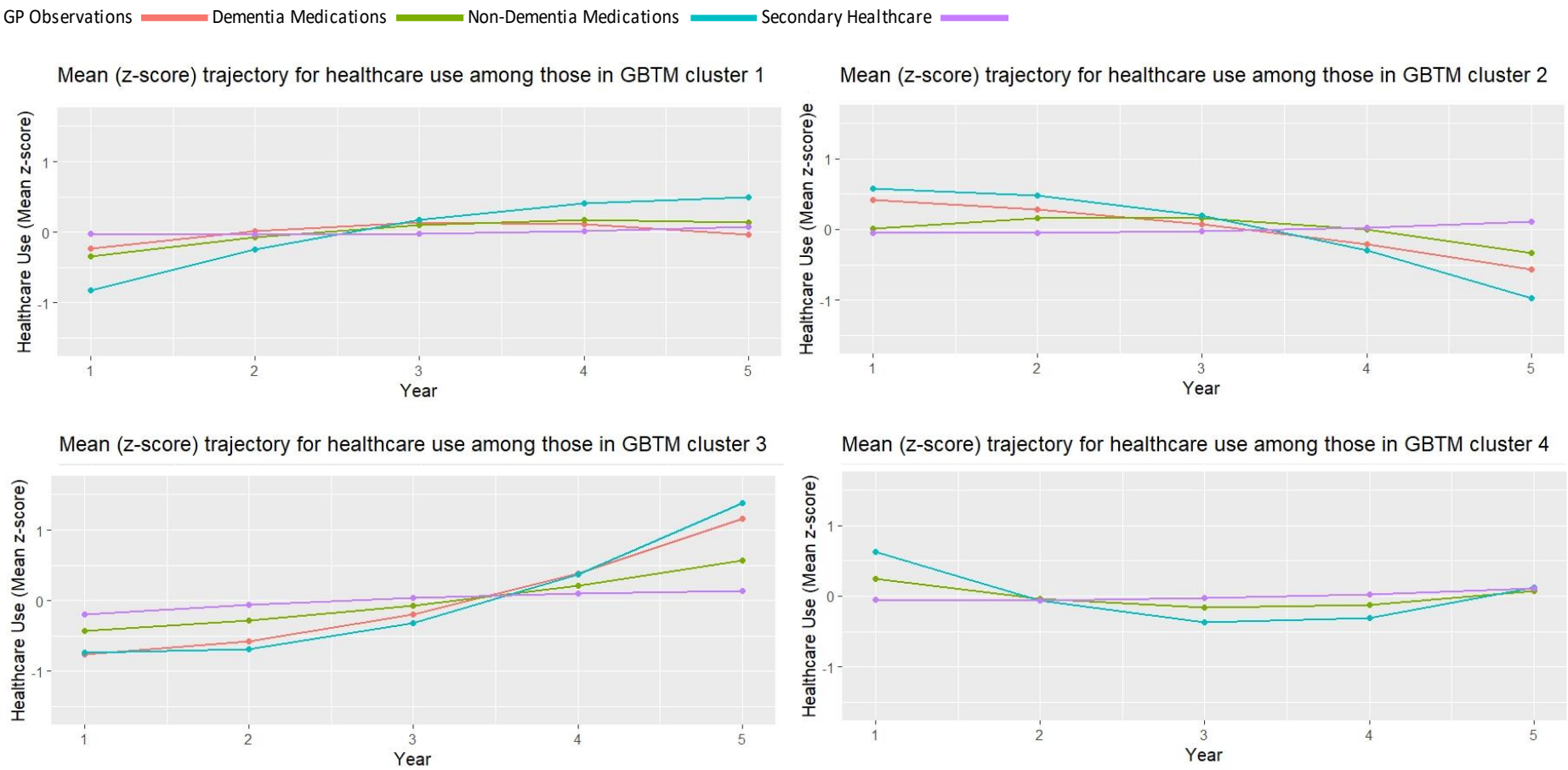


Figure 5.2: Late-onset sample population: Trajectories for mean use of each healthcare type in each group-based trajectory model (GBTM) derived cluster

5.3.5. Social and spatial variations in cluster membership

Descriptive and regression analysis highlighted differences in the demographic, geographic and socio-economic makeup of early- and late-onset clusters derived from GBTM (**Table 5.1**). Multinomial logistic regression also highlighted these variations in cluster membership (**Appendix 5.4**).

iii. Characteristics of early-onset healthcare trajectory clusters

Compared to the overall breakdown of the early-onset population (female = 54.3%, male = 45.7%), there was a greater proportion of women in the *Ongoing review of needs* cluster (58.4%) and men in the *Initial absence and delayed response* cluster (50.8%). Compared to the make-up of the overall population by age, a greater proportion of those aged under 45 in the *Ongoing review of needs* cluster (4.8%). The least deprived and second least deprived IMD quintiles were more greatly represented in the *Initial absence and delayed response* (21.3%) and *Ongoing review of needs* (25.6%) cluster respectively and those registered with rural GPs made up a higher proportion of those in the *Ongoing review of needs* cluster (16.8%). Differences in the make-up of clusters were also seen by GP region: the London and South-East Coast regions were overrepresented in the *Ongoing review of needs* cluster, the North-West in the *Initial absence and delayed response* cluster and the South-Central region in both *Initial absence and delayed response* and *Ongoing review of needs* clusters. Multinomial logistic regression was conducted to highlight significant differences in the social and spatial breakdown of healthcare use cluster populations, with *Drop-off in other chronic condition treatment* as our reference cluster. Though descriptive statistics indicate numerous variations in the breakdown of different clusters, few significant differences were found and only in the *Ongoing review of needs* cluster (**Appendix 5.4**): aged under 45 (RR: 1.05; CI: 0.14-1.95), from deprivation Quintiles 1 (RR: 0.83; CI: 0.11-1.55) and 2 (RR: 0.72; CI: 0.03-1.41), and in London (RR: 1.76; CI: 0.27-3.26), South Central (RR: 1.77; CI: 0.26-327) and South East Coast (RR: 1.65; CI: 0.12-3.18) GP regions.

iv. Characteristics of late-onset healthcare trajectory clusters

A greater proportion of the late-onset population were women (68.9%) compared to 31.1% men. Women were even more greatly represented in the *Appropriate early response to ill-health* cluster (73.1%). Differences in representation were also evident based on age group: those aged 65-74 were overrepresented in the *Getting to grips with treatment cluster* (23.8%), those aged 75-84-year olds in the *Enduring issues in primary care* cluster (56.4%) and those aged 85-94-year olds in the *Appropriate early response to ill-health* (35.0%) and *Diminishing contact and medications* (27.9%) clusters. The least deprived IMD quintile was overrepresented in the *Appropriate early response to ill-health* cluster (26.3%) and the most deprived in the *Enduring issues in primary care'* (19.5%), and those with urban GPs more greatly represented in the *Enduring issues in primary care'* (88.0%). The South-East Coast GP region was overrepresented in the *Appropriate early response to ill-health* cluster (10.5%). Multinomial logistic regression found few significant differences in the social and spatial breakdown of late-onset dementia healthcare use clusters (**Appendix 5.4**). Compared to *Getting to grips with treatment*, all clusters had more people aged 75-84 and 85-94 and some variation by GP region. The *Enduring issues in primary care* cluster also had significantly more from deprivation Quintile 1 (RR: 0.49; CI: 0.19-0.78) and fewer from Black ethnicity groups (RR: (-)0.86; CI: (-)1.62-(-)0.10).

Table 5.1: % representation of early- and late-onset sample populations in each cluster, by demographic, geographic and socio-economic variables

Social/Spatial Factor	Cluster % representation: early-onset population				Total EoD		Cluster % representation: late-onset population				Total LoD	
	Cluster 1	Cluster 2	Cluster 3	Cluster 4	n	%	Cluster 1	Cluster 2	Cluster 3	Cluster 4	n	%
Age Group	*n = 189*	*n = 125*	*n = 2016*	*n = 1402*			*n = 651*	*n = 2422*	*n = 401*	*n = 2750*		
Under45	1.6%	4.8%	1.9%	2.1%	77	2.1%			*Not Applicable*			
45-54	15.3%	12.8%	16.5%	15.4%	594	15.9%			*Not Applicable*			
55-64	83.1%	82.4%	81.5%	82.5%	3061	82.0%			*Not Applicable*			
65-74			*Not Applicable*				21.7%	19.2%	15.2%	23.6%	1316	21.1%
75-84			*Not Applicable*				56.2%	52.3%	49.1%	53.7%	3306	53.1%
85-94			*Not Applicable*				21.8%	27.6%	34.7%	22.0%	1554	25.0%
95+			*Not Applicable*				0.3%	0.9%	1.0%	0.7%	48	0.8%
Sex												
Female	49.2%	58.4%	56.6%	55.4%	2027	54.3%	69.6%	68.5%	73.1%	68.5%	4289	68.9%
Male	50.8%	41.6%	43.4%	44.6%	1705	45.7%	30.4%	31.5%	26.9%	31.5%	1935	31.1%
Ethnicity												
Asian	1.1%	0.0%	2.8%	3.0%	95	2.7%	0.7%	1.6%	0.8%	1.4%	80	1.3%
Black	2.2%	3.5%	2.7%	2.2%	88	2.5%	1.3%	1.8%	1.0%	2.4%	117	2.0%
Mixed/Other	2.2%	1.7%	1.3%	0.7%	40	1.1%	0.5%	1.3%	0.8%	0.7%	54	0.9%
White	94.4%	94.8%	93.1%	94.1%	3267	93.6%	97.6%	95.3%	97.4%	95.5%	5676	95.8%
IMD 2015 Deprivation Quintile												
5 Least Deprived	21.3%	12.8%	18.4%	18.4%	683	18.4%	20.9%	24.0%	26.3%	24.5%	1493	24.0%
4	23.4%	25.6%	21.9%	22.9%	837	22.5%	23.2%	24.0%	22.8%	22.2%	1432	23.1%
3	19.1%	22.4%	20.7%	20.8%	771	20.7%	16.9%	18.3%	18.5%	20.9%	1200	19.3%
2	18.1%	20.0%	18.9%	18.9%	703	18.9%	19.4%	18.8%	17.5%	17.4%	1129	18.2%
1 Most Deprived	18.1%	19.2%	20.0%	18.9%	724	19.5%	19.5%	14.9%	15.0%	14.9%	958	15.4%
Urban-Rural GP Classification												
Rural	14.8%	16.8%	12.2%	14.5%	498	13.3%	12.0%	14.7%	14.7%	14.1%	882	14.2%
Urban	85.2%	83.2%	87.8%	85.5%	3234	86.7%	88.0%	85.3%	85.3%	85.9%	5342	85.8%
GP Region												
East Midlands	2.6%	2.4%	2.7%	3.4%	110	2.9%	1.4%	2.6%	2.5%	2.1%	141	2.3%
East of England	3.2%	4.8%	5.4%	4.9%	189	5.1%	5.1%	5.2%	4.5%	5.7%	335	5.4%
London	10.1%	18.4%	13.1%	10.4%	453	12.1%	10.9%	10.7%	12.7%	10.5%	668	10.7%
North East	3.7%	2.4%	4.9%	5.7%	189	5.1%	6.5%	5.3%	2.5%	6.2%	351	5.6%
North West	24.3%	16.8%	20.5%	20.1%	763	20.4%	18.4%	19.4%	20.2%	18.4%	1178	18.9%
South Central	16.4%	18.4%	12.3%	15.3%	516	13.8%	15.1%	12.8%	14.5%	13.7%	843	13.5%
South East Coast	7.9%	12.8%	8.2%	6.9%	294	7.9%	8.6%	8.5%	10.5%	7.9%	520	8.4%
South West	11.6%	10.4%	11.9%	12.3%	447	12.0%	16.1%	13.0%	12.0%	15.1%	883	14.2%
West Midlands	15.3%	10.4%	16.7%	17.0%	617	16.5%	14.4%	18.2%	16.5%	16.0%	1040	16.7%
Yorkshire & The Humber	4.8%	3.2%	4.3%	3.9%	154	4.1%	3.5%	4.3%	4.2%	4.4%	265	4.3%

5.3.6. Healthcare use cluster survival

i. Early-onset

Our final analyses used cox regression models to examine if there were statistically significant differences in survival between the four clusters. In the early-onset sample population, compared to our reference cluster (*Drop-off in other chronic condition treatment*), the cluster *Ongoing review of needs* had a significantly lower risk of mortality (HR: 0.47; CI: 0.28-0.77), whereas both *Inefficient treatment of other chronic conditions'* (Hazard Ratio (HR): 1.37; Confidence Intervals (CI): 1.21-1.56) and *Initial absence and delayed response* (HR: 2.21; CI: 1.78-2.75) had significantly greater risk of subsequent mortality beyond the five-year healthcare trajectory period (**Appendix 5.5**). Kaplan-Meier survival curves (**Figure 5.3**) also graphically demonstrate the poorer survival among those in the *Inefficient treatment of other chronic conditions* and *Initial absence and delayed response* clusters. A larger percentage of people in *Inefficient treatment of other chronic conditions'* (22.9%) and *Initial absence and delayed response* (32.8%) had died within three years of the end of our trajectories, compared to lower rates of mortality in clusters *Ongoing review of needs* (5.6%) and *Drop-off in other chronic condition treatment* (13.6%).

The clusters with the greatest mortality risk - *Inefficient treatment of other chronic conditions'* and *Initial absence and delayed response* - both had healthcare trajectories defined by initial lower than average rate of GP observations and prescriptions for both dementia and non-dementia medications, followed by increases in values over time that saw them have the highest values and use of healthcare. The magnitude of the differences in the effect sizes modelled may also reflect the differences in the trajectory, with *Initial absence and delayed response* having a steeper and larger rise in healthcare utilisation and also a larger hazards ratio. *Ongoing review of needs*, which had a significantly lower risk of mortality than our reference cluster (*Drop-off in other chronic condition treatment*), had more settled rates of GP contacts and medications.

ii. Late-onset

We repeated our cox regression analyses for people living with late-onset dementia (**Appendix 5.5**). With the cluster *Getting to grips with treatment* as the reference group and accounting for all socio-economic, demographic and geographic factors as confounders, we found that mortality risk was significantly lower in cluster *Appropriate early response to ill-health* (HR: 0.35; CI: 0.25-0.40) and *Diminishing contact and medications* (HR: 0.72; CIs: 0.66-0.80). This is further illustrated by Kaplan-Meier survival curves demonstrating increased survival in these clusters (**Figure 5.4**). Both the *Appropriate early response to ill-health* and *Diminishing contact and medications* – those with significantly lower mortality risk than our reference cluster – had declining trends in healthcare utilisation over time. No statistically significant difference was found for *Enduring issues in primary care* compared to *the Getting to grips with treatment cluster*.

Early-onset

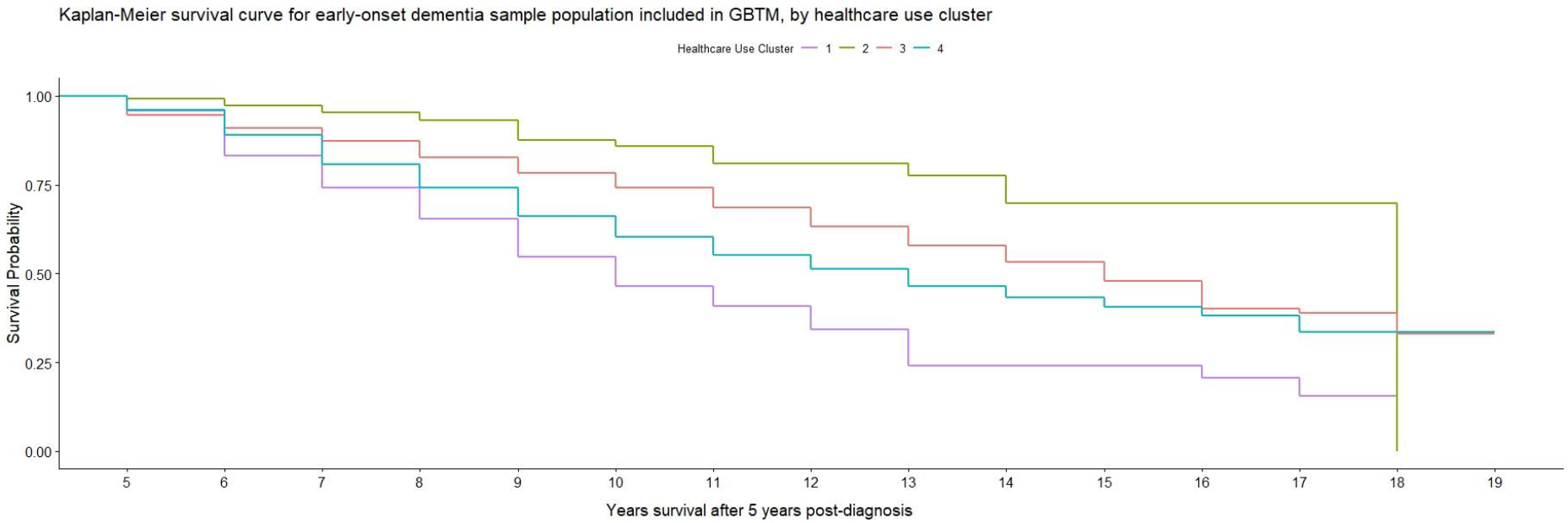


Figure 5.3: Kaplan-Meier survival curve for sample population with early-onset dementia included in GBTM, by healthcare trajectory cluster

Late-onset

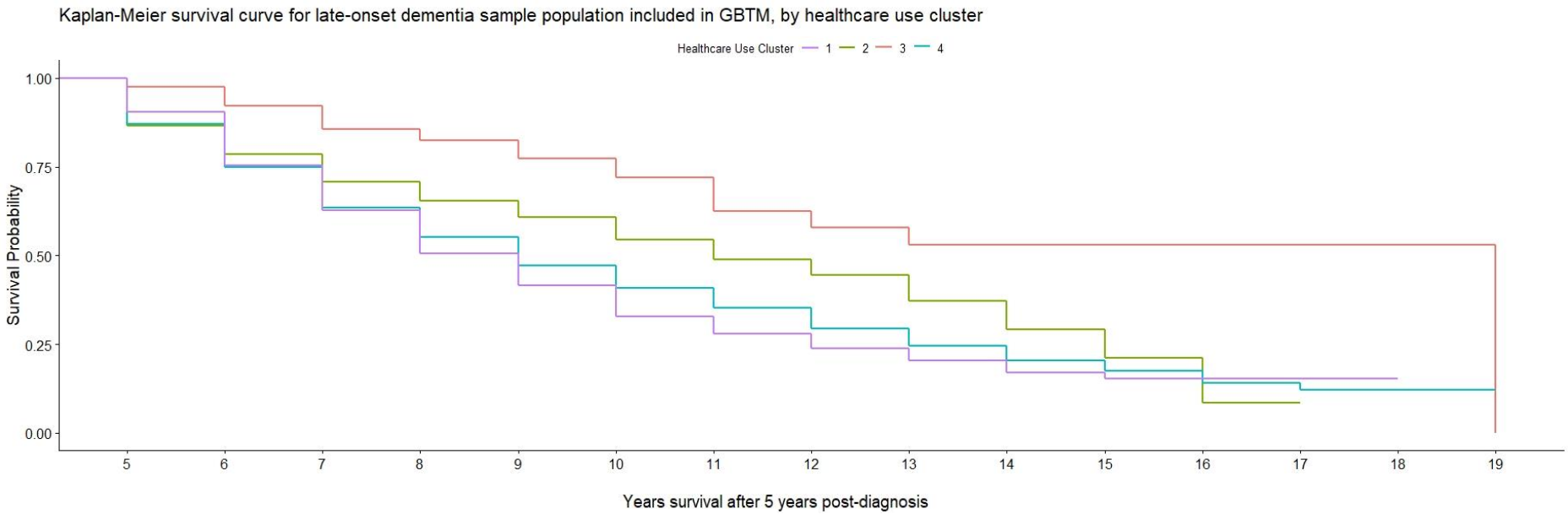


Figure 5.4: Kaplan-Meier survival curve for late-onset GBTM population, by healthcare trajectory cluster

5.4. Discussion

This study is one of the first to employ large-scale electronic health records to identify clusters of PLWD in their use of primary and secondary healthcare use to demonstrate the different pathways PLWD encounter in the years beyond their diagnosis. We also demonstrate how these different healthcare trajectories vary across social and spatial inequalities, as well as how these patterns translate to mortality risk. In people living with late-onset dementia, we found four groups including '*appropriate early response to ill-health*' and '*Diminishing contact and medications*'. The former saw changes over the five-years in primary healthcare use. High initial rates were followed by a reduction and subsequent late rise in primary healthcare use. The latter witnessed consistent reductions in primary healthcare use and medications. Both clusters had significantly lower mortality risk than our reference cluster '*getting to grips with treatment*' (a cluster defined by lower uptake of healthcare). Among people with early-onset dementia, we also found four groups. The '*Inefficient treatment of other chronic conditions"* cluster had increases over the period in all three primary healthcare variables, '*initial absence and delayed response*' showed low healthcare use initially, followed by late, exponential increases in healthcare use and, '*ongoing review of needs*' at the end of the five years, had the lowest rates of GP contact and medications. Differential mortality risk was noted between these clusters which did not seem to be specific to one particular type of healthcare use trajectory. Compared to our reference cluster ('*Drop-off in other chronic condition treatment*') higher mortality risk was observed in both '*Inefficient treatment of other chronic conditions"* and '*initial absence and delayed response*' and lower mortality risk was observed in '*ongoing review of needs*'.

We demonstrate that in the years following a dementia diagnosis, PLWD experience different pathways through healthcare. PLWD have greater, and more severe, other chronic conditions than the general population (Chen et al., 2021; Poblador-Plou et al., 2014). Additional chronic health conditions and the complexity of treating dementia can result in increased need for a greater range of healthcare among PLWD (Alzheimer's Society, 2021 (2)). However, care

need can be complex and unique for PLWD (Shuman et al., 2017) and as dementia progresses it can quickly alter what a PLWD requires (Brown, Tolson and Ritchie, 2020). Our findings show that this complexity in need produces different types of healthcare experiences that do not necessarily correspond to increasing need over time. Increased contact between a PLWD and their GP may be beneficial (Delgado et al., 2022). However, increased GP contact and medications may be a result of polypharmacy resulting from a lack of appropriate medication reviews or care management (Pfister, Jonsson and Gustafsson, 2017). Therefore, clinicians need to discuss with PLWD and carers the intended purpose and potential impacts of medications to make informed decisions on their use (Lim and Sharmeen, 2018). While no two PWLD are the same and their experiences will depend on their specific needs (Samsi and Manthorpe, 2014), there are collective similarities in experiences of healthcare (Black et al., 2013; Minyo et al., 2022).

Our study also demonstrates that for both early- and late-onset dementia, different trajectories of healthcare use were associated with differential subsequent mortality risks. In both early- and late-onset dementia exponential increases over the trajectory were associated with higher mortality risk. This study also highlights that consistent, or slowly diminishing rates of primary healthcare contact were associated with lower mortality risk. This would seem to indicate that PLWD who are receive appropriate treatment and care management from diagnosis experience longer-term health benefits (Delgado et al., 2020; Lindeza et al., 2020). Those who may not receive effective treatment early-on may endure poorer quality care as time goes on – in the form of increased inappropriate medications, which can result in poorer health outcomes (Delgado et al., 2020). These trajectories reveal the importance of acting early and appropriately in providing healthcare (Liu et al., 2022; Robinson, Tang and Taylor, 2015). Good primary healthcare in dementia does not necessarily mean increased service involvement, but rather that services need to be aware of changing needs for PLWD and be on-hand to provide timely and effective care (Brown, Tolson and Ritchie, 2020). Meeting specific and changing needs of PLWD is essential to providing the quality and consistency of

care required to allow better quality of life and reduce mortality risk (Delgado et al., 2022; Dyer et al., 2022). The different clusters identified indicate the potential benefits of tailored care, identifying need and future risks as a better means of managing care. Understanding patient pathways through the health system, including matching people to their most appropriate pathway, may help to improve health outcomes among PLWD. This is because PLWD are also more likely to experience ineffective or inappropriate healthcare use, including inappropriate medications (Delgado, Bowman and Clare, 2020), unnecessary transitions into nursing care (Hirschman et al., 2018) and avoidable emergency healthcare use (Phelan et al., 2012). Ineffective healthcare use is associated with increased negative health outcomes (Yoon et al., 2022) and greater financial cost to health and social care services (Chao et al., 2022; Shepherd et al., 2019).

In addition to our findings related to healthcare use pathways and subsequent morality risk, our study highlights some social and spatial groups of PLWD are more likely to experience certain healthcare pathways, and encountering different healthcare pathways is associated with differential health outcomes including mortality risk. Our healthcare trajectories highlight how PWLD from deprived or urban areas were more likely to belong to clusters associated with inadequate need or delayed care access. Receiving inappropriate treatment, encountering issues with service equity and accessibility and, poor care quality is more likely among PLWD from ethnic minority backgrounds (Dodd et al., 2022; Tsamakis et al., 2021; Watson et al., 2021;), more deprived (Cooper et al., 2017; Nuffield Trust, 2020; Watson et al., 2021) and rural areas. As these groups are more greatly impacted by unmet care needs (Black et al., 2013; Hu et al., 2022), they are at greater risk of negative care and the associated poor health outcomes, including lower quality of life, and increased falls risk, emergency healthcare use (Ma et al., 2019) and mortality risk (Black et al., 2013; Curnow et al., 2019; Gaugler, Kane and Newcomer, 2005). The causes of healthcare trajectory variations by different social and spatial groups of PLWD are nuanced. Differences in geographic provision and local service finances (Fortinsky et al., 2010; Pierse et al., 2020), variation in accessibility and

appropriateness for different population groups, and disparity in the quality of care and support (Watson et al., 2021) meaning PLWD encounter contrasting care pathways which impact the likelihood of poor health outcomes. However, the complex inequalities in healthcare trajectories we note, combined with associated differential mortality risk, may contribute to explaining social and spatial inequalities in dementia outcomes.

5.4.1. Limitations

Initially, it should be noted that no date of dementia diagnosis was available within CPRD data. Date of dementia diagnosis is difficult to define, given the nature of the condition, variation in presentation of dementia and, the potential for clinical testing of dementia to be applied inconsistently (Lin et al., 2015). This can present an issue of both selection bias and representation within data and findings. This is especially given PLWD from ethnic minority backgrounds and more deprived areas, are more likely to have the condition, but less likely to receive a diagnosis (Connolly et al., 2011; Pham et al., 2018). Although there is no clear way to rectify this, we have standardised the date of diagnosis to add precision to the sample population in this study.

Loss to follow-up and attrition have been discussed previously, and we highlight again that a substantial proportion of our original early- and late-onset sample populations were not included in our analyses. Research suggests that loss to follow-up of less than 5% of the sample population is unlikely to lead to any bias, but greater attrition will begin to impact validity of findings at 20% (Catalogue of Bias Collaboration, 2017; Luckman, 2000). There is the potential for attrition bias in such research, with members of some demographic groups being lost to follow-up earlier than others. The overall loss to follow-up rate by year five of the healthcare trajectory was greater than the level at which bias can be introduced (20%), for both early- and late-onset sub-sample populations. Although the CPRD sample is approximately 25% of the UK's GP patient population, and is representative of the overall UK population, if a GP opts out of CPRD or a patient leaves a CPRD practice for a non-CPRD GP, their data will end at this point. The loss to follow-up experienced in this study may have

introduced selection bias in our sample population. We tried to minimise these issues but were limited in our approach. Future research should look to take our approaches and apply it to more complete/generalisable datasets.

In conjunction with loss to follow-up during the five-year healthcare use period, there was a long follow-up period used to test for associations between healthcare use cluster membership and subsequent mortality risk (up to 19 years after dementia diagnosis). With such a long period, this could mean people were lost from the data for reasons other than mortality – such as leaving a CPRD-registered GP, or withdrawing their consent for their data to be sent from their GP to CPRD. This could impact both the reliability of the estimates for mortality risk, and the validity of these findings. As with the discussion of loss to follow-up during the healthcare use trajectory period, such findings need to be treated with some degree of caution and would need further investigation. Also, regression analyses test for associations between a set of variables and any differences in an outcome measure. In this study, associations between membership of healthcare use clusters and risk of mortality were tested. However, as with previous research, regression analyses alone cannot clarify the direction of causality in these associations-based analyses (Pornprasertmanit and Little, 2012). With the association between differential healthcare use and mortality, it is important to note the potential importance of dementia severity (Gungabissoon et al., 2020), and healthcare need (Browne et al., 2017) in healthcare use and health outcomes among PLWD. No data for dementia severity was available in this study, nor was a measure of comorbidity as a proxy for healthcare need. Though the importance of healthcare need and comorbidity as a factor in health outcomes have been discussed, it should be addressed in future research and identified as a variable that could improve the efficiency and strength of future association-based findings between healthcare use and health outcomes measure among PLWD.

Formal healthcare is only part of the care picture for PLWD, with so many people playing a vital role at different times throughout a person's experience of Dementia. The majority of people receiving home-care services, and living in care homes have dementia are PLWD

(Alzheimer's Society, 2022), emphasising the critical role social care services play in the care of PLWD, both in the community and institutional. No social care use data was available for this study, but future research should endeavour to explore temporal patterns in social care contact and transitions in care, alongside healthcare use, and the individual and collective impact they have on health outcomes in dementia. A further limitation of this study is the smaller membership of some healthcare use trajectory clusters. Of the eight clusters across both early- and late-onset populations, three clusters represented less than 10% of their respective overall population. This may limit the representativeness of these clusters of the general healthcare pathways of PLWD. Although this may be an issue with the robustness and generalisability of the findings related to these specific clusters, there will be some PLWD who are more in the minority in their temporal use of healthcare services, and so their experience needs to be represented as well as those healthcare use clusters representing a greater number of PLWD.

5.4.2. Conclusion

This study has identified different trajectories in healthcare use among PLWD, how they relate to social and spatial inequalities, and the risk of subsequent mortality. Our findings point towards thinking beyond singular pathways for healthcare design at the population level to leverage the heterogeneity in experiences, as well the importance of identifying particular trajectories early before they become problematic. The benefits of person-centred care in dementia have been established for both PLWD and the wider health social care system (Jennings et al., 2018). Involving PLWD and informal carers in care discussions and decisions can help to better meet their needs. Our trajectories can help clinicians and others involved in care discussions to understand not only the current picture for a PLWD, but also what the future possibilities of their care could look like. It is a priority to make services more appropriate and accessible to the breadth of PWLD in need, and to promote better care quality for all PLWD. Future research should provide a more complete picture of care among

PLWD, incorporating trajectories in health and social care use, and exploiting the complexity in different experiences and outcomes related to pathways through the health system.

5.5. Appendices

Appendix 5.1: Loss to follow-up for early- and late-onset population, for 10 years after date of diagnosis

Year After Diagnosis	Early-Onset		Late-Onset	
	Remaining		Remaining	
	(n)	%	(n)	%
Total	5210		137077	
0	5157	99.0%	131749	96.1%
1	4996	95.9%	118836	86.7%
2	4717	90.5%	101273	73.9%
3	4263	81.8%	80948	59.0%
4	3732	71.6%	62264	45.4%
5	3184	61.1%	45943	33.5%
6	2604	50.0%	32843	24.0%
7	2087	40.1%	22598	16.5%
8	1644	31.6%	15289	11.2%
9	1227	23.6%	10171	7.4%
10	923	17.7%	6588	4.8%

Appendix 5.2: Bayesian Information Criterion (BIC) and Log-likelihood (logLik) values for group-based trajectory models of one to ten groups (k) for both early- and late-onset sample populations

No. # groups in model	Early-Onset		Late-Onset	
	BIC	logLik	BIC	logLik
1	167410.7	-83597.2	281555.2	-140663.8
2	162357.8	-80957.6	273089.7	-136317.3
3	155647.7	-77494.4	261287.5	-130302.4
4	149099.4	-74102.3	258323.7	-128691.1
5	14613.5	-6883.9	12360.0	-5605.8
6	5153.1	-1932.4	24266.5	-11564.2
7	5056.5	-1775.9	8552.2	-3458.8
8	4274.6	-1276.8	8183.1	-3165.6
9	3704.3	-878.6	15753.1	-6971.3
10	-55039.0	28596.3	19281.3	-8502.6

Appendix 5.3: Inclusion in GBTM analyses, missing data and those who died in early- and late-onset dementia populations, by explanatory factors[3]

Explanatory Factor	Of entire early-onset population				Of entire late-onset population			
	GBTM-included		Population with missing data		GBTM-included		% missing data	
	#	%	% <5 years data	*% died*	#	%	% <5 years data	*% died*
Female	2027	54.3%	49.8%	48.2%	42638	68.9%	65.0%	64.2%
Male	1705	45.7%	50.2%	51.8%	19606	31.1%	35.0%	35.8%
Under45	77	2.1%	1.8%	1.5%				
45-54	594	15.9%	18.7%	17.8%				
55-64	3061	82.0%	79.6%	80.7%				
65-74					13343	21.1%	9.6%	7.4%
75-84					32876	53.1%	40.5%	37.9%
85-94					15521	25.0%	44.8%	48.3%
95+					504	0.8%	5.1%	6.4%
Asian	95	2.5%	2.3%	2.2%	946	1.3%	1.5%	1.2%
Black	88	2.4%	3.0%	2.3%	1192	1.9%	1.8%	1.1%
Mixed/Other	40	1.1%	1.0%	1.1%	521	0.9%	0.8%	0.6%
White	3267	87.5%	87.2%	94.4%	56756	91.2%	87.0%	97.1%
Quintile 1 (Most deprived)	724	19.4%	20.0%	21.8%	9921	15.4%	15.2%	15.9%
Quintile 2	703	18.8%	20.2%	21.4%	10793	18.1%	17.5%	17.5%
Quintile 3	771	20.7%	20.4%	19.4%	12421	19.3%	20.2%	20.5%
Quintile 4	837	22.4%	20.2%	20.1%	14297	23.0%	23.1%	23.4%
Quintile 5 (Least deprived)	683	18.3%	18.4%	17.4%	14707	24.0%	23.6%	22.7%
Rural	498	13.3%	12.5%	12.1%	8946	14.2%	14.8%	14.4%
Urban	3234	86.7%	87.5%	87.9%	53298	85.8%	85.2%	85.6%
East Midlands	110	2.9%	2.0%	1.8%	1307	2.3%	2.1%	1.9%
East of England	189	5.1%	5.1%	3.5%	3489	5.4%	6.0%	5.9%
London	453	12.1%	11.4%	11.1%	7032	10.7%	9.6%	8.9%
North East	189	5.1%	4.9%	6.2%	3471	5.6%	4.9%	5.3%
North West	763	20.4%	17.9%	18.5%	11396	18.9%	17.4%	17.9%
South Central	516	13.8%	13.3%	14.6%	8352	13.5%	14.0%	14.7%
South East Coast	294	7.9%	9.4%	10.2%	5061	8.4%	8.8%	8.5%
South West	447	12.0%	13.4%	14.9%	8907	14.2%	15.0%	15.2%
West Midlands	617	16.5%	17.9%	15.4%	10485	16.7%	17.9%	17.6%
Yorkshire & The Humber	154	4.1%	4.7%	3.7%	2744	4.3%	4.2%	4.0%

[3] *There are some members of early- and late-onset sample population who do not have Ethnicity or IMD 2015 deprivation quintile available in CPRD data, as such the sum total for such categories may be lower*

Appendix 5.4: Multinomial logistic regression output for likelihood of cluster membership based on socio-economic and geographic explanatory factors

Explanatory Factor	Early-Onset Dementia Healthcare Trajectory Cluster (ref: cluster 3)						Late-Onset Dementia Healthcare Trajectory Cluster (ref: cluster 4)					
	Cluster 1		Cluster 2		Cluster 4		Cluster 1		Cluster 2		Cluster 3	
	Log odds *(95% Confidence Intervals)*	Std.Er	Log odds *(95% Confidence Intervals)*	Std.Er	Log odds *(95% Confidence Intervals)*	Std.Er	Log odds *(95% Confidence Intervals)*	Std.Er	Log odds *(95% Confidence Intervals)*	Std.Er	Log odds *(95% Confidence Intervals)*	Std.Er
(Intercept)	***-2.559***	***0.451***	***-4.457***	***0.785***	***-0.215***	***0.187***	***-1.758***	***0.232***	***-0.517***	***0.152***	***-3.436***	***0.411***
Sex (ref: Female)												
Male	0.205	*0.158*	-0.342	*0.199*	-0.050	*0.073*	-0.042	*0.098*	0.046	*0.062*	-0.142	*0.125*
Age Group (ref: 55-64)												
<45	-0.066	*0.611*	1.048	*0.462*	0.198	*0.261*						
45-54	-0.019	*0.214*	-0.276	*0.287*	-0.089	*0.099*						
75-84							0.130	*0.114*	0.153	*0.074*	0.330	*0.159*
85-94							0.043	*0.138*	0.438	*0.086*	0.853	*0.170*
95+							-0.580	*0.756*	0.562	*0.331*	0.815	*0.575*
Ethnicity (ref: White)												
Asian	-0.785	*0.735*	-11.999	*187.462*	0.155	*0.220*	-0.879	*0.534*	0.170	*0.241*	-0.606	*0.611*
Black	0.048	*0.560*	-0.351	*0.569*	-0.068	*0.251*	-0.863	*0.389*	-0.274	*0.210*	-0.959	*0.531*
Mixed/Other	0.661	*0.559*	-0.108	*0.759*	-0.542	*0.395*	-0.488	*0.627*	0.536	*0.301*	-0.044	*0.630*
IMD 2015 Quintile (ref: Quintile 5: Least Deprived)												
Quintile 4	-0.046	*0.238*	0.552	*0.334*	0.110	*0.115*	0.171	*0.136*	0.094	*0.085*	0.016	*0.160*
Quintile 3	-0.184	*0.257*	0.599	*0.346*	0.098	*0.119*	-0.043	*0.147*	-0.153	*0.090*	-0.211	*0.172*
Quintile 2	-0.025	*0.257*	0.716	*0.352*	0.115	*0.123*	0.269	*0.147*	0.095	*0.093*	0.016	*0.178*
Quintile 1 (Most deprived)	-0.195	*0.272*	0.828	*0.368*	0.033	*0.127*	0.489	*0.152*	0.050	*0.101*	0.124	*0.189*
Urban-Rural GP Classification (ref: Urban)												
Rural	0.153	*0.240*	0.493	*0.283*	0.217	*0.111*	-0.094	*0.143*	0.105	*0.085*	0.129	*0.164*
GP Region (ref: North East)												
North West	0.361	*0.427*	0.923	*0.756*	-0.219	*0.175*	0.069	*0.207*	0.221	*0.137*	1.262	*0.384*
Yorkshire & The Humber	0.071	*0.559*	0.820	*0.884*	-0.324	*0.235*	-0.150	*0.294*	0.101	*0.184*	1.119	*0.448*
East Midlands	0.251	*0.620*	1.249	*0.941*	0.060	*0.263*	-0.330	*0.421*	0.348	*0.224*	1.326	*0.504*
East of England	-0.307	*0.585*	1.005	*0.862*	-0.336	*0.228*	0.109	*0.271*	0.034	*0.176*	0.882	*0.451*
West Midlands	0.092	*0.448*	0.744	*0.779*	-0.184	*0.180*	0.026	*0.216*	0.310	*0.140*	1.212	*0.390*
London	-0.043	*0.483*	1.763	*0.761*	-0.371	*0.197*	0.238	*0.229*	0.176	*0.153*	1.440	*0.400*
South East Coast	0.101	*0.494*	1.653	*0.781*	-0.405	*0.210*	0.211	*0.245*	0.200	*0.161*	1.431	*0.409*
South Central	0.476	*0.453*	1.766	*0.767*	0.016	*0.190*	0.313	*0.220*	0.079	*0.148*	1.177	*0.399*
South West	0.170	*0.460*	1.040	*0.780*	-0.225	*0.189*	0.122	*0.214*	-0.023	*0.144*	0.895	*0.397*

Appendix 5.5: Cox Proportional Hazards regression outputs for association between mortality risk and explanatory factors[4]

Explanatory Factor	Early-onset dementia				Late-onset dementia			
	Hazard Ratio (HR)	***95% Confidence Intervals***	**p-value**	**sig**	**Hazard Ratio (HR)**	***95% Confidence Intervals***	**p-value**	**sig**
Cluster 1	2.21	*(1.78 – 2.75)*	0.00	***	1.08	*(0.96 – 1.21)*	0.21	
Cluster 2	0.47	*(0.28 – 0.77)*	0.00	**	0.72	*(0.66 – 0.80)*	0.00	***
Cluster 3	*Not Applicable (reference group)*				0.32	*(0.25 – 0.40)*	0.00	***
Cluster 4	1.37	*(1.21 – 1.56)*	0.00	***	*Not Applicable (reference group)*			
Age At Diagnosis	1.02	*(1.00 – 1.03)*	0.01	*	1.06	*(1.05 – 1.07)*	0.00	***
Male	1.09	*(0.97 – 1.23)*	0.14		1.21	*(1.11 – 1.32)*	0.00	***
Asian	0.72	*(0.45 – 1.13)*	0.15		1.03	*(0.71 – 1.48)*	0.89	
Black	0.98	*(0.64 – 1.49)*	0.92		0.89	*(0.65 – 1.21)*	0.46	
Mixed/Other	0.81	*(0.42 – 1.58)*	0.54		1.33	*(0.87 – 2.03)*	0.19	
Quintile 4	1.04	*(0.86 – 1.26)*	0.66		1.06	*(0.94 – 1.19)*	0.36	
Quintile 3	1.13	*(0.93 – 1.38)*	0.23		1.05	*(0.93 – 1.19)*	0.45	
Quintile 2	1.16	*(0.95 – 1.42)*	0.15		1.05	*(0.92 – 1.20)*	0.46	
Quintile 1 (Most Deprived)	1.02	*(0.82 – 1.26)*	0.86		1.16	*(1.01 – 1.33)*	0.03	*
Rural	1.00	*(0.83 – 1.20)*	0.99		1.01	*(0.90 – 1.14)*	0.87	
North West	1.04	*(0.77 – 1.40)*	0.81		0.88	*(0.73 – 1.05)*	0.15	
Yorkshire & The Humber	0.99	*(0.67 – 1.49)*	0.98		0.82	*(0.64 – 1.05)*	0.11	
East Midlands	0.78	*(0.49 – 1.24)*	0.29		0.95	*(0.70 – 1.30)*	0.75	
East of England	1.27	*(0.87 – 1.85)*	0.22		0.81	*(0.64 – 1.02)*	0.07	
West Midlands	0.95	*(0.69 – 1.29)*	0.73		0.78	*(0.65 – 0.94)*	0.01	**
London	0.94	*(0.67 – 1.32)*	0.72		0.63	*(0.51 – 0.78)*	0.00	***
South East Coast	1.07	*(0.75 – 1.53)*	0.71		0.64	*(0.51 – 0.80)*	0.00	***
South Central	1.24	*(0.91 – 1.70)*	0.17		1.01	*(0.83 – 1.22)*	0.93	
South West	1.10	*(0.80 – 1.51)*	0.58		0.91	*(0.75 – 1.09)*	0.30	

*Please note significance levels: '***' = <0.001; '**' = <0.01 '*'' = <0.05*

[4] *Reference groups for explanatory factors: Healthcare cluster: Early-onset = cluster 3; Late-onset = cluster 4; Sex = female; Ethnicity = White; IMD 2015 Deprivation Quintile = Quintile 5 (Least Deprived); Urban-Rural GP classification = Urban; GP Region = North East; as a continuous variable there is no reference for Age At Diagnosis*

6. Chapter 6: Discussion

This section will provide a summary of the key findings and contributions of this PhD thesis. The main findings will be discussed in relation to the aims of the PhD project (see Chapter 1, page 9), integrating the findings from each paper and highlighting their wider narrative for how they all fit together. Given the nature of this PhD project and the papers encompassed, findings will then be discussed under sub-headings. The first is focused on healthcare use trajectories, then moving on to the findings related to each of the socio-economic or geographic factors explored in this PhD project. The strengths and limitations of the PhD project and research conducted will then be discussed. Finally, this chapter will draw conclusions from the findings and the narrative discussed, setting out recommendations, noting how findings can be used to introduce policy and practice changes and recommend ideas for future research.

6.1. Introduction

The number of PLWD has been increasing in the UK and globally, and is expected to continue to do so in the coming years and decades, particularly among those with more severe symptomatology and greater day-to-day care needs. Health and social care services in the UK are struggling to meet current demand, and an increasing population of PLWD, particularly those with more acute care need, will present even greater pressures on services. Social and spatial inequalities exist from the point of trying to access a dementia diagnosis, to the frequency and quality of subsequent care and treatment they receive, through to their likelihood of moving into nursing care, and risk of mortality. There is a lack of forthcoming funding from central government to support services and improve staffing levels. As a result, the increased pressure of additional need is only likely to exacerbate current inequalities, meaning PLWD from the most disadvantaged groups in society are likely to endure further inequalities in care and health outcomes.

To address current and negate future inequalities in the care and health outcomes for PLWD, it is vital we understand the picture currently. Routine, cohort datasets, including big data and secondary datasets of electronic health records have been used to examine inequalities in the care and outcomes of PLWD (Cooper et al., 2017; van de Vorst et al., 2016). However, this thesis has highlighted several key gaps in the existing literature which need to be investigated. Firstly, there was no synthesis of the findings from studies using routine, cohort datasets of electronic health records have been used to evidence inequalities among PLWD. Secondly, the current research does not include more than one or two social or spatial variables as potential factors associated with inequalities in care, nor does it simultaneously examine the use of a range of healthcare services as outcome measures. Finally, the existing research does not tend to investigate healthcare use as a series of cumulative, interlinked events, but rather it examines healthcare use as a series of individual, separate events. This thesis sought to address these gaps in the literature through four primary aims, which would be achieved via four sequential research papers:

1. Explore the potential of routinely collected data for investigating dementia inequalities
2. Examine potential inequalities in healthcare use among PLWD
3. Examine potential inequalities in health outcomes (e.g. mortality risk) among PLWD
4. Identify variations in healthcare use and its impact on health outcomes.

6.2. Key Findings

The foundation of this PhD project was to demonstrate the potential of secondary data to improve health and care, and narrow inequalities, among PLWD as a means to improve quality of life and save lives. This began with conducting a systematic review on how routine datasets have been used to explore inequalities in the care and health outcomes among PLWD. This review highlighted that there were inequalities and differences in access, use and quality of health and social care among different socio-economic and geographic groups, across numerous - primarily Western – countries. The review also demonstrated substantive and important gaps in the knowledge of dementia inequalities. Firstly, existing

literature explores few studies examining multiple factors together in the same analysis of inequalities in care and health outcomes among PLWD. This may have been partly due to a dominance of clinical focused studies, whose focus was not on the social determinants of dementia. Secondly, the systematic review highlighted that existing research has often examined health and social care as a series of one-off events, rather than a collection of interlinked events that reflects an integrated and comprehensive pathway. These gaps in the literature bring to light wider implications in how researchers and policy makers should be utilising electronic health records for improving dementia-related outcomes and their associated inequalities.

In light of these findings, the systematic review demonstrated the avenues through which secondary data could be used within this PhD project. Using CPRD data, I explored how healthcare use and mortality risk differ between social and spatial groups, and how healthcare trajectories vary among PLWD and can impact mortality risk. The first quantitative paper from this thesis explored socio-economic, demographic and geographic variables as potential factors in inequalities in mortality risk. The findings showed that some socio-economic and geographic groups had a greater risk of mortality after dementia diagnosis, specifically older PLWD, men, PLWD from White ethnicity groups, those from more deprived areas, and people in some GP regions. Additionally, frequency of primary healthcare utilisation was examined as factor in mortality risk. Findings showed increased rates of GP contact for PLWD was associated with increased mortality risk, and for late-onset dementia an increased rate of prescribed dementia medications was associated with greater risk of mortality.

The first quantitative paper (Chapter 3) was based on the gaps in the literature identified from the initial systematic review, and the evident benefits of employing healthcare use variables in inequalities research, as highlighted by the first quantitative paper. The second quantitative paper (Chapter 4) employed the same geographic and socio-economic variables as factors for variation in the use of different types of primary and secondary healthcare.

Based on the same sample population, *frequency* of GP contact, and both dementia and non-dementia medications, and the *likelihood* of A&E attendance, and emergency and elective admissions to hospital varied based on age, sex, ethnicity, level of deprivation and geography. These inequalities were often nuanced and inconsistent across outcome measures suggesting strategies aimed at tackling inequalities need to be multi-faceted.

The first two quantitative papers (Chapters 3 and 4) investigated a greater number of simultaneous socio-economic and geographic factors in outcome measures among PLWD than has been explored in previous research. However, a major gap in the literature highlighted from the systematic review illustrated that existing literature does not tend to examine temporal trajectories in the use of healthcare services among PLWD. As a result, the final quantitative paper (Chapter 5) examined temporal healthcare trajectories among PLWD. The findings indicated – among both people with either early- or late-onset dementia – there were four distinct pathways experienced and mortality risk varied between different healthcare pathway clusters. Mortality risk was not associated with a single distinctive healthcare use trajectory in either early- or late-onset dementia populations. Instead, increased mortality risk was observed among clusters with gradually or exponentially increasing rates of healthcare use, and significantly lower mortality risk occurred among clusters with increasing or falling rates of primary healthcare use. The fourth and final paper from this PhD project is novel, demonstrating how big-data can be leveraged to identify patterns in differential use of various services among PLWD, and the degree to which patterns in service use can impact health outcomes.

6.2.1. Healthcare use

A PLWD's use of health and social care is influenced by their background and where they live. I have added to the wider literature through demonstrating how the frequency of healthcare use is impacted by demographic, geographic and socio-economic factors (Chapter 4), and frequency of primary healthcare use can impact mortality risk (Chapter 3). I have also illustrated that temporal patterns in primary and secondary healthcare use are

associated with variations in mortality risk among PLWD (Chapter 5). There are direct and indirect ways in which socio-economic and geographic factors can impact the frequency and quality of health and social care use. Services can be less accessible and appropriate for some population groups, as highlighted for example among women struggling to get appropriate care after diagnosis (Cooper et al., 2017; Sundermann et al., 2016), in PLWD from ethnic minority backgrounds accessing appropriate treatment and ongoing support (Thorpe et al., 2016; Tsamakis et al., 2021), among PLWD from rural areas attaining good quality and continuity in primary healthcare (Baird and Wright, 2006), and PLWD from deprived areas being treated and managed in an integrated and comprehensive way (McMaughan, Oloruntoba and Smith, 2020).

Healthcare pathways are an ongoing series of interconnected events, with each contact representing a PLWD's need at a point in time. Depending on appropriateness and quality of the healthcare contact, these events have the potential impact the type and degree of future healthcare need (Bunn et al., 2017; Chen et al., 2021). PWLD struggling to receive a dementia diagnosis or subsequent appropriate healthcare involvement can have a detrimental impact on their experiences of dementia, reducing treatment options for dementia, increasing the rate of dementia progression, use of emergency healthcare, and impairing quality of life (Alzheimer's Association, 2017; Robinson, Tang and Taylor, 2015). My analyses show no one trajectory in healthcare is conducive to better outcomes among PLWD, but rather each experiences their dementia differently (Melis, Haaksma and Muzi-Terrera, 2019). It is therefore imperative that we understand treatment and support needs for PLWD from diagnosis, and follow up checks to identify any potential changes which may alter their need and treatment. Meeting comprehensive and changing care needs can increase the chances of PLWD staying at home and maintain their quality of life, and slow down the decline in their condition (Kim and Park, 2017; Moore and Crawley, 2020).

6.2.2. Age

Increasing age was found to have a significant impact on the use of services and health outcomes among PLWD across all research papers. The systematic review (Chapter 2) showed that increasing age among PLWD was associated with fewer surgical consultations, but greater emergency healthcare contact. It also noted that increasing age in dementia was linked to greater likelihood of transitions into nursing homes and more rapid dementia progression. From the quantitative research papers (Chapters 3 and 4), we additionally demonstrated that older PLWD – those aged 85 years and over – had fewer elective hospital admissions and greater likelihood of mortality than their younger counterparts. These findings are not necessarily surprising. Ageing increases the likelihood of ill-health, and PLWD are even more likely to have a greater number, and more severe, long-term health conditions than the general population (Divo, Martinez and Mannino, 2014). Spouses contribute a great deal of the informal care to PLWD, and ageing can mean increased burden – caregiver ill-health and stress - in providing the breadth of care in dementia (Barbosa et al., 2021; Tsai et al., 2021). Caregiver strain and ageing can increase the likelihood of movements into formal care (Banerjee et al., 2003; Gaugler, Pot and Zarit, 2007). Transitions into nursing homes can in-turn heighten the risk of care mismanagement and negative health outcomes (Manderson et al., 2012), including dementia progression and how rapidly their general health may deteriorate (Ryman et al., 2019).

It can also be noted that the youngest PLWD – e.g. the youngest people with early-onset dementia – had fewer elective hospital admissions (Chapter 3) and are less likely to have annual dementia reviews with their consultant (Chapter 2). People with early-onset dementia are less likely to have multiple long-term health conditions and severe ill-health (Gerritsen et al., 2016) than older PLWD. However, people with early-onset dementia are more likely to have rare forms of dementia than their older counterparts which are harder to treat (Alzheimer's Society, 2020), and are more likely to have upheaval in their personal and working life (Rossor et al., 2010). Spousal care presents a substantial proportion of the day-

to-day care and support provided to PLWD, especially when the person with dementia does not have adult children capable of supporting a spouse in the role (Brodaty and Donkin, 2009). The person diagnosed with early-onset dementia may have to give up employment as a result of their diagnosis. This can have a detrimental impact on their mental health and their family finances (Kilty et al., 2023). This can place further pressure on spouses to manage the financial dichotomy between needing to provide care for their spouse with dementia and the cost of buying in formal care to do so (Bayly et al., 2021; Mayrhofer et al., 2021). Age is therefore an important determinant of inequalities in the experiences of PLWD.

6.2.3. Sex

This thesis highlights distinct differences between men and women in how they interact with health and social care and their health outcomes. The review demonstrated that women were more likely than men to be living with dementia and also to be institutionalised earlier after dementia diagnosis, with more mild symptomatology (Chapter 2). Women often survive longer with dementia, and are diagnosed earlier in their dementia, but men and women can often present differently. Women are more likely to retain their memory in the early stages and score better on screening tests (Sundermann et al., 2016). This may mean missed diagnoses, or perceptions of less severe symptomatology and lesser requirement for support (Alzheimer's Research UK, 2022). In later-life dementia tends to progress at a more rapid rate for women than men (Podcasy and Epperson, 2016) and concurrently, women are more likely to move into nursing home care in later-life than men (Zafeiridi et al., 2021). Moving into nursing care can increase the speed at which somebody's condition deteriorates, particularly later in life, which can increase the chances of using emergency healthcare (Bartlett et al., 2016), and mortality risk (Aneshensel et al., 2000).

I have illustrated that men were more likely to experience faster dementia progression (Chapter 2) and have greater contact with both primary and secondary healthcare (Chapter 4) across our quantitative analyses and the systematic review. Males were also more likely to die than females (Chapter 3), but understanding these patterns is complex. Men's more

severe pattern of multiple long-term conditions - particularly as they age (Bauer et al., 2014; Gambassi et al., 1999) – creates greater challenges to providing comprehensive treatment. Men are therefore more likely to require frequent healthcare contact to provide appropriate care and treatment. However, men are more likely to show a reticence to engage with health and social care (Schaffler-Schaden et al., 2021; Wang et al., 2013) or adhere to treatment (Mahmoodi et al., 2019), combined with greater complexity of conditions (Bauer et al., 2014). This can result in transitions into nursing home care, a lack of appropriate pharmacological treatments and comprehensive care, rapid dementia progression, greater use of emergency healthcare, and increased mortality risk (Delgado et al., 2020; Gungabissoon et al., 2021; Kim and Lee, 2020; Peterson et al., 2008).

6.2.4. Ethnicity

I have demonstrated that PLWD from ethnic minority groups have greater frequency of GP contacts, but a lower likelihood of secondary healthcare contact (Chapter 4), and reduced mortality risk than PLWD from White ethnic groups (Chapter 3). PLWD from ethnic minority groups were also less likely to move into formal care settings, but have increased difficulties in accessing and adherence to taking anti-dementia medications (Chapter 2). The impact of ethnicity on health and social care use, and health outcomes among PLWD, is nuanced (Watson et al., 2021). Dementia tends to be less severe among PLWD from ethnic minority backgrounds (Parveen and Oyebode, 2018) and they also have a younger population than that of White populations (ONS, 2022). In combination with societal expectations among some ethnic groups to provide care for older relatives, this can increase the likelihood of greater informal care at home for PLWD from ethnic minority groups (Duran-Kirac, 2022; Parveen and Oyebode, 2018). Care at home for longer and less severe dementia are both strongly associated with a greater probability of better health outcomes (Brodaty and Donkin, 2009; Schultze et al., 2022). Care at home can maintain quality of life, but doing so requires an accurate diagnosis and adequate care and treatment from formal services (Olsen et al., 2016). PLWD from ethnic minority backgrounds are more likely to be living with dementia

(Tsamakis et al., 2021), but are more likely to encounter incorrect or delayed diagnoses (Gianattasio et al., 2019; Lin et al., 2021), and poor accessibility and quality of healthcare (Duran-Kirac et al., 2021;). They are also more likely to have poor health and a greater number of multiple long-term conditions than their counterparts from White ethnic groups (Price et al., 2013; Quinones et al., 2019).

6.2.5. Deprivation

Increased levels of deprivation are associated with suboptimal health and social care contact and worse health outcomes. The systematic review (Chapter 2) demonstrated that a greater proportion of PLWD live in areas of greater deprivation, but experience lower rates of anti-dementia medication initiation. The quantitative research additionally highlighted that deprivation is associated with higher frequency of GP contact and increased likelihood of emergency healthcare use, but a lower probability of elective healthcare (Chapter 4). This would seem to indicate that PLWD from more disadvantaged areas are in greater need of a range of services, but don't necessarily experience the level or quality of healthcare they require (Cooper et al., 2016). This may be borne-out by our finding of much greater risk of mortality for PLWD from the most deprived areas compared to the most affluent (Chapter 3), and the literature demonstrating poorer quality of life and wellbeing among PLWD in deprived areas (Wu et al., 2018). The pattern in healthcare use demonstrated among PLWD from deprived areas (Chapter 4) has been shown in previous research to be associated with worse health outcomes (Cooper et al., 2016; Jitlal et al., 2021). The proportion of undiagnosed and incorrectly diagnosed dementia in areas of greater deprivation is higher than in affluent areas (Petersen et al., 2021). This is alongside a lack of appropriate or accessible healthcare services, and poorer healthcare quality for people who do receive a diagnosis (McMaughan, Oloruntoba and Smith, 2020). Whether diagnosed or undiagnosed, there is high unmet need among PLWD in more deprived areas (Connolly et al., 2011), which could be reflected in the frequent GP and emergency healthcare contact I highlight. Areas of higher socio-economic deprivation have greater dementia prevalence (Arapakis et

al., 2021). However, PLWD from deprived areas are more likely to be diagnosed when their condition is advanced (Petersen et al., 2021), and have more multiple long-term conditions (Browne et al., 2017). Increased severity of ill-health, difficulties accessing services, and poorer quality care for PLWD, will increase the likelihood of faster deterioration in health, emergency healthcare utilisation and transitions into nursing home care – factors associated with greater likelihood of worse health outcomes, including increased mortality risk (Leniz et al., 2019; Sommerlad et al., 2019; Van de Vorst et al., 2016).

6.2.6. Geography

Geography is a critical factor which can affect healthcare use and health outcomes for PLWD. Our systematic review (Chapter 2) demonstrated that previous research has not investigated geography widely as a potential factor for inequalities among PLWD. When accounting for confounders, I highlighted significant variations in healthcare use (Chapter 4) and mortality risk (Chapter 3) between people living in different regions of England, and between PLWD registered with rural and urban GPs.

Firstly, looking at urbanity and rurality, I illustrated that PLWD with rural GPs were more likely to attend A&E, but less likely to see their GP or have emergency hospital admissions (Chapter 4). Geography and deprivation are inherently bound and issues persist in healthcare variation. This can be seen in rural areas with social and service isolation for people in more localised communities (Alzheimer's Society, 2018; Rahman et al., 2020). PLWD in rural and remote areas often have fewer care and support options and may have to travel further to receive adequate diagnosis or treatment (Morgan et al., 2019; Xu et al., 2022). With limited choice in primary care, PLWD may be reliant on the availability, capacity and knowledge of their local GP, who can represent the gateway through which a PLWD will access diagnosis, treatment and onward referrals for support (Bourque and Foley, 2020; Rural Services Network, 2017). Differing care needs for PLWD from rural and urban areas, represents an important policy area for minimising spatial inequalities.

There were also variations in healthcare use and health outcomes between the regions of England. PLWD in the North East had less contact with their GP and fewer anti-dementia medications, but more medications prescribed for their multiple long-term conditions, and greater likelihood of emergency hospital admissions (Chapter 4). Along with the North West, PLWD in the North East also had increased mortality risk. Both the North East and North West have high levels of morbidity, shortest life and healthy life expectancies of any region in England (NHS England, 2022; ONS, 2022 (2); The Health Foundation, 2022). This is at least in part due to growing healthcare inequalities driven by variation in service provision, treatment accessibility and care quality (Corris et al., 2020). Greater ill-health in areas like the North East of England will increase the need for health and social care among PLWD (Wu et al., 2018). However, with staff and finances more constrained in areas of greater deprivation this will likely increase unmet need in these areas (Read et al., 2021).

6.2.7. Contribution to wider research and knowledge

This PhD thesis aimed to address gaps in the existing literature of social and spatial inequalities in healthcare use and health outcomes for PLWD, using secondary datasets of electronic health records. In synthesising the exiting literature which used routine, cohort datasets to examine health and social care service use and quality, and health outcomes for PLWD, I highlight the potential of using secondary datasets to examine inequalities (Aim 1), as well as demonstrating several key research gaps. This addressed both the first aim of the study (see Introduction, pages 7-8), and demonstrated further gaps in the current knowledge. Aims two, three and four were developed to account for these limitations, by encompassing multiple social and spatial variables as potential factors associated with both mortality risk (Aim 2), and frequency or likelihood of contact with an array of primary and secondary healthcare services (Aim 3) among PLWD. Finally, research has tended to investigate use of healthcare services as individual, unlinked event. The final aim of this thesis was to demonstrate different temporal patterns in the use of multiple healthcare

services, and highlight any association between healthcare pathways and subsequent mortality risk.

The contribution of this thesis comes in two strands: the methods and application of data, and the additional knowledge generated on inequalities in dementia. Firstly, it is important to highlight the novel methods used in some of the research in this thesis, particularly in the final paper (Chapter 5). Clustering methods have barely been used in dementia research, especially not in investigating the use of a wide array of healthcare services. Using clustering methods for temporal patterns in service use, I have not only employed methods novel to understanding variation in the care of PLWD, but I have begun to highlight the potential effect that healthcare patterns can have on health outcomes for PLWD.

Within Chapters 3-5 I have highlighted variations and inequalities in healthcare use and mortality risk associated with age, sex, ethnicity, deprivation and geography. In doing so I have demonstrated the importance and potential to include a wider array of social and spatial variables as potential factors associated with variation in service use, service quality, and experience of health outcomes. These novel methods and applications of data have come from the use of large datasets of linked, electronic health records. With over 120 million records of healthcare contacts for over 142,000 PLWD, I have been able to explore primary and secondary healthcare use, and mortality risk, and the impact demographic, geographic and socio-economic factors can have on the experience a PLWD can have of them. There is great potential in using existing datasets to examine inequalities in the care and outcomes for PLWD, but further research can go a long way to demonstrating the impact that social and spatial factors, and patterns in health and social care use can have on the ongoing health, and health outcomes on PLWD.

From the findings highlighted through this thesis and brought together in Chapter 6, I have added to the knowledge of social and spatial inequalities and variations in healthcare use and mortality risk among PLWD. This is particularly important given the limited existence of research which included more than one or two potential factors for variation in outcome

measures. Including several demographic, geographic and socio-economic factors as confounders in this research has not only highlighted the associations between these factors and outcomes, but also the importance of incorporating a greater breadth of confounding factors, given there are a myriad of variables which can impact the frequency and quality of health and social care use, and the experience of health outcomes among PLWD.

6.3. Strengths and Limitations

6.3.1. Strengths

This PhD thesis has provided two novel strands of evidence related to inequalities in service use and health outcomes among PLWD: (i) embedding social and spatial inequalities thinking into understanding healthcare and health outcomes among PLWD, and (ii) examining healthcare use as a series of interlinked events, rather than a set of unrelated, one-off events.

Previous research has often focused on few explanatory factors of the role of the wider determinants of health in the care and health outcomes for PLWD (Chapter 2). This thesis however has illuminated how a variety of simultaneous geographic and socio-economic factors impact the frequency or likelihood of PLWD coming into contact with primary and secondary healthcare and their mortality risk. In particular, the thesis has added novel evidence of the role of geography in explaining healthcare patterns (Chapter 4) and mortality risk (Chapter 3) which the systematic review identified as a significant research gap. Specifically, variations in healthcare use and mortality risk have been noted based on the geographic region somebody accesses primary healthcare, and whether they are registered with a rural or an urban GP. This PhD project has produced new knowledge related to the variation in healthcare use pathways among PLWD, the social and spatial differences in likelihood of encountering different healthcare pathways, and their subsequent mortality risk (Chapter 5).

I have demonstrated the potential for investigating inequalities in a variety of measures of healthcare and health outcomes among PLWD by using secondary data sources. Though there is great potential for future research employing similar datasets – including examining multiple long-term conditions and other time-to-event analyses (e.g. time to hospital admissions from diagnosis) – the research forming this thesis has gone beyond previous research into inequalities in care and outcomes among PLWD. The data employed in the quantitative studies (Chapters 3-5) here is related to PLWD from the same original sample population, emphasising the possibilities of investigating multiple outcomes using the same dataset. Understanding inequalities across a series of different outcomes and examining longitudinal trajectories in healthcare use among the same population can set a precedent in providing novel evidence, whilst also being pragmatic and efficient with secondary data. The final research paper (Chapter 5) also applied data science methods underused in quantitative dementia research. This paper has employed group-based trajectory models to demonstrate a variety of longitudinal healthcare pathways. Further analysis has then explored how social and spatial factors can impact a PLWD's likelihood of encountering specific healthcare pathways, and subsequent mortality risk.

6.3.2. Limitations

This thesis is subject to some limitations. Firstly, the research encompassed within this PhD thesis are more exploratory in nature than hypothesis-led. The research papers (Chapter 2-6) explore gaps in the existing knowledge of variation and inequalities in dementia care and mortality, but there are limitations to exploratory research of this nature. Hypothesis-led research can identify a research question, with a very specific aim, which we can test. In more exploratory research we do not have a specific, focused, hypothesis or research question. Exploratory research – without a very specific hypothesis – can be more prone to bias, including false-negative results. The lack of research encompassing multiple social and spatial factors of variation among PLWD, and a lack of research of healthcare as pathways,

means that the exploratory research in this PhD has helped to identify areas for future research which can support more hypothesis-led studies.

Though less of an issue in the first two quantitative papers (Chapters 3 and 4), attrition rates from the population with both early- and late-onset population were high, presenting a potential issue with selection bias. Attrition in itself is an issue if seen in large enough numbers from a study population, but given there were already small sub-populations within our study – particularly for ethnic minority groups and within the much smaller early-onset population – the loss to follow-up in the final quantitative study presents issues in the generalising of findings to the wider population of PLWD. There were also data-specific issues, specifically regarding date of dementia diagnosis. Inclusion within the data was based on people's presence on a CPRD-registered GP dementia-register at data source, but the CPRD data does not include a dementia diagnosis date. As such, I had to define a date for each member of the study population which could be standardised and applied rigorously for everyone. Date of dementia diagnosis was generated for each member of the study population, using the first GP observation in which a dementia-specific term was given. This standardised date of diagnosis could be applied rigorously for all members of the sample population, negating this potential issue within the data.

Data availability could also present an issue with explanatory variables for the associations examined in this PhD thesis. Geographic factors examined for potential associations with outcomes were at the GP region level and static at the point of entry to the data. Unfortunately, within the available CPRD data, only GP region and rural-urban GP classification variables were available. Differences in funding, staffing and quality of health and social care services at a very local level mean that the larger-area geographic variables may not encompass the level of granularity required to understand the complexity of the experience among PLWD. Lower-level geography would at greater nuance to findings and potentially emphasise smaller pockets within England which may be encountering differential use of healthcare services, or more likely to experience poorer health outcomes and greater

risk of mortality. A lack of residential variables, or time-varying geographic variables has drawbacks. The large area covered by regions can hide some of the nuance in funding and service availability in smaller geographic areas. Given the nature of dementia, and the size of the GP regions, it is unlikely many of the sample population will have moved from one geographic region to another during the study. However, with access and quality of care varying at such a local level, it is important to note that the lack of time-varying and residential-linked geographic factors can limit the application of findings.

There is also a limitation regarding direction of causality between exposure and outcome variables. This is particularly the case in regards to mortality risk and patterns in healthcare use. The frequency and the type of healthcare services a PLWD used can change as a result of their care need, which can be impacted when their condition is progressing and they move towards the end of life. In this instance, defining direction of causality without data related to level of care need (i.e. comorbidity) or their dementia severity is not entirely possible. Furthermore, as dementia is a condition that can change greatly and at times, rapidly, a lack of temporal data to demonstrate changing healthcare need and dementia severity is identified as a limitation. Inclusion of greater depth of longitudinal data could benefit association-based research and help to provide stronger clarification of the direction of causality between healthcare use and health outcomes, and identify changing care need. More generally, the inclusion of further variables capturing wider dimensions of socio-economic and geographic inequalities that were not included could have also strengthened our analyses. Data relating to wider ill-health and multiple long-term conditions, a person's sexuality, lower-level geography (e.g. local authority, or super-output areas), social care use and transitions into nursing home care, and informal care availability are all factors with great potential for research, but limited exploration among PLWD. These data variables were either not available, or not possible to analyse from CPRD datasets. This is not a flaw of the project, but shows the potential to benefit from a wider dataset related to the individual,

environment, health and the wider determinants of health than can all impact lived experience.

The findings within the encompassed quantitative research studies (Chapter 3-5) are a result of association-based analyses, which describe inequalities rather than explain the pathways and mechanisms for why inequalities may exist. Causal inference is a process that allows us to draw causal conclusions between the input or explanatory variables and outcome measure(s) from our data (Pearl, 2009), and could have provided further weight to the research conducted.

6.4. Future Research

This thesis emphasises the benefits of using secondary datasets to explore socio-economic and geographic inequalities in healthcare and health outcomes for PLWD. We also illustrated the potential of large secondary datasets, to identify temporal trajectories in healthcare use, and their impact on health outcomes in dementia. However, there are multiple potential avenues to explore in research using large-scale, routine datasets for the health, service use and health outcomes of PLWD.

6.4.1. Additional variables, potential inequalities and outcomes

There are inherent limits to different secondary datasets. They are standardised and routinely-collected, which has practical benefits, but they may not include the extent of the data required. Dementia subtype can impact the symptomatology in dementia and the type and level and need a PLWD has. As such, it would be beneficial to include this as not only a factor which can drive potential inequalities of variations in healthcare use and outcomes, but also as a variable for understanding the needs among different sub-population of PLWD. These can be potential explanatory or confounding factors of inequalities in outcome measures, for example, a person's sexuality, number of comorbidities or comorbidity scale rating, and a variety of geographies.

There are also limits to the breadth of the datasets available. Throughout this thesis, I discuss the degree to which demographic, geographic and socio-economic factors can impact outcomes among PLWD, but there is an emerging need to understand the interplay between intrinsically linked factors. Specifically, there is an overlapping impact on outcomes for PLWD, between where somebody lives or accesses services, and the levels of socio-economic deprivation in these areas have on outcomes for PLWD, which needs to be truly drawn out through intersectional analysis. Intersectionality between multiple explanatory factors in outcomes has seen limited research in health, but could help to better define the extent to which overlapping explanatory factors impact health inequalities (Holman et al., 2022). There is also potential in time-to-event analysis for different outcomes measures. I explored mortality risk and use of different healthcare types, but it could provide a great deal of evidence to frame care discussions. Better knowledge of time from diagnosis to transition into nursing care, to first A&E attendance or admission to hospital could generate further understanding of care and inequalities among PLWD.

6.4.2. Comprehensive and integrated trajectories in care

Healthcare use provides only one part of the picture of care for PLWD. Dementia is a complex health condition, and often PLWD have more severe multiple long-term conditions (Bunn et al., 2014). Alongside the potential for rapid changes in health and social care need, this can mean it is difficult to understand the entirety of the picture of health and need among PLWD. However, there is a need for greater inclusion of social care, transitions in care and use of community support and social groups, and informal care availability to portray a more complete picture of a PLWD's service engagement, ongoing support and health and how service involvement and movements in care impact their health outcomes. Having access to informal care provision, alongside the routinely collected information from health records, would strengthen this measurement.

6.4.3. Applying methods internationally and cross-country comparisons

There are many countries collecting standardised datasets related to the health and healthcare of large populations, for example the Danish and Dutch Population Registries and English Longitudinal Study for Ageing (ELSA). Some of the research methods employed in this thesis have seen limited application in investigating inequalities in health and health outcomes in dementia. This is specifically the case in in using secondary data to define clusters of PLWD with similarities in healthcare pathways and variations in subsequent health outcomes. Little existing research has investigated inequalities across multiple countries (Kahle-Wrobleski et al., 2017; Verbeek et al., 2015), but there are opportunities to build upon and expand such research. Countries may have differences in their standardised datasets, such as the variables collected, or the measurement used. However, applying the methods from this PhD project to routine datasets globally could provide a picture of patterns in service use and subsequent health outcomes within countries, and also develop international and regional comparisons of health and care for PLWD. These comparisons can allow different countries or regions to learn from one another and emphasise the benefits of different healthcare systems for PLWD. This could aid in improving services globally, fostering better care and more positive health outcomes for PLWD.

6.4.4. Machine learning for supporting person-centred care

The focus of this thesis was to provide evidence to support health and social care staff, PLWD and informal carers in person-centred care discussions. Machine learning using large datasets can provide a great deal of support to clinicians. Using a swathe of previous data, machine learning can predict future need and outcomes based on a person's previous health and social care use, multiple long-term conditions, care support and environment, and other factors. Dementia is complex and situations and care need can change quickly for PLWD, as such, there is a call for decision-making to be fully supported by evidence. Machine learning methods can support clinicians to identify the best potential care and treatment options (Javaid et al., 2022). These choices can then be brought into care discussions and provide

PLWD and carers with options in their own care (Belam and Nilforooshan, 2021). This could involve PLWD and carers in care decisions more, have a positive impact on the health and quality of life for PLWD, and reduce the cost to health and social care through reduced use of emergency healthcare services (Javaid et al., 2022; Lennox-Chhugani, 2022). However, there are ethical and practical issues in machine learning and in providing the most appropriate, effective and empathetic care for PLWD, which would need to be overcome to leverage this technology (Belam and Nilforooshan, 2021; Hine, Nilforooshan and Barnaghi, 2022).

6.5. Policy and Practice Recommendations

There are several recommendations that can be made as a result of the findings from this research, particularly when contextualised within the wider literature and the changing nature of dementia in the UK. Beyond future research implications, there is a need for additional support for health and social care professionals. Central Governmental has made commitments to dementia research, and funding of services, but they have not been enacted. There is a need for additional financial and staffing support for health and social care services in the UK, and the opportunity for staff to continue personal, and professional development, to aid current shortfalls in staffing, and enhance to capacity within the existing workforce. Potential policy and practice changes can improve treatment, care and support for PLWD. These should all be viewed in the current climate, particularly in understanding the pragmatic and practical potential in an environment with restricted funding and staffing.

6.5.1. Reduce health inequalities for disadvantaged groups through improved access and continuity of care

While most PLWD face barriers to receiving care, some demographic, geographic and socio-economic groups are more likely to experience inappropriate, disjointed or poor-quality health and social care services (Watson et al., 2021). Improving the appropriateness, accessibility and continuity of health and social care can improve the management of health and treatment for PLWD, reducing the impact of potential symptoms and hospitalisations,

and the risk of poor health outcomes (Bunn et al., 2017; Delgado et al., 2022). Poor access to diagnosis and treatment is noted among PLWD from deprived backgrounds (Mukadam et al., 2013; Vohra et al., 2021). GPs and post-diagnostic services need to be aware of the different ways in which dementia can present and of the early signs for dementia, particularly among different demographic groups who are currently diagnosed later, or receive an unspecified diagnosis (Jitlal et al., 2021; Petersen et al., 2021). Improving access to diagnosis and in-turn enabling better access and quality of post-diagnostic treatment and support, can enable better access to treatment and help maintain health and foster better health outcomes (Robinson, Tang and Taylor, 2015; Woods et al., 2018).

6.5.2. Improve provision and access to care for PLWD in rural areas

Quality and capacity in primary care can lead to differential experience in access to diagnosis and subsequent treatment (Ahmad et al., 2010). Improving knowledge of dementia and capacity in primary care, as well as service equity and accessibility is critical. Rural areas may have fewer services and are more reliant on their GP to act as a referral gatekeeper to specialist services (Bradford et al., 2010). A PLWD from a rural or deprived area may be dependent on their GP as they have restricted options of primary care provider, and so the ability of their GP to recognise symptoms and care needs is crucial (Rasmussen and Langerman, 2019). Continuity in care from diagnosis onwards includes health and social care staff communicating effectively with each other, and with PLWD and carers (Zimmerman et al., 2005). Maintaining continuity in who is providing care and where it is provided can promote a more stable social environment and care situation for PLWD (Reckrey et al., 2022). Consistency in care can be crucial to prolonging quality of life and positive health among PLWD (Delgado et al., 2022). Managing the treatment and support can be difficult, but PLWD and informal carers being involved in care choices and decision can further continuity and maintain positive health for longer among PLWD (Kim and Park, 2017).

6.5.3. Develop infrastructure and practice in primary care to enable better access to diagnosis and care

Provision of appropriate and accessible care with greater continuity will require a great deal of infrastructure development. Health and social care services for PLWD do not tend to be standardised across the UK and good quality care and services can often be unequally provided across the UK (Chase et al., 2020; Pierse et al., 2020), and PLWD from different geographic areas, demographic and socio-economic backgrounds (Giebel et al., 2021). The appropriateness of care can differ from person to person and between different population groups, so being aware of individual needs and local service availability is imperative to providing effective care (Iliffe et al., 2009). This is no different in rural areas that are more sparsely populated, with further to travel to services, and for health and social care staff to make home and community visits (Bauer et al., 2019).

6.5.4. Person-centred care

There are numerous practical benefits to both the PLWD and the wider health and social care system of providing person-centred care. This focus on an individuals' need has been shown to reduce the burden and severity of symptoms of dementia and mental health comorbidities and improve the quality of life for PLWD (Kim and Park, 2017). Involving PLWD - in different care settings - and informal carers in care discussions and decision-making can also reduce the financial cost to the health and social system. Effective management of treatment and care can help to reduce the use of inappropriate hospital care and unnecessary GP contacts (Tay et al., 2018; Mayor, 2018). Person-centred care requires health and social care staff to be mindful of changes in a PLWD's symptoms, environment and needs, with changing frequency and levels of contact between clinicians and PLWD. Noting changes and discussing needs throughout a person's trajectory is critical to maintaining practical and pragmatic person-centred care as dementia develops.

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